# Anlage:
# Präsentationen des Fachgesprächs „Vermeidung von Gewalt in der häuslichen Pflege von Menschen mit Demenz – Präventions- und Interventionsmaßnahmen in europäischen Staaten“ am 8./9.12.2016 in Berlin

# Inhaltsverzeichnis

# 1 Gewalt(tät)ige Fürsorge – Ao. Univ.-Prof. Dr. Andrea Berzlanovich, Fachbereich Forensische Gerontologie, Medizinische Universität Wien, Österreich

## Abusive Care

**Ao.Univ.-Prof. Dr. Andrea Berzlanovich**

Department of Forensic Medicine
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## Elder abuse

Definition

- Individual/repeated action(s), or the lack of appropriate actions, occurring in a relationship where trust is to be expected, and which inflict(s) harm or suffering on an elderly person
- A human rights violation, and a significant cause of injuries, illness, and despair...

The Toronto Declaration on the Global Prevention of Elder Abuse. WHO, 2002

## Elder abuse

### Active forms of abuse

- Physical abuse
- Sexualised abuse
- Psychological abuse

## Manifestations

### Physical abuse

- Injuries: Skin redness, haematoma, fractures, cuts, contused lacerations, burns etc.
- Permanent disabilities: reduced vision, hearing, movement
- Death

## Manifestations

### Sexualised abuse

- = Any unapproved or unwanted sexual practices, or any sexual practices which are “tolerated”
- This ranges from the unwanted creation of a sexualised atmosphere and/or indecent exposure, through to the compulsion to commit sexual acts, and/or rape

## Manifestations

### Sexualised abuse

Starts with a disregard for embarrassment thresholds

- Carers do not look away when treating someone requiring their help
- Touching intimate areas without consent
- A woman being cared for by a male nurse when she would prefer to have a female nurse

## Manifestations

### Sexualised abuse

Starts with a disregard for embarrassment thresholds

- Carers do not look away when treating someone requiring their help
- Touching intimate areas without consent
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## Manifestations

### Psychological abuse

- Characterised by disrespectful or offensive statements, actions and/or attitudes from abusers
- Examples: Threats, accusations, humiliation, debasement, intimidation, constant supervision, deprivation of food, psychological terror

## Manifestations

### Abuse through the omission of acts

- Passive neglect
- Active neglect
- Psychological neglect

## Manifestations

### Neglect of people requiring care

- Conscious/unconscious denial of urgently needed services and interpersonal care
- Disregard, restriction/denial of communication, distance

## Manifestations

### The neglect of people requiring care

- Is usually subtle, and takes place in private
- It is not always even perceived by those affected, those in the surrounding environment, or possibly even by those committing the abuse
- ⇨ Most examples of abuse are not recorded High number of unrecorded cases

## Measures restricting freedom

### Health consequences

- Muscle wasting
- Contractures
- Bedsores
- Leg vein thrombosis
- Hospital-acquired infections
- Injuries
- Death

## Abusive consequences

| | |
|---|---|
| **Physical consequences**<br>Acute injuries e.g. caused by slaps, bites, blows, cuts, contused lacerations, burns, haematoma, fractures (nose, arms, ribs), jaw and tooth injuries.<br>Permanent disabilities.<br>Gynaecological complaints. | **Psychological consequences**<br>Post-traumatic stress disorders (PTSD).<br>Depression, anxiety, and panic attacks.<br>Nervousness, sleep disturbances, loss of concentration.<br>Loss of self-respect and self-esteem.<br>Suicidal behaviour. |
| **(Psycho)somatic consequences**<br>Chronic pain including head, back, chest, and/or abdominal pain. Stomach and/or bowel disorders, nausea, vomiting.<br>General: Chronic tenseness, anxiety and insecurity, which can manifest as stress responses in psychosomatic complaints. | **Risk-taking behaviour hazardous to health**<br>Smoking.<br>Excessive use of medication, alcohol and/or drugs.<br>Eating disorders. |

## WHO study

- The consequences of abuse can continue to be felt long after the abuse stops
- The effect on physical and psychological health increases as the abuse becomes more severe
- Various forms of abuse and severe, repeated ill-treatment are cumulative over time

WHO 2002

## Extent of elder abuse

- 1-10%  of all elderly people are victims of abuse within their own family
- 2/3 of caregivers are female
  ⇨ psychological abuse
- One in 4 elderly women experiences abuse in her immediate social environment within 12 months

## Detecting abuse

- People working in the health/social services sector are often the first and only points of contact for the victims
- The detection of abuse is not only crucial for providing concrete help in emergency situations, it is also essential in clarifying the type of abuse being perpetrated
- Interface between victims, the institutions providing protection, and the police

## Detecting abuse

- Abusive situations are rarely observed directly
- Emotional and psychological abuse, and financial exploitation are more difficult to detect that physical abuse, negligence, or neglect
- First step ⇨ Addressing the issue sensitively

## Indications of elder abuse

Those affected:

- Are frightened, shy, or aggressive
- Have unexplained physical symptoms that occur repeatedly and in a similar fashion
- Are severely undernourished/in a poor condition of care
- Keep changing doctors ("doctor hopping") and/or missing appointments

