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# Support for carers in Germany – opportunities for mutual learning

Hanneli Döhner, Gabriele Schröder, wir pflegen (we care), Hamburg, Germany

# wir pflegen (we care)

Interessenvertretung begleitender Angehöriger und Freunde in Deutschland e.V. Representing the interests of informal carers (relatives

Representing the interests of informal carers (relatives and friends) in Germany

#### 2003 – 2005: EU funded project **EUROFAMCARE** 2006: **EUROCARERS**

#### 2007: wir pflegen

To bring together the different problems and needs of carers

 of all ages

 $_{\odot}$  for all kinds of dependencies

- To support cooperation between different initiatives on different levels to form a basis for a common voice for carers
- To develop an interface between carers and decision-makers on regional, national and European level, to reach more awareness, recognition an rights for carers

## **1995: Long-Term Care Insurance in Germany**

#### Entitlement:

 Assessment by Health Insurance Medical Service: According to ADL scheme, 3 levels of care, no age limit. Definition of LTC: very strict, cognitive impairments not considered properly when LTC is measured

#### Benefits:

- Cash benefits, in kind benefits (for home care) and benefits for nursing home care: with choice for the beneficiary
- Out of pocket payment higher than LTCI benefits in all care levels

#### **Principle:**

• Favouring home care to institutional care

## **Improvements: LTC Insurance in Germany**

#### Background:

- More than 2/3 cared at home, mainly family members (women)
- Well developed medical care (health insurance)
- Prognosis: Increase in prevalence of dependency, esp. dementia

#### Challenges:

- A better reconciliation of work and care is needed to sustain the willingness for care at home by informal carers
- More and qualified professionnel staff is needed, better working conditions are requested, to enable a good care mix

#### **Political framework:**

- No real adaptations in the LTC insurance introduced in last years
- Since 2013: stepwise legal improvements > much more money goes in the system. The presentation will show the most important developments and some good practice to support carers

## First LTC Strengthening Act (PSG I)

- Since January 2015: expanded benefits for all 2.7 million beneficiaries. LTC benefits for people living at their private homes have been increased by 1.4 billion Euro for every year, for people in residential care by 1 billion Euro for every year.
- **Benefits** for long term care at home were significantly **improved**. The **services** available for care at home have been **expanded**.
- The working staff in residential care homes has been increased significantly.
- In addition, a Capital Reserve Funds for the Long-Term Care Insurance has been established.

## Second LTC Strengthening Act (PSG II)

- Starting January 2017: Introduction of a **new vision** for LTC
- LTC will aim at supporting self-reliance of people in need of care. Nursing centered long-term-care services remain essential. But regular benefits will be expanded by services for personal support and daily live assistance. This is of particular importance for people with dementia.
- New assessment system: instead of calculating the time needed for nursing care > degree of self-reliance restrictions assessed: physical, mental health and cognition
- 3 care levels (**Pflegestufen**): replaced by 5 new care degrees (**Pflegegrade**).
- Contribution rates to the LTC Insurance (payroll-tax) are increased

## Third LTC Strengthening Act (PSG III)

- **Municipalities** get a new responsibility for local and citizen near coordination and integration in a very splitted system
  - $_{\odot}$  to guarantee advice from a single source
  - to provide enough support offers and efficient care structures
  - to improve quality of advice for caring, integration assistance and old people's welfare
  - to provide more services for everyday assistance for people in need of care and their families
  - to integrate representatives of self-help organisations, incl. carers organisations in decision processes
- Model projects will be established and evaluated for 5 years nationwide, starting in January 2017

## **Support for carers - overview**

- Part-time institutional care: day and night care (seldom available)
- Residential short-term care and respite care: benefits are to be expanded and more easily combined with each other
- Supplementary benefits
- **Rehabilitation** for carers (together with the cared-for)
- Reconciliation of work and care
- **Pension insurance** contributions
- Unemployment insurance contributions
- Information and Counselling

## Rehabilitation for carers with cared-for

- Since January 2013: Better conditions for inpatient rehabilitation for carers (paid by the health insurance)
- More clinics have to take into account the special needs of carers
- Sometimes carers would not leave their relative in need of care alone. Therefore:
  - Carers should have the possibility to take the cared-for person with them.
  - Clinics should offer a special area for short-term care or cooperate with an institution.

## Supporting reconciliation of work and care

win-win-situation for carers, enterprises and the whole society

#### Carers wishes:

- Most want to stay in work. Carer's burden would be reduced by more flexibility and security
- Broadend perspective: institutions of basic and further education (schools, colleges, universities > special offers for young (adult) carers)

#### **Political answers / New Acts:**

- Short-term absence from work and carers grant: up to 10 days paid
- Caregiver leave act: complete or partial release from work up to 6 months unpaid, interest-free loan possible
- Family caregiver leave act: partial release up to 24 months, interest-free loan, later full work with lower earnings

#### Enterprises' change in thinking:

 Awareness of win-win-situation is growing: prevent to lose the knowledge and experience of their qualified employees (esp. middle aged women).
 Measures: inhouse information and internal /external guides

#### Societies' interest:

Cost savings by supporting the preservation of family care potential

## **Increased pension insurance benefits**

- The care insurance will pay pension contributions for more carers caring for a person in need of care living at home with care grade 2 to 5.
- **Prerequisite**: minimum of 10 hours per week, distributed to regularly a minimum of 2 days: addition of care for 2 or more people is possible.
- Pension contributions increase with the grade of care
- When the carer already gets his full old age pension or is employed for more than 30 hours per week: no pension contributions will be paid. No improvement against today.

