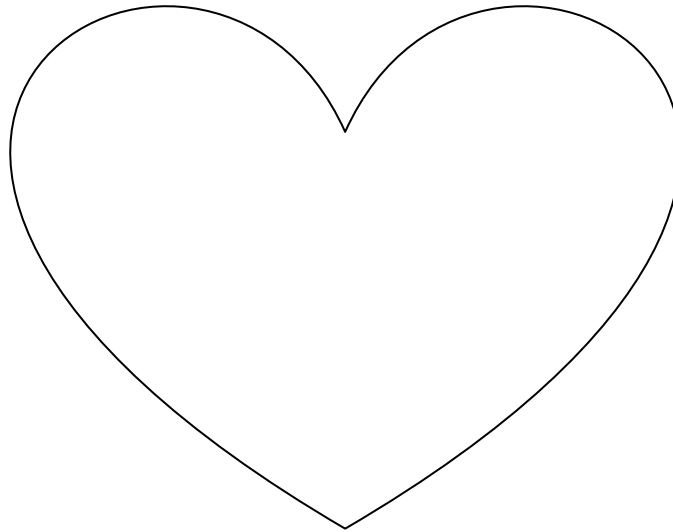


**21st Annual Meeting of the International Alliance of ALS / MND
Associations,
Milan, 3 - 4 December 2013**

**One love, one heart - let 's care
together !**



Deutsche Gesellschaft für Muskelkranke DGM e.V.

Antje Faatz, social counselling



ALS Self-Help & Palliative Care

different points of origin - same values & attitude

There is need for cross-border, interprofessional, trans-organisational, context exceeding communication, fighting for a common language, the idea and history of each unique person. (...)

Patients' needs lead us to get together willing to struggle (... for their dignity, autonomy and quality of life)



Our Questions

As a patient organisation - are we part of the ALS palliative care network?

... while counselling ALS patients and their families?

... while running a support group?

... doing what else?

And if we are...

... what do we need?

... what can we offer and share?



Self-help and palliative care with ALS/MND

ALS volunteers

needs:

- education and supervision on palliative care and bereavement counselling
- local support network

offers:

- (rare) disease knowledge
- experience on ALS patients special needs and solutions
- early contact and credit, bridge to palliative care services

palliative care services

needs:

- special knowledge and experience on ALS patients special needs (rare disease)
- bridging contact and credit

offers:

- skills: education on palliative care and bereavement counselling
- coaching / supervision
- local support network

Bridge and basis for engaging:

Attitude, concepts, targets and methods

Target group ALS-patients and their families

Incorporating palliative care model 1: ALS support group Syke

- 5 ALS widow/ers constantly leading support group since 1996, offer quarterly meetings, 20 – 35 participants
- counselling via telephone, face to face and home visit
- Mindful teamwork caring for the ALS group and caring for themselves: different tasks according to personal preferences, team meetings several times a year



Skills and cooperation

model 1: ALS support group Syke

- 1 team member qualified in leading hospice groups, chairmanship and management of conflicts
- belongs to leading team of local hospice groups
- offers education to volunteers in hospice and palliative care
- counselling local hospice group on ALS specific aspects of care before they act in the field
- supervision of hospice volunteers caring for ALS patients
- another team member qualified in bereavement counselling



Engaging with a local hospice group model 2: ALS support group Lübeck

- Mrs. B., leader of the ALS support group, qualified in volunteering in hospice and palliative care
- Takes part in local hospice group
- Hospice group acknowledges her focus on leading ALS support group
- Gets support and supervision on aspects of dying and grief
- Offers hospice volunteers counselling on ALS specific aspects of care before acting in the field



Engaging with a local hospice group

model 3: support group for ALS family caregivers Marburg

- Mrs. S., ALS widow, started support group for ALS family caregivers (meetings every 2 months)
- Annual meeting for ALS patients and families
- Wanted to retire from group responsibility > need for succession
- Leader of local hospice group took over
- Mrs. S. still involved in the background: supporting and counselling the hospice volunteers, ALS patients and families too, planning and undertaking the ALS annual meeting



Education of ALS volunteers

Workshop (1 weekend)

Objectives:

- incorporate palliative care to our ALS services.
- care for our ALS volunteers
- find ways to engage with local hospice movement / palliative care services.



Education of ALS volunteers

Workshop (1 weekend)

Contents:

- education on basics of palliative care and bereavement counselling
- care for the caregivers: experience methods to care for themselves, cope with stress, prevent burnout
- network and share experience on challenging fields of activity
- discuss models of incorporation and engaging with palliative care services practically
- think about next steps

**Thank you for listening
and...**



...take heart towards the future!