Berzlanovich A, Schleicher B, Rásky É: Gewalt gegen ältere Pflegebedürftige. Medical Tribune, Plattform Geriatrie 2012; 39:30

## Red flags

Clear warning signs

- Multiple injuries on multiple occasions
- Injuries which do not coincide with the explanation of how they happened
- Chronic complaints that have no obvious physical causes
- Bruises in places where they are not commonly caused by falling over or walking into something, contoured haematoma, fractures
- Wrist or ankle fractures

## Court-ordered investigations

- Type and degree of injuries
- Duration of health impairments resulting from the injuries, and/or permanent consequences
- Causes of injuries
- Torture
- Type and frequency of the abuse
- Injuries caused by physical/sexual abuse
- Identification of the perpetrator

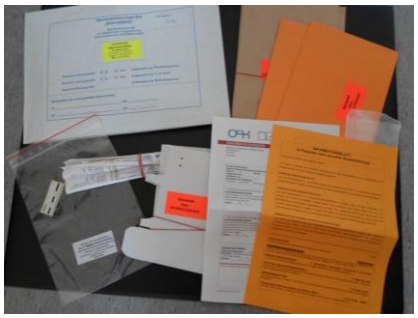
## Medical examination

- General examination
- Genital examination
- Gynaecological examination
- Documentation
- Securing of evidence

## Medical examination

- Securing of evidence if physical and/or sexual abuse has taken place during the last 24 - 96 hours

## Forensic set



Information sheet for the victim

Securing of evidence:
- Foldable cardboard boxes
- Cotton swabs

Securing of clothing:
- A4 envelopes
- Paper bags

Blood and urine samples:
- Plastic bags

Documentation:
- Checklist for examination
- Checklist for collection of samples

.BK
REPUBLIK ÖSTERREICH
BUNDESMINISTERIUM FÜR INNERES
BUNDESKRIMINALAMT

## MedPol – Examination sheet for the documentation of injuries

Project management: Martina Stöffelbauer, Federal Criminal Police Office (FCPO) 1.4 Criminal Strategy
Implementation: Rudolf Gross, FCPO 6.1; Gerhard Rubenz, FCPO 6.2;
Andreas Schmidl, Federal Ministry for the Interior (FMI) II/1/a; Oberst Harald Stöckl, FMI II/2;
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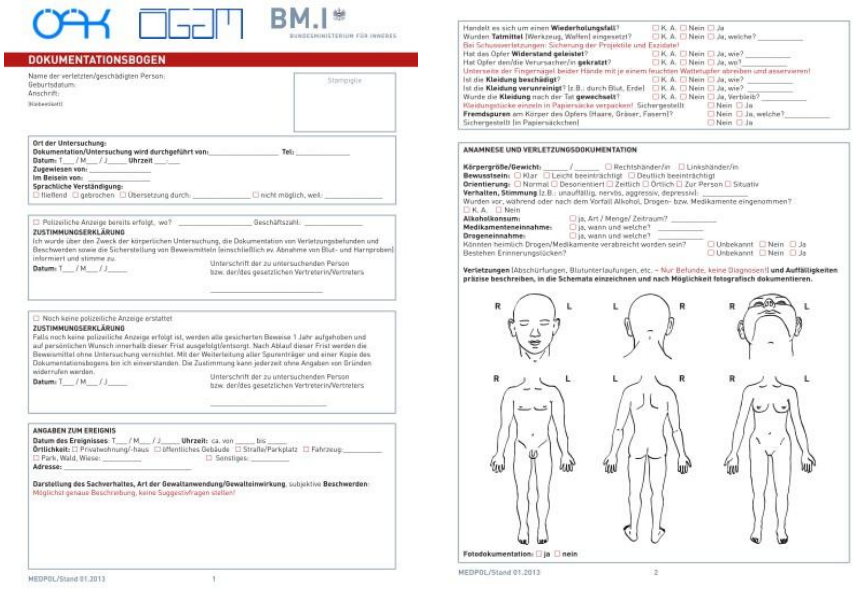
FCPO 1.4 Criminal Strategy; Dr. Jochen Rausch, aä. Service
Conceptualisation: Ao.Univ.-Prof. Dr. Andrea Berzlanovich
Project support: Austrian Society for Forensic Medicine and Austrian Medical Association

## Examination sheet



DOKUMENTATIONSBOGEN

Name der verletzten/geschädigten Person:
Geburtsdatum:
Anschrift:
(Kleberetikett)

Stempigliè

**Ort der Untersuchung:**
**Dokumentation/Untersuchung wird durchgeführt von:** _____ **Tel:** _____
**Datum:** T___ / M___ / J____ **Uhrzeit** ___:___
**Zugewiesen von:** _____
**Im Beisein von:** _____
**Sprachliche Verständigung:**
☐ fließend ☐ gebrochen ☐ Übersetzung durch: _____ ☐ nicht möglich, weil: _____

☐ Polizeiliche Anzeige bereits erfolgt, wo? _____ Geschäftszahl: _____
**ZUSTIMMUNGSERKLÄRUNG**
Ich wurde über den Zweck der körperlichen Untersuchung, die Dokumentation von Verletzungsbefunden und Beschwerden sowie die Sicherstellung von Beweismitteln (einschließlich ev. Abnahme von Blut- und Harnproben) informiert und stimme zu.
**Datum:** T___ / M___ / J____ Unterschrift der zu untersuchenden Person bzw. der/des gesetzlichen Vertreterin/Vertreters
_____

