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# Addressing caregivers/relatives needs

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**Community Rehabilitation in Neurology Training Programme**



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# In what aim?

- To reduce social isolation
- To decrease dysfunction in areas important for the patient
- To prevent psychological disability
- To reduce costs (e.g. caused by repeated hospitalizations)



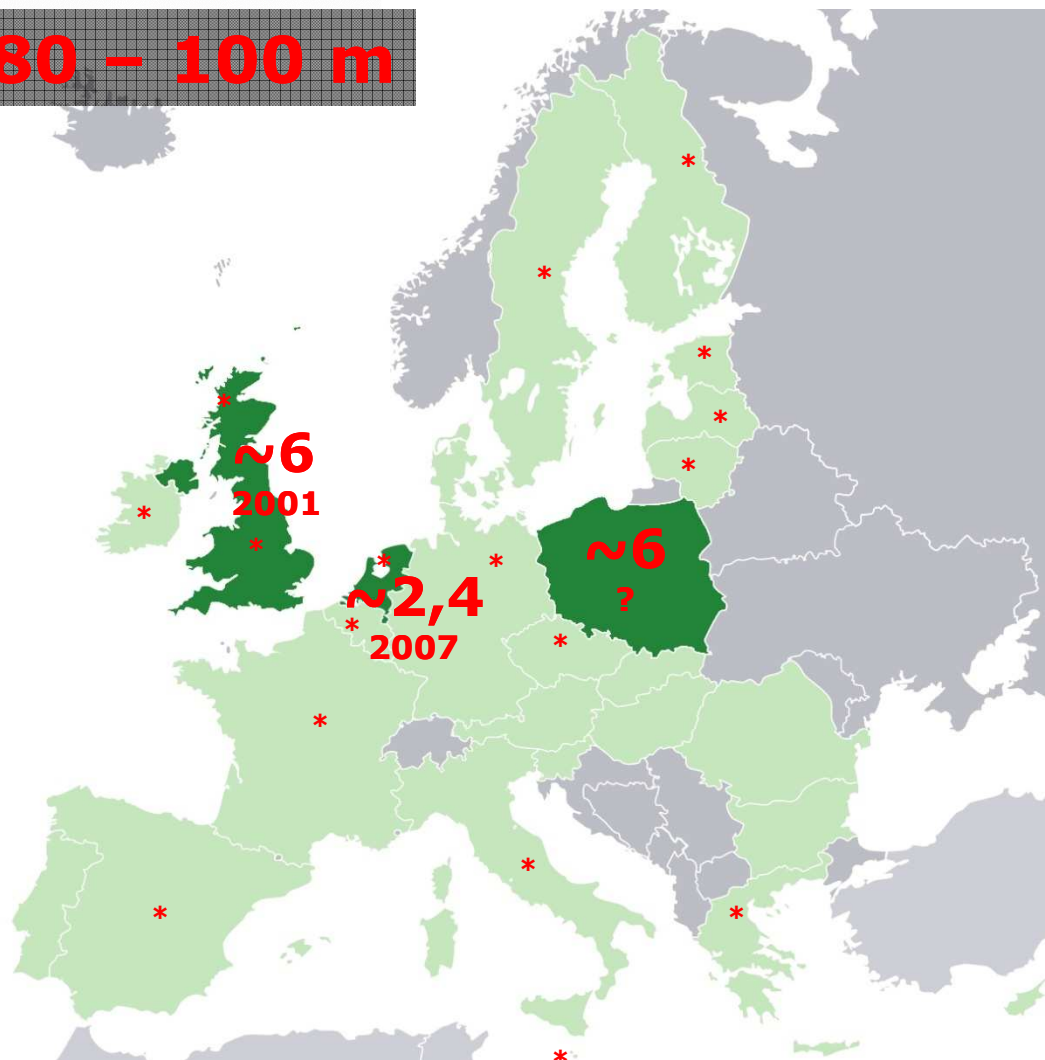
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# Caregivers in EU

~ 80 – 100 m



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<http://www.eurocarers.org/>

**EUROCARERS aims to advance the issue of informal care at both national and EU levels through:**

- Supporting the development of Carers organisations
- Providing a united voice at European level
- Influencing policy at national and EU levels
- Promoting awareness of Carers issues
- Dissemination of experience and good practice
- Developing an informed research agenda
- Providing information on relevant EU policy developments

Eurocarers defines a carer as a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework.



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# 10 Guiding Principles



- **Principle 1: Recognition**

Carers should be recognised for the central role they play in community care, and this recognition should be reflected in all policies having effect on carers.

- **Principle 2: Social Inclusion**

Carers have a right to a social life.

- **Principle 3: Equality of opportunity**

Carers should have equal opportunities in all spheres of life.