## **Unemployement insurance benefits**

- The care insurance will pay the contributions for the unemployment insurance of the carer for the whole period of caring, if carers gave up their employment because of care for a person in need of care with grade 2 to 5 – independend of the utilisation of the caregiver leave offered through the caregiver leave act
- **Prerequisite** (same as for pension): time for caring a minimum of 10 h per week, distributed to regularly a minimum of 2 days: addition of care for 2 or more people possible.
- Carers are entitled to unemployment benefits and services for employment promotion, in the case they have problems in reentering the labour market after finishing care work.
- Same rights for carers, who interrupt the entitlement from the unemployment insurance because of care.

## Access to information, advice, accompany

#### 1. General approach

 Internet and print media: ministries, insurances, private companies, NGOs

#### 2. Individual approach

- Face-to-face
  - Informal network (family, neighbours, friends, collegues)
  - professionell (counselling agencies, GPs, hospitals: discharge management, nurses, pharmacies)
- By phone
  - Hotlines: ministries, NGOs like German Alzh. Soc..
  - Psychotherapeutic counselling: models
- Online counselling by emails

#### 3. Group approach

- Face-to-face: Courses and self-help groups
- Telephone / Video conferences (mainly moderated by professionals)

## "Hamburger Angehörigenschule gGmbH" (1)

#### A good practice example of courses from Hamburg

- 2011 founded as a **nonprofit organisation** and member of the Diakonie Hamburg. Two part-time jobs
- Offers care courses in many districts of Hamburg in cooperation with care insurances and other institutions of the Diakonie – also in Turkish and Polish language
  - Target groups: informal carers or supporting volunteers
  - Financing: care insurances cover the costs
  - Numbers: about 140 courses with about 1.000 participants per year
  - Group size: 8 participants on average
  - Group duration: 3 9 hours

## "Hamburger Angehörigenschule gGmbH" (2)

- Many different topics: the benefits of long-term care insurance, practical care, mostly requiered dementia care, but palliative and end of life care as well
- Regular feedback from informal carers and adapted contents of the courses
- Course instructors are professionnel carers
- How do we reach the target group?
  - Advertisements in local weekly free newspapers
  - Various internet portals
  - Course brochure
  - Network partners
  - Care consultants of health insurance companies
  - Personal recommendations
  - Lectures at events.

## "Hamburger Angehörigenschule gGmbH" (3)

- Most contacts to carers by phone, email.
- Every contact contains advice. Is a course in the group most helpfull at the moment?
- Sometimes care for the cared-for has to be organized.
- Sometimes free training at home might be usefull as well.
- Course instructors discover personal needs.
- "I am not alone with the problems", find like-minded people
- Carers are experts in several aspects!
- A free event for informal carers during care congress
- Diakonie cultural event for carers in autumn
- Moreover: dementia crisis hotline, elder care for employees

# Concept 2014: New responsibilities of GPs and their staff for carers

- Identification of carers (high number of unreported cases)
- **Assessment** of their health situation and risks as well as advice for prevention and further health care
- Preliminary information / advice of support possibilities
- Information concerning the disease of the cared-for and first information about available help
- Further references and eventually direct mediation to a specific care counselling agency
- **Coordination function:** referral to e.g. specialists, rehabilitation, exchange with other professions involved, monitoring of the situation

## **Further needs for carers**

- **Prevention of poverty**, esp. for women: lower earnings, more care responsibilies, more often reduction of work, stop work
- Equal access to support for all citizens, mainly in rural areas – esp. day and night care, care courses, self-help groups
- First information by regular contacts: e.g. GPs, pharmacies
- More **time-out** for recreation and health promotion
- More individually planned care arrangements (case and care management): good mixture of informal and formal care
- Make a career in formal care-giving / nursing more attractive
- Stabilize family care: support for informal carers and improved opportunities to combine caring and employment
- Give carers a voice in more political advisory boards !

## Some links for further information 1. Federal Ministries

 German's Long-Term Care Strengthening Acts (PSG I, II, III)

http://www.bundesgesundheitsministerium.de/en/en/long-termcare/germanys-long-term-care-strengthening-acts.html

### Supporting reconciliation of work and care

https://www.bmfsfj.de/blob/93366/eca900825bbbfbdd6e91fc0f3bd4205d/be ssere-vereinbarkeit-von-familie--pflege-und-beruf-flyer-englisch-data.pdf

### Hotlines for general information and counselling on care

#### Pflegetelefon BMFSFJ : 030 20179131 ,,quick help for carers"

https://www.bmfsfj.de/bmfsfj/aktuelles/alle-meldungen/das-pflegetelefon-schnelle-hilfe-fuer-angehoerige/78686?view=DEFAULT

#### • Bürgertelefon zur PV des BMG

http://www.bundesgesundheitsministerium.de/service/buergertelefon.html

## Examples of links for further information 2. Others

- Information and counselling on care
  - Psychological online counselling by emails "pflegen und leben", Berlin

https://www.pflegen-und-leben.de/

 Online training and counselling for carers of people with dementia "Demas", Berlin

https://www.demenz-anders-sehen.de/

 Psychological counselling by phone for carers of people with dementia "Tele.TAnDem", Jena

http://www.teletandem.uni-jena.de/

 New responsibilities of GPs and their staff for carers (KBV-Versorgungsvertrag)

(http://www.kbv.de/html/10117.php)

20 Min. are not enough for mutual learning, but we would like to continue exchange!

## Thank you for your attention!

## doehner@wir-pflegen.net

## www.wir-pflegen.net