☐ Noch keine polizeiliche Anzeige erstattet
**ZUSTIMMUNGSERKLÄRUNG**
Falls noch keine polizeiliche Anzeige erfolgt ist, werden alle gesicherten Beweise 1 Jahr aufgehoben und auf persönlichen Wunsch innerhalb dieser Frist ausgefolgt(entsorgt). Nach Ablauf dieser Frist werden die Beweismittel ohne Untersuchung vernichtet. Mit der Weiterleitung aller Spurenträger und einer Kopie des Dokumentationsbogens bin ich einverstanden. Die Zustimmung kann jederzeit ohne Angaben von Gründen widerrufen werden.
**Datum:** T___ / M___ / J____ Unterschrift der zu untersuchenden Person bzw. der/des gesetzlichen Vertreterin/Vertreters
_____

**ANGABEN ZUM EREIGNIS**
**Datum des Ereignisses:** T___ / M___ / J____ **Uhrzeit:** ca. von ____ bis ____
**Örtlichkeit:** ☐ Privatwohnung/-haus ☐ öffentliches Gebäude ☐ Straße/Parkplatz ☐ Fahrzeug: _____
☐ Park, Wald, Wiese: _____ ☐ Sonstiges: _____
**Adresse:** _____

**Darstellung des Sachverhaltes, Art der Gewaltanwendung/Gewalteinwirkung**, subjektive **Beschwerden:**
Möglichst genaue Beschreibung, keine Suggestivfragen stellen!

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Handelt es sich um einen **Wiederholungsfall**? ☐ K. A. ☐ Nein ☐ Ja
Wurden **Tatmittel** (Werkzeug, Waffen) eingesetzt? ☐ K. A. ☐ Nein ☐ Ja, welche? _____
Bei Schussverletzungen: Sicherung der Projektile und Exzidate!
Hat das Opfer **Widerstand geleistet**? ☐ K. A. ☐ Nein ☐ Ja, wie? _____
Hat Opfer den/die Verursacher/in **gekratzt**? ☐ K. A. ☐ Nein ☐ Ja, wo? _____
Unterseite der Fingernagel beider Hände mit je einem feuchten Wattetupfer abreiben und asservieren!
Ist die **Kleidung beschädigt**? ☐ K. A. ☐ Nein ☐ Ja, wie? _____
Ist die **Kleidung verunreinigt**? (z.B.: durch Blut, Erde) ☐ K. A. ☐ Nein ☐ Ja, wie? _____
Wurde die **Kleidung** nach der Tat **gewechselt**? ☐ K. A. ☐ Nein ☐ Ja, Verbleib? _____
Kleidungsstücke einzeln in Papiersäcke verpacken! Sichergestellt ☐ Nein ☐ Ja
**Fremdspuren** am Körper des Opfers (Haare, Gräser, Fasern)? ☐ Nein ☐ Ja, welche? _____
Sichergestellt (in Papiersäckchen) ☐ Nein ☐ Ja

**ANAMNESE UND VERLETZUNGSDOKUMENTATION**
**Körpergröße/Gewicht:** _____ / _____ ☐ Rechtshänder/in ☐ Linkshänder/in
**Bewusstsein:** ☐ Klar ☐ Leicht beeinträchtigt ☐ Deutlich beeinträchtigt
**Orientierung:** ☐ Normal ☐ Desorientiert ☐ Zeitlich ☐ Örtlich ☐ Zur Person ☐ Situativ
**Verhalten, Stimmung** (z.B.: unauffällig, nervös, aggressiv, depressiv) _____
Wurden vor, während oder nach dem Vorfall Alkohol, Drogen- bzw. Medikamente eingenommen?
☐ K. A. ☐ Nein
**Alkoholkonsum:** ☐ ja, Art / Menge/ Zeitraum? _____
**Medikamenteneinnahme:** ☐ ja, wann und welche? _____
**Drogeneinnahme:** ☐ ja, wann und welche? _____
Könnten heimlich Drogen/Medikamente verabreicht worden sein? ☐ Unbekannt ☐ Nein ☐ Ja
Bestehen Erinnerungslücken? ☐ Unbekannt ☐ Nein ☐ Ja

**Verletzungen** (Abschürfungen, Blutunterlaufungen, etc. – Nur Befunde, keine Diagnosen!) **und Auffälligkeiten präzise beschreiben, in die Schemata einzeichnen und nach Möglichkeit fotografisch dokumentieren.**




**Fotodokumentation:** ☐ ja ☐ nein

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## Examination sheet

Fand eine **Gewalteinwirkung gegen den Hals statt?** ☐ Nein ☐ Ja, in welcher Form (z.B.: Würgen, Drosseln)?

