



The impact of Mental Illness on families and carers

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Typical scenario: at the usual age of onset of a child's mental illness, the age of family carers, generally between 40 and 60, means they are at a time of greatest family stress and pressure.

Mental illness develops in older teenager or young adult

age: **15** **20** **25** **30** **35**

Provide special care at onset

Provide continuing support

Family carer's commitments and responsibilities

age: **40** **45** **50** **55** **60**

Work career reaching peak

Pre-retirement

Provide support at school or college

Provide support at time of grandparents' retirement

Provide increasing care and support

Other children in family

Grandparents

age: **65** **70** **75** **80** **85**



Impact on Families

- Diagnosis of Mental illness
 - a major life crisis
 - impact on the family structure
- Feelings of disempowerment, misunderstood, isolated, stigmatised
 - psychological turmoil
- Current trend community
 - families are providing a major portion of the care
 - one of the most significant sources of support

The journey – a family member perspective

Shock, fear and uncertainty



Trying to cope with the situation



Despair, disappointment, frustration and isolation



Becoming active: seeking information and support, communicating



New strength for family (carers) through interaction with others, positive stories and personal experience



Learning and growing



Challenges faced by families and carers

- Stigma and discrimination
- Limited access to health services
- Disruption of own and family life
- Lack of information, training, support and involvement
- Isolation
- Deterioration of own health – both physical and mental
- Financial strain



Impact on Families

Feelings experienced
Fear of the unknown
Personal guilt
Self blame
Helplessness
Stress
Anxiety
Distress
Depression
Economic strain

Martens L et al. *Soc Psychiatry Epidemiol* 2001.
Addington J et al. *Schizophr Res* 2005.



Stigma

- The stigma surrounding mental illnesses, such as schizophrenia and bipolar, is strong in our community
- Discrimination is experienced constantly, e.g.
 - employment
 - accommodation
 - healthcare
 - finance
 - simply making friends
- **Stigma affects not only those with the illness, but their families and carers as well**

“I now feel it is all my fault that my daughter is the way she is. I could see the neighbours treating me differently. Turning their heads, becoming occupied when I approached. It has gotten so bad that I only go out at night, when there is non one around.”

Jean (mother of Ann, 26, student with severe mental illness)



Stigma - consequences

- Stigma - one of the most serious and oppressing factors confronting persons with mental illness and their families
- Impact can be devastating and sometimes fatal
- Result of stigmatisation
 - Feelings of isolation and depression are a common
- The effects of stigma include
 - Discouragement, hurt and anger
 - Lowered self-esteem
 - Broken or disrupted relationships
 - Negative labelling
 - Decreased chance of employment



Employment

- Constant challenge
- Balancing work and personal life
- Increased stress on the ‘bread winner’
- Marriage Breakdown possibility increases

‘I have had to take early retirement to support my son, who suffers from mental illness. I had no other option, as my employer could only see black and white. The stress of mental illness in a family can have wide spread and deep effects, stretching also into the work force. Although my boss was aware of my circumstances, no allowances were made. Not that I wanted favours. Just some flexibility. I wasn’t on any production line. I worked in the office; so there was a reasonable case for some flexibility in shifting working hours. But it began to get worse, with jibes taking over. Eventually I decided for the sanity of all our family to retire. At least I now only have the worry of my son. I don’t have to live with a continuous strain of feeling worthless in work.’

Joe (father of son with mental illness)



Housing

'Recently our daughter, who suffers with severe mental illness, was judged as being capable of adopting an "independent life style", in other words to live in her own apartment. Both my husband and I were absolutely delighted, as for so long we had been living with what I would call the 'hell' of mental illness. But our joy was short lived after we started to help our daughter in the search for an apartment. Time and time we got to the stage of locating the ideal one. And then came the question – does your daughter work? Although we were there to assure the landlords that the rent was guaranteed, they all came up with excuses, none truthful bar one who admitted that if others in the block found out about her daughter, he would have a lot of trouble. So every night for almost two weeks, we went home and honestly, I cried myself to sleep. What ever about us, and it was bad, can you imagine what our daughter must have felt? Thankfully, we did eventually find an owner of an apartment who agreed to rent. While we were negotiating, it emerged that he had had personal experience of mental illness.'

