

## 'I'm not just a visitor'

#### Blended Learning Networks focusing on family carers' experiences and need of support in a residential or a nursing home context.

6th International Carers Conference Gothenburg 4-6 September 2015

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# Content

- Blended learning networks (BLN) A partnership method for change
- Family carers' experiences and needs/preferences for support in relation to Residential/Nursing Home context as expressed in BLN



## Blended Learning Networks (BLN)

- A heterogeneous Community of Practice involving people with various backgrounds and different experiences. Participants share a common interest and work together to achieve a common goal.
- Participants support and learn from each other to make use of relevant research and development results within everyday practice and/or their own organization. Hanson et al. (2011), Nolan et al. (2003)



Local BLN: 10-14 partners contribute to the discussion with knowledge and experiences.



- Carers' first-hand experiences
- Practitioners and managers within health and social care services
- Organizational and policy knowledge amongst decision makers
- Voluntary organisations



## The organization of BLN



Practitioners & leaders in Health & Social services

Local politician Voluntary organisation

Local network leader Carers Practitioners & leaders in Health & Social services Local politician Voluntary organisation Web- meetings Local network leaders Nka Facilitator/practioner Nka Researcher/facilitator

Local notes outlines Summaries Local network leader Carers Practitioners & leaders in Health & Social services Local politician Voluntary organisation

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Older family member's relocation into a Nursing Home (NH) - a carer transition process

Carers' involvment in making the decision about relocation to NH for an older family member

> Carers' involvement in making the move into the NH

Carers' adjustment into NH as a permanent living arrangement for an older relative

Carers' and reorientation

Sandberg, J. (2001)



## 'Making the decision' phase Carers' experiences expressed in BLN

- Carers expressed constraints, insecurity, exhaustion, ill-health. "I've come to the end of my rope"
- > Feelings of grief, worry, guilt and powerlessness.
- Having to face, deal with and understand often unfamiliar concepts and issues, eg. application procedures, assistance, social services decision making etc.

What is missing and what do carers request? Carer support focusing the `decision making phase':

- A need to know & learn
- about the social- and elder care organization, local NHs available and introduction information.

- 'Hands on' help to fill in
- Be given information & updates

- applications, forms, notifications
- regarding the NH's decision process



#### Continued...

Carer support focusing `decision making phase'

Individual contact person

Given opportunity

On a regular basis

Be given time

- Someone carers learn to know by name
- to view, visit and assess different eligible NH's
- be invited to individual and carer support groups
- to get used to the idea of the NH arrangement when the formal decision is made by social services



## 'Making the move phase' Carers' experiences expressed in BLN

## □ Feelings and emotions

### The geographical move

- Grief, guilt, void, self- blaming thoughts of not having tried hard enough, worry, concern, apprehension about what the changed living arrangement will bring related to quality of care and finances (costs & expenditures).
- Knowing one's relative is taken good care of by staff is a relief and gives the carer a feeling of security
- Planning and practical tasks related to the NH relocation are important and allow carer also to get to know the staff and fellow residents



What is missing and what do carer request? Carer support focusing 'Making the move phase'

#### Information : oral, written, internet based etc

#### Someone to turn to

- details about the NH's premises, locality, flat/room.
- about what is expected of new residents and how to get in contact with staff
- all about the relatives illness, treatment, prognosis, risks and rehabilitation for all involved, staff included
- Having a contact-nurse assigned to whom the carer always can turn to and who can explain, inform and support all parties involved



## Carers experience focusing 'Adjustment to NH phase' -A home as well as a workplace

- The NH context turns into a new place where carers, families, relatives and friends will find ways to meet and socialize.
- The relationships with staff are essential and are developed over the course of time; continuity is important
- Having assurance that things will be carried out in a way the relative needs, also in the absence of the carer, is a condition for carers giving up some of the caring responsibility for the relative



## What is missing and what do carer request? Carer support focusing 'Adjustment to NH phase'

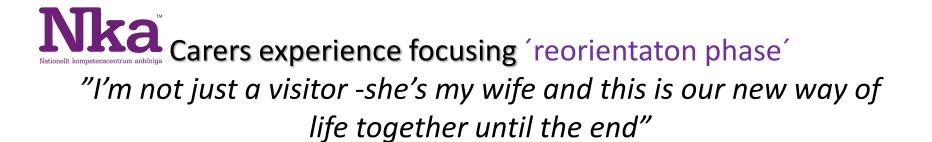
## Care plan meetings

## NH Staff

### To be involved

# The community carer support

- Recieve written invitations including aims and issues that will be discussed as well as summaries focusing on what was discussed, decided and how to evaluate or follow up.
- Visible NH nurse/leader, easy to be in contact with on a daily basis
- Be able to tell and get staff's 'hands on' help to document the resident's personal life story
- Be invited to contribute with carer's perspective in public information contexts held by NH staff or organization aswell as in developmental teamwork related to NH's activity and change
- continues to initiate and organize meetings for carers with a supportive aim also when the relative no longer lives at home



Finding new routines in daily life and combining how and when to meet and be together with one's relative

Worrying thoughts about what the future will bring pops up. "You have to live one day at a time" What is missing and what do carers request? Carer support focusing reorientaton phase

Carer support

Initiate development of collaboration

Development of information material related to end of life issues

- Implementation of individual/group support
- between social and health care services as well as voluntary organizations and education course activity
- Invitation to meet with staff to talk about the relative's life and death





# Thank you!

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