Sichtbare Verletzungen am Hals: ☐ Nein ☐ Ja _____
Welche **Begleitsymptome/Beschwerden** waren/sind noch vorhanden?
☐ Stauungszeichen (punktförmige Einblutungen in der Haut /Schleimhäuten des Gesichtes), wo konkret?
_____
☐ Schmerzen im Halsbereich ☐ Schluckbeschwerden ☐ Sehstörungen ☐ Schwindel
☐ Urin- und/oder Stuhlabgang ☐ Bewusstlosigkeit ☐ Sonstige: _____

Erkennbares Verletzungsmuster (z.B.: Doppelstriemen, Schuhsohlenabdruck) vorhanden?
☐ Nein ☐ Ja, welches? _____

**ZUSÄTZLICHE ERHEBUNG UND SPURENSICHERUNG BEI SEXUALDELIKTEN**

Letzte Regelblutung: _____ / _____ / _____ Verhütungsmaßnahmen: _____
Gynäkologische Beschwerden: _____
Konsensueller Geschlechtsverkehr: ☐ Nein ☐ Ja, wann? _____
Mit wem? _____ Wie? _____ Mit Kondom? ☐ Nein ☐ Ja

**Orale Penetration:** ☐ Unklar ☐ Nein ☐ Versucht ☐ Ja
**Vaginale Penetration:** ☐ Unklar ☐ Nein ☐ Versucht ☐ Ja
**Anale Penetration:** ☐ Unklar ☐ Nein ☐ Versucht ☐ Ja
**Andere sexuelle Handlungen:** _____
**Wurde ein Kondom verwendet:** ☐ Unklar ☐ Nein ☐ Ja, Verbleib? _____
**Ejakulation:** ☐ Unklar ☐ Nein ☐ Ja, wohin? _____
Ejakulat auf Hautoberfläche mit feuchtem Wattetupfer abreiben! Sichergestellt ☐ Nein ☐ Ja
**Tampon, Binde, Slipeinlage, ect. vorhanden:** ☐ Nein ☐ Ja Sichergestellt ☐ Nein ☐ Ja
Ist eine Reinigung erfolgt? ☐ Ja, wie? (gewaschen, geduscht, gespült, ect.) _____ ☐ K. A. ☐ Nein
Falls nur abgewischt, womit? _____
Uriniert? ☐ Nein ☐ Ja
Sind möglicher Weise **fremde Speichelspuren auf Hautoberfläche** vorhanden (z.B.: nach erfolgtem Küssen, Saugen, Lecken, Beißen?) ☐ Unbekannt ☐ Nein ☐ Ja, wo? _____
Haut an angegebener Lokalisation mit feuchtem Wattetupfer abreiben! Sichergestellt ☐ Nein ☐ Ja

**ORALE PENETRATION**
Abstrich Oral (mit einem trockenen Wattetupfer) KEIN AUSSTRICH! Sichergestellt ☐Nein ☐ Ja

**VAGINALE PENETRATION**
Strikte Einhaltung der Abstrichreihenfolge von außen nach innen, je ein Abstrich mit trockenem Wattetupfer!
Forensische Spuren vor diagnostischen Proben abnehmen!
**Abstrich große Schamlippen und Dammbereich** Sichergestellt ☐ Nein ☐ Ja
**Abstrich kleine Schamlippen und Scheideneingang** Sichergestellt ☐ Nein ☐ Ja
**Abstrich hinteres Scheidengewölbe** Sichergestellt ☐ Nein ☐ Ja
**Abstrich Zervikalkanal** Sichergestellt ☐ Nein ☐ Ja

**Verletzungen** (Abschürfungen, Blutunterlaufungen, etc. – Nur Befunde, keine Diagnosen!) **und Auffälligkeiten präzise beschreiben, in die Schemata einzeichnen und nach Möglichkeit fotografisch dokumentieren.**



**Fotodokumentation:** ☐ ja ☐ nein

**ANALE PENETRATION** (je ein Abstrich)
**Abstrich Anus** (mit einem feuchten Wattetupfer abreiben!) Sichergestellt ☐ Nein ☐ Ja
**Abstrich Rektum** (mit einem feuchten Wattetupfer abreiben!) Sichergestellt ☐ Nein ☐ Ja

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**SICHERSTELLUNG WEITERER BEWEISMITTEL**

**Vergleichsmundhöhlenabstrich**
M+A Sichergestellt ☐ Nein ☐ Ja

**Blut / Urin**
9 ml EDTA -/NaF-/KF-Blut immer und 30-50 ml Urin nur bei Verdacht auf Drogen und/oder Medikamente asservieren.
EDTA -/NaF-/KF-Blut ☐ Sichergestellt ☐ Nein ☐ Ja
Urin ☐ Sichergestellt ☐ Nein ☐ Ja

**Aktuelle Gefährdung** (z.B. Wiederholung) ☐ Unklar ☐ Nein ☐ Ja

**Information über Opferschutz aushändigen!**

**Ende der Untersuchung:** T___ / M___ / J____ **Uhrzeit** ___:___

Unterschrift des/der Untersuchers/Untersucherin _____

**EWEITERGABE DER BEWEISMITTEL**

Sichergestellte Spuren samt Kopie des Dokumentationsbogens für Gerichtsmedizin
Übernommen von _____ am _____
Übergeben von _____ am _____
MHA für DNA-Analyse
Übernommen von _____ am _____
Übergeben von _____ am _____
Blut- und Urinproben für chemisch-toxikologische Untersuchungen
Übernommen von _____ am _____
Übergeben von _____ am _____
Asservate (Kleidung, Tatmittel, Projektile, Exzidate, ect.)
Übernommen von _____ am _____
Übergeben von _____ am _____

