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Pain and family

Can a “Carers’ Association”
improve the situation?



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Aus Liebe zum Menschen.



Background

- Every 4th family in Austria is confronted with care related issues
- The number of Austrians in need for help and care will rise to 800.000 in 2011 (appr. 10% of population)
- 420.000 Austrians receive a care allowance (appr. 5% of population)
- 17% of those live in nursing homes





Background

- Informal carers provide 80% of care at home (67% are female)
- Care-giving by informal carers is the strongest pillar of our care system
- Approx. 20% of the concerned families benefit from home care services



Background



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- 42% of the caregivers reported that they can not afford home care
- Decision makers rely on these “natural” non-budgeted services of informal carers





Background

- Pain and its inadequate treatment result in an increased need for care thus putting an additional burden on informal and institutional carers
- Our mental models about pain treatment must be changed





Background

- Informal carers are not yet integrated in the complex issue of pain management
- Informal carers especially of people suffering from dementia could provide an important resource for improved pain management





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The situation of informal care-givers

- The care of family members
 - is a physical, mental and emotional challenge
 - is too little noticed and appreciated in the public debate,
 - is mostly unpaid
 - is competing against other demands in life





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The situation of informal care-givers

If no or too little support is being provided, the heavy **physical, mental, social and financial burden** of informal care-givers can result in **health problems** and need for **long-term care** of their own.





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Care-givers need ...

- ... financial, emotional and practical support.
 - education, information, training
 - public recognition
 - support and relief by affordable day-care-facilities, respite care and more flexible services





Care-givers need....

- ...to make decisions based on informed consent
- ...to be consulted when therapies are being decided as their quality of life is concerned as well
- ...to be supported and enhanced in their caring efforts by the provision of adequate pain therapies
- ...to be trained and empowered to be able to carry out effective therapies for their patients





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Who benefits from the “Carers’ Association”?

- People who care for family members/friends at home
- People who care for and assist family members/friends in residential care facilities
- Professionals in the field of care and assistance





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Who benefits from the “Carers’ Association”?

- People interested in care issues
- Self-help groups
- Organizations in the field of health care
- Communities; the public sector
- Insurance companies, corporations etc.
- Opinion leaders and decision makers





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Objectives of the “Carers’ Association”

- Advocate for the needs of informal caregivers
- Improve their living situation by lobbying and advocacy among decision makers in the public, private and third sector
- **Advocate for adequate therapies with special regard to pain treatment for an improved health and wellbeing of patients and carers**





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Objectives of the “Carers’ Association”

- Raise awareness for the social relevance, burden and challenges of informal caregivers
- Empower informal caregivers to speak for themselves
- Provide information and advice relative to existing services and network structures
- Act as a virtual or real meeting point for caregivers and their concerns
- Provide a platform for scientific exchange

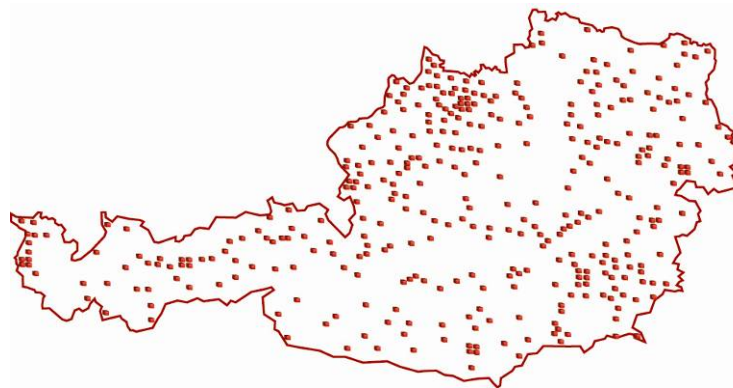


The role of the Austrian Red Cross



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- Facilitate the national Roll-Out of the association
- Give support in Marketing / Public relations with the aim of raising awareness on the situation of informal caregivers as well as gaining members



The role of the Austrian Red Cross



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- Provide essential infrastructure (office space, IT; secretariat etc.) within first 3 years
- Provide comprehensive information concerning existing services



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Carers' Associations in the EU



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Country	UK	Ireland	Sweden	Finland	Austria
Name of association	Carers	Caring for Carers	Anhörigas Riksförbund	Omaishoitajat ja Läheiset - Liitto ry	Interessengemeinschaft pflegender Angehöriger
Founded	40 years	20 years	10 years	20 years	1 month !
Providing services	x	x		x	
Lobbying + Advocacy	x		x	x	x
Providing information	x	x		x	x
Websites	http://www.carersuk.org/	http://www.caringforcarers.ie/	http://www.anhrisverige.se/	http://www.omashoitajat.com/	http://www.ig-pflege.at/





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Thanks for your attention!

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