
STATEMENT OF EUFAMI'S POSITION ON *FAMILY CARERS' NEEDS*

This paper reflects the expressed needs of family caregivers of persons suffering from mental illness. EUFAMI asserts that:

- the caregiving experience of relatives make's them experts in their own right;
- caregivers should be recognised and respected by policy makers, health and social care practitioners for the important role they play in the care and recovery of their sick relative;

provided that:

- the person with mental illness recognises the readiness of family members to provide care and accepts their support; and
- the family is committed to provide such care and has the ability to do so.

EUFAMI further asserts that meeting the expressed needs of family caregivers will quicken the recovery of their loved ones.

The expressed needs of Family Cargivers

- Families have a right to an effective assessment of their own needs. These include health, emotional, financial situation and ability to cope with the overwhelming responsibility of regular caregiving.
- Such an assessment should lead to a carer's support plan.
- Families need to have access for information to obtain knowledge and skills. These include factual information, training in caregiving skills, strategies that help them deal with anger, anxiety and insecurities
- They may need access to counselling, advocacy, self-help groups, help lines, peer support.
- Families need to be empowered to acquire the necessary coping skills to fulfil their caring role effectively.
- Carers should be able to obtain access to quality healthcare service for their relative with mental illness at any time and location and irrespective of their own status or knowledge.
- Families need affirmation and feedback from service providers and an appropriate level of support and advice.

Practitioners should proactively provide written, jargon-free information, in the caregiver's language about carers' rights, the nature of the illness, the available range of care and treatment (including medications), services available especially in times of crisis, and how to access them.

- Families have a right to provide care or not to provide it.
- Families should not be discriminated against or held responsible, legally or financially, for their family member who has a mental illness.

Recommendations

Governments should legislate to protect the rights of both persons with mental illness and their caregivers through independent monitoring mechanisms. Caregivers' rights include the following:

1. Assessment of caregivers' needs prepared by a professional. This is to be reviewed on a regular basis.
2. Resources made available to meet the assessed needs. These include training, counselling or Family Therapy, written information from a range of sources including the internet, financial help for respite breaks, and travel costs to visit their relative.
3. Legislation that protects the caregiver from abnormal risk and disruption.
4. Lifelong learning opportunities, adequate leisure time and opportunities for flexitime to enable them to sustain their caregiving responsibilities.
5. Social Welfare benefits to free them from the financial burden .
6. State provision of respite, group homes, club houses and drop-in centres.
7. Special home-based support to caregivers at the time of transition from hospital to home care.
8. Detailed information about community-based support schemes and services including those provided by the voluntary sector.
9. A state-recognised complaints mechanism which will feed back into actions to improve care services.

EUFAMI will lobby for:

1. Measures to fight discrimination due to a relative's condition. These include early education in schools and continuous anti-stigma interventions.
2. More research on the affect of mental illness on individual family members .
3. Best practice of care for both the persons with mental illness and their relatives across Europe.
4. A Europe-wide Ccharter for families of persons with mental illness.