**ANMERKUNGEN**

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http://oeggm.com/oeggm-service.html

## Contact information

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## 2 Demenz als Risikofaktor - Ursachen und Risikofaktoren von Missbrauch und Gewalt verstehen – Heike von Lützau-Hohlbein, Deutsche Alzheimer Stiftung, Deutschland

**Dementia as a risk factor – understanding the causes and risk factors of abuse and violence**

Expert Meeting

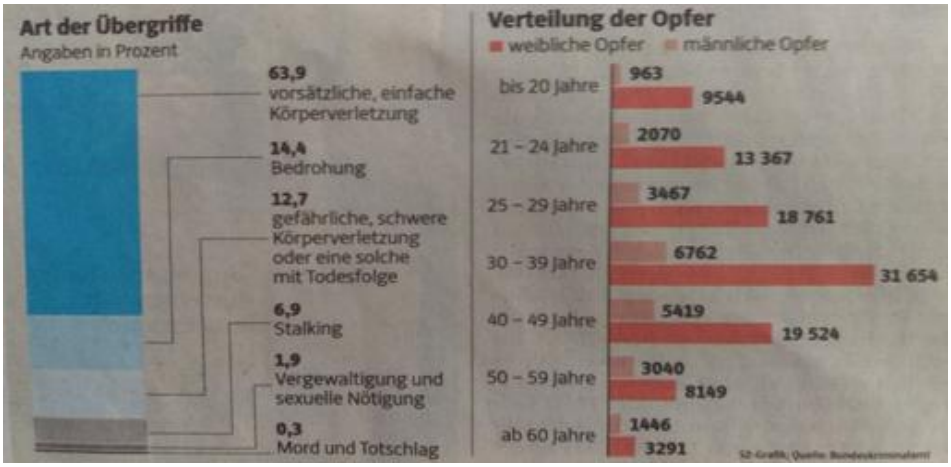
German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Dec. 8./9. 2016, Berlin

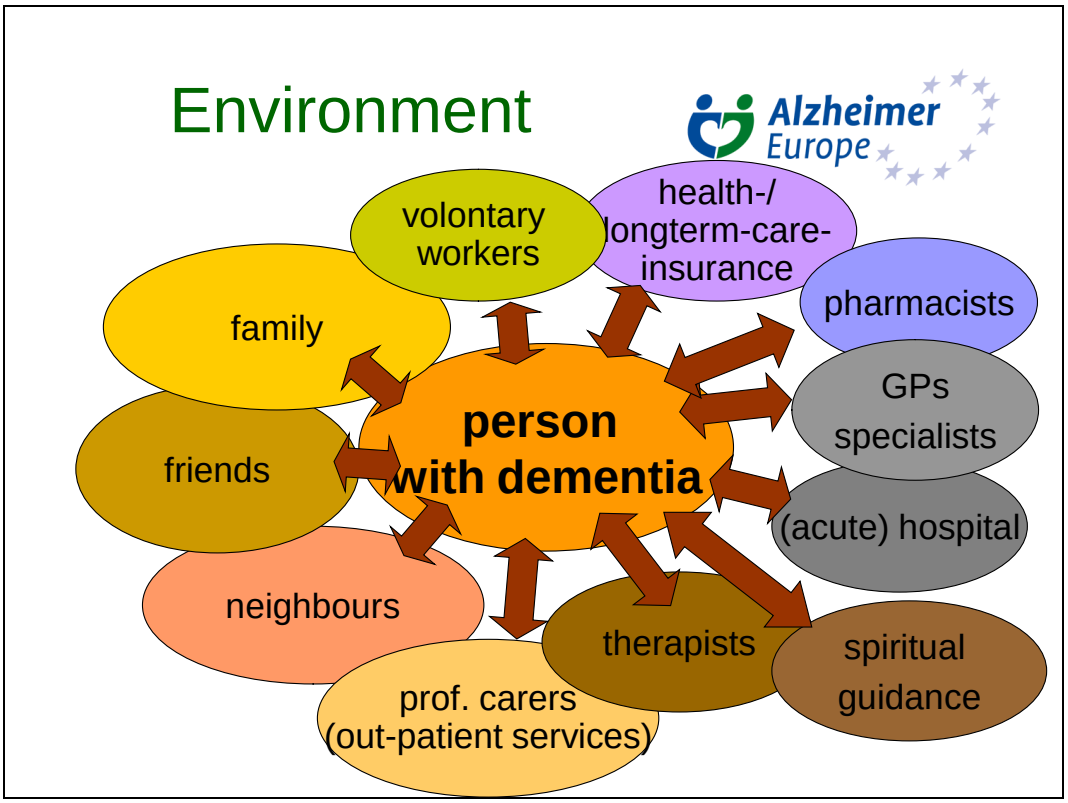
**Heike von Lützau-Hohlbein**

**Alzheimer Europe, Luxemburg**
**Deutsche Alzheimer Stiftung, Berlin**

**In the privacy of one's home**

(Der Horror der eigenen vier Wände)
(SZ 23.11.2016)






## Definition of Abuse

Alzheimer Europe

**Source: German Wikipedia (Dec. 5, 2016):**
**Missbrauch** (lateinisch *abusus*) bezeichnet allgemein den anerkannten Regeln oder Rechtsnormen widersprechenden Gebrauch von Gegenständen oder speziell den sexuellen Missbrauch und den sexuellen Missbrauch von Kindern.

