



Running in the family

Why is it important to study fHR cohorts

**General introduction
Perspectives of a parent
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RUNNING IN THE FAMILY

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- PERSONAL BUT VERY TYPICAL TESTIMONIAL
IN A CHRONOLOGICAL AND INCREASING ORDER OF BURDEN
 - Constant quest for information
 - When do questions become focused on serious mental health issues
 - Lengthy and unpredictable collection of visits to a MH Practitioner
 - No indication of reasonable expectations – no idea of a lifetime issue
 - No predictability
 - Self-stigma – stigma by close family members
 - Perception that patient is conscious of the problem
 - Late awareness that there is no end to the problem –importance of peer to peer education and training in resilience fostering techniques
 - Organization of after life time – financial – heritage – guardianship –administration of goods
 - Intergenerational transmission-: stigmatization and ostracization of entire families



Running in the FAMILY

THE MOST IMPORTANT LIFE DOMAINS THAT CAUSE HEAVY BURDEN

- EMOTIONAL BURDEN
 - SOCIAL BURDEN
 - ANXIETY OVER RELAPSE
 - PHYSICAL BURDEN
 - FIANCIAL BURDEN
 - RELATIONSHIP BURDEN
 - CUMULATION OF BURDEN
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- Cfr: EUFAMI KUL RESEARCH CARING FOR CARERS



RUNNING IN THE FAMILY

WHAT IS NEEDED FROM MHC AND RESEARCH

Cfr EUFAMI Position Paper on Family Carers Needs

DESTIGMATITATION BY INFORMATION

- Requests for help from carers need to be taken seriously and addressed
- Partners in care – involvement in diagnosis -
- Reasonable information about likely outcome and influence on life style of patient and carers
- Accessible organization of first line and more specialized assistance
- Strong peer organizations
- No abuse of confidentiality – medical secret
- Clear, understandable and personalized information about intergenerational transmission (lacks most)



RUNNING IN THE FAMILY

CARING FOR CARERS SURVEY REPORT 2016

(EUFAMI AND KUL INTERDISCIPLINARY CENTER FOR CARE
RESEARCH AND CONSULTANCY)

REPORT ON THE VALUE OF CARING 2020

With recommendations for Policy Makers, Mental Health and
Social Care Services, Family Carers and Civil Society
LSE Care and Policy Center



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

**Represents circa 25 million families
in Europe**

**38 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.**





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Thank you!