- **Principle 4: Choice**

People should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring; people needing care should have the right to choose who they wish to be their carers.

- **Principle 5: Information**

Carers should have easy access to the information, guidance, advocacy, advice and training they desire - fitting to the stage of their carer's career.





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## 10 Guiding Principles cd.



- **Principle 6: Support**

Carers need financial, practical and emotional support in their role as carers as well as access to needed formal care that is available and affordable.

- **Principle 7: Time off**

Carers should have the opportunity of taking time off. Therefore, adequate relief i.e. respite care arrangements, acceptable both to the carer and the cared for person, must be readily available and tailored to carers' needs.

- **Principle 8: Compatibility of care and employment**

Carers should have the possibility to combine caring with paid employment. This presupposes labour market policies that allow for caring activities as well as formal care available during working hours.

- **Principle 9: Health promotion and protection**

Carers' own health care needs should be recognised.

- **Principle 10: Financial security**

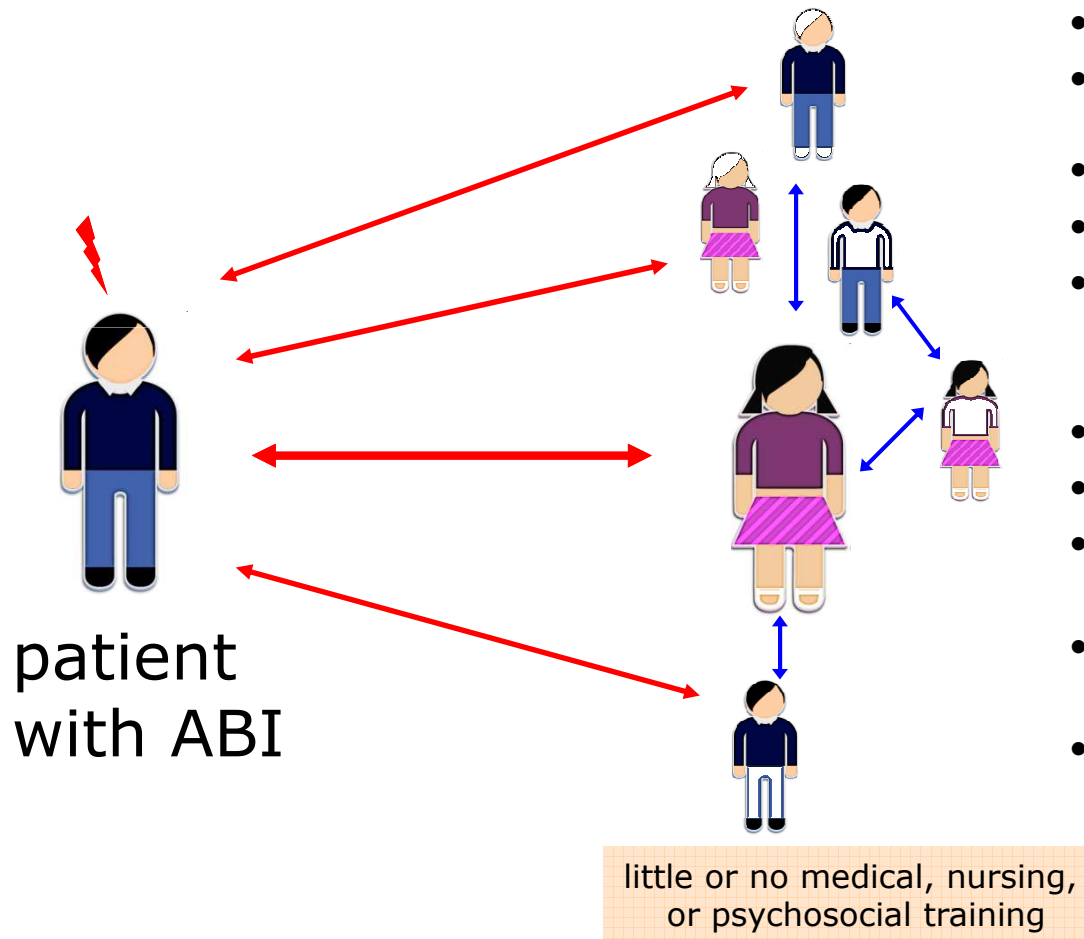
Carers should be covered by social security schemes such as income replacement benefits, accident insurance and old age pensions, in order to avoid impoverishment as a consequence of caring.