**Source: English Wikipedia (Dec. 5, 2016):**
**Abuse** is the improper usage or treatment of an entity, often to unfairly or improperly gain benefit. Abuse can come in many forms, such as: physical or verbal maltreatment, injury, assault, violation, rape, unjust practices, crimes or other types of aggression.

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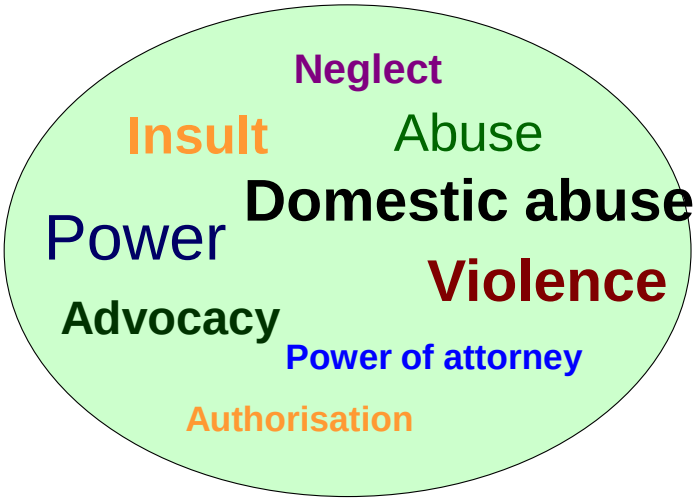
## Complex situation




Beleidigung
Vernachlässigung
Missbrauch
Gewalt
Häusliche Gewalt
Macht
Vollmacht
Gesetzliche Vollmacht
Fürsprache/Vertretung

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## Find out about abuse against elderlies

**(German WikiHow, up to Dec.5, 2016, 1333 accesses)**

Abuse against elderlies is every intentional action or act of negligence which leads to harm or impairment. This may happen by family members, friends or caregivers. Abuse can be distinguished in three areas: **physical or sexual**, **emotional or mental** and **financially**. If you have a suspicion, that a person in your environment is under abuse, you should report it to the civil service that the person is getting aid, support and protection needed.

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## In case of dementia: Abuse of…

- Verbal Abuse
- Abuse of power
- Abuse of trust
- Abuse of discretion
- Physical abuse
- Emotional abuse
- Financial abuse
- Patient abuse
- Sexual abuse
- Abuse of human rights

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## Causes / Risk factors (in case of dementia)

- Behaviour modifications
- Compensation of deficits
- Ignorance of deficits
- Shame
- Guilt
- Fear
- Power
- Vulnerability
- Helplessness

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## In case of dementia: Behaviour modification

- Memory loss
- Loss of orientation (local and time)
- Withdrawal
- Carelessness
- Inattentiveness
- Concentration
- Restlessness
- Agitation
- Anxiety
- Aggression
- Loss of sense of shame
- Sense of safety
- Loss of sense of reality

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## Relationship in the care setting

- Spouse
- Daughter/son
- Daughter-/son-in-law
- Grandchildren
- Foreign caregiver
- …

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## Model Case 1

(Example picture copied from „Dementia in Europe Yearbook 2016“ Alzheimer Europe)

Spouse:

- Couple married since 45 years
- Man develops Alzheimer
- He was the „manager“ in the family
- He is the only driver
- She spent her life as housewife and mother

→ Aggression from his side
Physical abuse from both sides

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## Model Case 2

Daughter-in-law / Mother-in-law:

- Daughter is married to the only son
- Mother develops dementia
- Mother lived in another town, moved to the son‘s home
- Jealousy of mother to daughter-in-law