Ann (mother of 28 year old girl with schizophrenia)



Understanding the Carer's Role

- Family members are the most common carers for people who are affected by severe mental illness
- Majority of carers live with the illness 24 hours each day, 365 days of the year¹
- Support is both emotional and practical
 - e.g. cooking, chores, keeping medical appointments, financial
- 40% of carers feel they provide support on a daily basis²
 - Mean time of caring 13.1 years

1. *EUFAMI survey into carer needs . 1996*

2. *EUFAMI 2007*



Families have specific needs

-
- Be involved in discharge plans
 - Want to work with all members of the care team
 - Look for support - unity can help to achieve policy changes
 - Break down barriers
 - Include family perspectives in their studies
 - Appreciation - burden of care from the family perspective
 - To be informed about the illness and side effects of medication
 - Need quality information
 - Use of common (every day) language
 - Right to live beyond their caring role
-



Needs of families and carers

- Perspective
- Hope
- Faith
- Information
- Someone to turn to
- Professional and emotional support
- To be involved
- Meaning and appreciation for what we are doing



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**

**48 member organisations in 28
countries**

**Founding Principle: Commitment to
improving care and welfare for all
people affected by mental illness –
including families and carers**

Based in Leuven, Belgium





Mission

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.



Values

-
- Family carers should be acknowledged as equal partners with professional staff and the person with mental illness in decisions relating to the planning and delivery of treatment and care.
 - **Systems of mental health care should be adequate to enable family members of people with mental illness to choose whether to be their carers or not.**
 - People with mental illness should be cared for in an appropriate environment and provided with all necessary health and social services.
 - **The needs of carers themselves for support and understanding should be recognised and fully provided for.**
 - It is the human right of all people with mental illness to share as fully as they can in the opportunities, enjoyments and responsibilities of everyday living.



Aims of EUFAMI

- To be recognised and involved as the leading European authority and advocate for families of people with mental illness
- **To support member associations in their efforts to improve standards of treatment, care and quality of life of people with mental illness and their family carers and friends**
- To help member associations combine their efforts at regional and European levels and to reach out to more family associations
- To lobby European policy makers to support legislation providing mental health and social care services as a human right in each member state
- **To campaign for adequate resources to be provided for these services for people with mental illness and their family carers**



Aims of EUFAMI - continued

- To identify examples of good practice in the field of mental illness and communicate them appropriately throughout Europe
- To promote further research into the causes and management of mental illness and its treatment.
- **To campaign for changes in public attitudes so as to help remove stigma and discrimination against people with mental illness and their family carers**
- To develop and strengthen partnerships between EUFAMI and mental healthcare professionals and other organisations having similar purposes and objectives



Dublin Declaration

released

Dublin, Ireland

Friday, 24th May 2013



The role of families

The central role and rights of family members in the care and treatment of people with mental ill health should be fully acknowledged and provided for throughout Europe. Family carers should be acknowledged as equal partners with professional staff and the person with mental ill health in decisions relating to the planning and delivery of treatment and care.

*Families and individual family members have a right to choose and define the role they are willing and able to play. This must include the right **not** to be involved directly with their relative's care, or to be involved in planning services, campaigning and monitoring services.*

Families should not be discriminated against or held responsible legally or financially for their family member directly affected by mental ill health. State mental health care should be adequate to enable family members of people with mental illness to make their choice without any feelings of personal guilt.



The need of families - 1

The needs of families and carers themselves for support and understanding should be recognised and fully provided for by the state authorities. Families should have a right to the opportunity to state their emotional, practical and financial needs so that they can be empowered to acquire the necessary coping skills to fulfil their caring role.

Families need to be cared for to ensure that their own physical and mental health is well maintained and supported. Evidence exists widely to show that this is not happening and that family member's health suffers. Depression amongst families is increasing and much is going undiagnosed. Families should be provided with a statement of their own needs on a routine basis, with written records of these needs, and continuing assessment. Plans for meeting identified needs should be implemented and audited.



The need of families - 2

The need for families and carers to recover from the experience and trauma of mental illness must be formally recognised and services provided to help them with their own recovery.



Public Authorities and statutory service providers - 1

Resources must be made available to meet those needs to enable family carers to carry out their role effectively. This may involve costs of training, counselling or other emotional help, providing information and financial help (for respite breaks, and travel costs to visit their relative)

Such resources should be available to meet the family's needs, over time, in a planned way. They may include factual information, training in new skills (identifying signs of relapse, communication and problem-solving skills), support for themselves, e.g. counselling, advocacy, and support for self-help carer groups, help lines, peer support (carer to carer), respite, or help with identifying their role.



Public Authorities and statutory service providers - 2

Legislators and statutory service providers must be proactive in providing evidence-based family intervention services. They should not leave this to voluntary groups. The evidence for family interventions has been available now for thirty years, and it is negligent that these approaches are not yet widely available.

The development of Comprehensive Community based services is seen as both essential and desirable if recovery is to be a realistic possibility. However, it is imperative that mental health care services provide the services outlined above to family members so that they can carry out frontline care, which is essential as a consequence of community care, more effectively. The sharing of information on the wellbeing of the person affected by mental ill health is essential.



THANK YOU