# Brain injury and the family

## Problems:

- Physical
- Cognitive
- Affective
- Behavioural
- Social
- Vocational



- Family strain
- Depression (60%!)
- Anxiety
- Burden
- Problems adjusting to new roles
- Violence
- Social isolation
- Financial problems
- Increased mortality
- „Burnout“



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# Protective and deleterious factors

(Hanks et al. Neurorehabilitation 2007;22: 43-52  
Oddy & Herbert Neuropsych Rehabil 2003;13: 259-73  
Rivera et al. NeuroRehabilitation 2007;22: 3-8  
Prigatano, 1999)

- Task-oriented coping with stress
- Cognitive adaptation (illness as a challenge; sense of control; realistic and optimistic expectations; distance)
- Resolved problem of loss and grief
- Social support
- Sense of mastery in caregiving
- Emotion-focused coping
- Denial
- Ineffective problem solving
- Learned helplessness
- Unrealistic expectations





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# Family carers' needs:

(Sinnakaruppan & Williams, Brain Injury 2001;15: 653-72)

1. Need for information regarding the head injury, its effects, and the techniques for adjusting to the subsequent changes in their injured relatives;
2. Need for healthcare professionals to answer questions with honesty;
3. Concern for the future care of the head-injured relative in the event of carer disability or death;
4. Need for respite;
5. Need for hope for the future.
6. Need for social belonging.

more unmet needs associated with behavioural and affective change



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# Family carers' needs:

## 1

Need for information (and education) regarding the head injury, its effects (behavioural, affective, QoL), and techniques for adjusting to the subsequent changes in their injured relatives;

### Examples:

- To be given an explanation of the patient's condition
- To discuss the patient's prognosis
- To learn about community resources
- To obtain information about financial assistance
- To learn the methods of adjusting to behavioural changes



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# Family carers' needs:

2

Need for healthcare professionals to answer questions with honesty;

## Examples:

To feel that the hospital personnel cared about the relative

To have specific facts concerning the relative's progress

To have explanations that are understandable

To be assured that the best possible medical care is being given to the patient

To have different staff members agree on the best way to help the patient

To have help preparing for the the worst

To be told about all changes in the patient's medical status

To be told how long each of the patient's problems is expected to last



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# Family carers' needs:

3

Concern for the future care of the head-injured relative in the event of carer disability or death;

## Examples:

To have help getting over doubts and fears about the future



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# Family carers' needs:

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Need for respite;

Examples:

To have time and activities for myself outside the home



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# Family carers' needs:

5

Need for hope for the future;

## Examples:

To feel there is hope

To have help getting over doubts and fears about the future





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# Family carers' needs:

6

Need for social belonging and support.

## Examples:

To discuss feelings about the patient with someone who has gone through the same experience

To have emotional support



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# The central role of the family in rehabilitation

(Proulx, 1999)

- Social integration and functional independence – core objectives
- Shift of services from hospital care to home care
- Provision of important information about patient's everyday functioning
- Planning, training and evaluating generalization of rehabilitation gains to the home environment
- Patient's adaptation to the family – promotion of optimal outcome
- Family involvement may be more cost efficient
- Early identification of dysfunctional families



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# Specific interventions: recommendations

(Boschen et al. NeuroRehabilitation 2007;22: 19-41; Proulx, 1999  
Charles et al. NeuroRehabilitation 2007;22: 61-76  
Sinnakaruppan & Williams, Brain Injury 2001;15: 653-72  
Harvard Mental Health Letter 2009)

- Comprehensive training programmes for family caregivers (associated with lower rate of admission to institutions, mortality rate)
- Education and training of individual family (promotion of recovery, decreasing carer depression, increasing communication skills)
- Information about how to interact with people with brain injury in order to readjust demands and expectations realistically
- Preventive family interventions
- Encouraging active and problem-solving strategies of coping



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# Specific interventions: recommendations

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- Providing emotional and social support
- Multifamily groups within community settings (reducing feelings of isolation, sharing experiences, engaging children, breaking the silence on family violence)
- Matching family members' needs with appropriate interventions at the right time
- Telephone/internet-based interventions (overcoming geographical barriers)
- Respite care (break from the demands of caregiving – informal family assistance or volunteer/paid companionship)



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# Practical issues on work with relatives

(Prigatano, 1999)

- Appreciate that the family's situation is difficult. They are frightened and want to ensure that the patient's needs are met.
- Hear the family members out-take their critiques about the limitations of rehabilitative care seriously.
- Help family members get their needs met in a fair and honest way. Achieving this goal may mean changing their relationship to the brain-injured patient. Do not be frightened to work toward this change-it is a part of reality.



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# Practical issues on work with relatives

(Prigatano, 1999)

- Recognize that the family's anger is real and must be managed. It will not go away on its own.
- Do not rush toward psychotherapy if family members are coping adequately with the situation. Establish a good working relationship with them.
- Have both family members and patient participate as part of the rehabilitation team. As a responsible professional, however, recognize that they do not direct the team efforts. Such decisions must be made collectively.





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Thank you

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