→ Verbal abuse
Emotional abuse
Physical abuse from both sides
…

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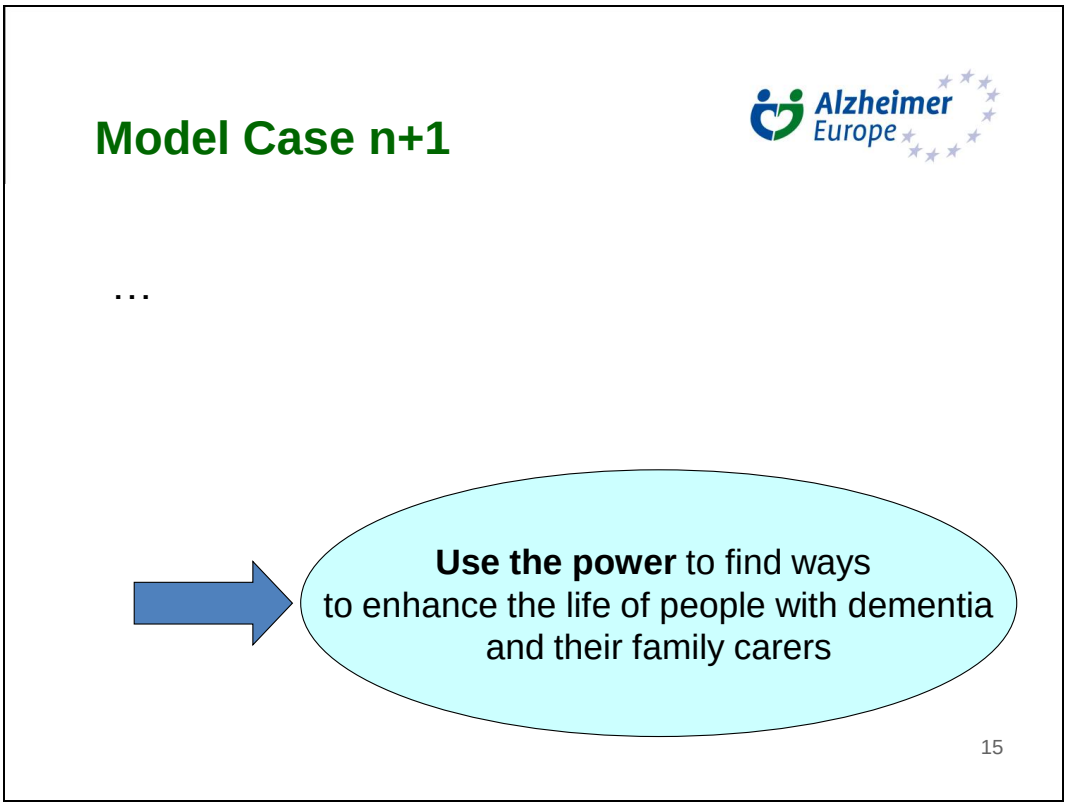
Model Case n+1
Alzheimer Europe
…
Use the power to find ways
to enhance the life of people with dementia
and their family carers
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# 3 Würdevolles Altern und die Bekämpfung von Gewalt gegen ältere Menschen auf europäischer Ebene – Borja Arrue, AGE Platform Europe, Belgien

*Avoiding elder abuse in the home care of people with dementia*, Berlin, 8-9 December 2016

## Dignified ageing and the fight against elder abuse at European level

Borja Arrue, Project and Policy Officer

## Summary

1. AGE: who we are and what we do
2. Long-term care in Europe
3. European-level actions to tackle elder abuse
4. Upcoming actions and goals

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## AGE: who we are and what we do

- European network: 130 organisations

  Germany:
  - Bundesarbeitsgemeinschaft der Senioren-Organisationen (BAGSO)
  - Kuratorium Deutsche Altershilfe, Wilhelmine-Lübke-Stiftung e.V.
  - Sozialverband VdK Deutschland E.V.

- **Mission**: advocate for the rights of older people (50+) at European level

AGE Platform Europe

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## AGE: who we are and what we do

- Areas of work

  - Employment
  - Pensions
  - Active and healthy ageing
  - Accessibility and age-friendly environments
  - **Long-term care: quality and dignity, informal care and work-life balance, adequate social protection, independent living and the transition towards community-based care**
  - **Elder abuse**

  + work on European research projects

AGE Platform Europe

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## Long-term care in Europe

- Wide diversity in availability/quality/organisation of services
- BUT, common challenges:
  - Care organised in silos
  - Financial pressure on care systems
  - Insufficient social protection
  - Lack of recognition of care professionals
  - Lack of support to informal carers
  - Insufficient specific support to older people living with dementia
  - Elder abuse: lack of awareness and missing data

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## European-level actions to tackle elder abuse

- Societal challenge: persistent ageism
- Drives neglect, abuse and undignified care
- Additional factors: overload of professional and informal carers, inadequate training, etc.

→ *Need to develop a rights-based approach and focus on prevention*

AGE Platform Europe

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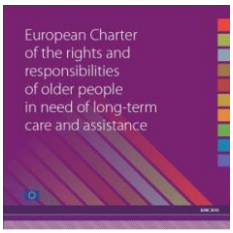
## European-level actions to tackle elder abuse

Two key reference documents:

- European Charter of rights and responsibilities of older people in need of long-term care and assistance (2010)
- European Quality Framework for long-term care services (2012)





AGE Platform Europe

## European-level actions to tackle elder abuse

The Charter and the Quality Framework

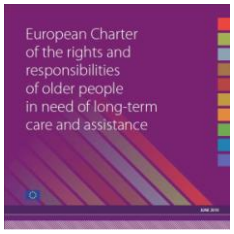
- **Objectives:**
  - Raise awareness of the rights and dignity of older people in need of care, as the means to **prevent elder abuse**
  - Build a shared understanding and a partnership to implement real change, in policy and in practice

AGE Platform Europe

8

# European-level actions to tackle elder abuse

European **Charter** of rights and responsibilities of older people in need of long-term care and assistance (2010)




- 10 articles:
  - Art. 1: Right to dignity, physical and mental well-being, freedom and security
  - Art. 2: Right to self-determination
  - Art.3: Right to privacy
  - Art. 4: Right to high quality and tailored care
  - Art. 5: Right to personalized information, advice and consent
  - Art. 6: Right to continued communication, participation in society and cultural activity
  - Art. 7: Right to freedom of expression and freedom of thought/conscience: beliefs, culture and religion
  - Art. 8: Right to palliative care and support, and respect and dignity in dying and in death
  - Art. 9: Right to redress
  - Art. 10: Your responsibilities

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# European-level actions to tackle elder abuse

European **Quality Framework** for long-term care services (2012)


- Quality principles
  1. Respectful of human rights and dignity
  2. Person-centred
  3. Preventive and rehabilitative
  4. Available
  5. Accessible
  6. Affordable
  7. Comprehensive
  8. Continuous
  9. Outcome-oriented and evidence based
  10. Transparent
  11. Gender and culture sensitive

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## European-level actions to tackle elder abuse

European **Quality Framework** for long-term care services (2012)

- Areas of action: a quality service should contribute to:

1. Preventing and fighting elder abuse and neglect
2. Ensuring good working conditions and working environment and investing in human capital
3. Empowering older people in need of care and create opportunities for participation
4. Developing adequate physical infrastructure
5. Developing a partnership approach
6. Developing a system of good governance
7. Developing an adequate communication and awareness-raising


11

## European-level actions to tackle elder abuse

The Charter and the Framework: what concrete impact?

- Trainings for care professionals and the general Public (WeDO2 Training Package)
- Policies: European Commission's orientations and national policy reforms
- Exchange of practices

http://wedo.tttp.eu/

AGE Platform Europe

12

## European-level actions to tackle elder abuse

Ongoing actions:

- "A human rights-based approach to LTC" project (ENNHRI)
- Annual event on elder abuse
  "Fighting elder abuse in health and long-term care", 16 June 2016, Brussels
- European policy processes: European Pillar of Social Rights and work-life balance package
- **European Union Victims' Rights Directive (2012)**

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## Upcoming actions and goals

- Highlight the challenges facing the detection and reporting of elder abuse and the protection of **victims**: workshop
- Investigate **financial abuse**: conference with AGE members
- Continue to **raise awareness** at European level: AGE's Annual Conference
- Reinvigorate and extend the **WeDO partnership**
- Towards an **EU action plan** on elder abuse?

AGE Platform Europe

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***Thank you!***

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# 4 Vorstellung der Projekte Monitoring in Long-Term Care (MILCEA) und Gewaltfreie Pflege (GfP) – Uwe Brucker, Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (MDS), Deutschland

## Presentation of the projects „Monitoring in Long-Term-Care (MILCEA)“ and Prevention of elder abuse (Gewaltfreie Pflege)

**Expert Meeting „Avoiding elder abuse in the home care of people with dementia – Prevention and intervention measures in European countries**

**8th and 9th December 2016**

**German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth**

08.12.2016 Uwe Brucker

MDS MEDIZINISCHER DIENST DES SPITZENVERBANDES BUND DER KRANKENKASSEN

## Background

milcea
Monitoring in Long-Term Care
Pilot Project on Elder Abuse

**How ist elder abuse actually treated in LTC?**

**How to avoid elder abuse?**

- In Germany: differentiated system of benefits in LTC
- The Long-Term-Care-Insurance is not a comprehensive insurance
- Responsibilty für quality in professional care is legally defined; at least annual inspections of LTC-facilities take place
- Many professions are in contact with persons, who are in need of care (MDK-experts; medical specialists; GPs)
- Counselling- and Supportoffers (e.g. „Pflege in Not“ in Berlin)

GEWALTFREIE PFLEGE | 16.01.2017 | 2 MDS

## Background

milcea
Monitoring in Long-Term Care
Pilot Project on Elder Abuse

- The Individual: Taboo topic; Action alternatives are not known & perceived; deep sense of schame and of being „left alone“
- The Organization: competence and the assumption of responsibility are not seen
- There are no binding regulations of competences ; no networks between the actors in LTC
- „Walk-in-model“ of many counselling and support offers (e.g. „Pflege in Not“)
- There are many assessment instruments , measuring „risks“ of elder abuse BUT: these assessments are not integrated in the strutcures of the organizations

GEWALTFREIE PFLEGE | 16.01.2017 | 3 MDS

## Background

milcea
Monitoring in Long-Term Care
Pilot Project on Elder Abuse

### How to avoid elder abuse in LTC ?

- Trainings to the topic elder abuse; awareness-rising for the own responisbility as a caregiver or doctor
- Assuming responisbility and creating competences (the individual and the organization, the supply system in total)
- Specifying and publishing procedures for actions
- Enabling easy access to counselling and supplying-offers (networking and communication)
- Near to social environment → municipality or district
- Defining a responsible contact person

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Results milcea (2009-2012)

## Analysis of current monitoring structures

milcea
Monitoring in Long-Term Care
Pilot Project on Elder Abuse

- All participating countries (A,D,E,LU,NL) have already structures that need to be involved to put monitoring structures in place
- Before evaluating the structures, main criteria for actors to be potential key actors in a monitoring system were defined:

  1) there is regular contact to the client

  2) (legal) responsibility concerning of elder abuse elder abuse

  3) legal power to intervene to protect the victim

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Results

## Analysis of current monitoring structures

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Monitoring in Long-Term Care
Pilot Project on Elder Abuse

- In the participating countries no actor has direct legal responsibility in the prevention of elder abuse; but there are some actors that have the indirect legal responsibility: e.g. service providers, inspection bodies of nursing homes, legal guardians, general practitioner -> these actors also have in general regular contact to the client
- There are overall countries institutions that have legal power to intervene with direct measures in the case of elder abuse: police, prosecutor office in some countries also the inspection bodies of nursing homes (Austria and Germany: only Care-Home-Inspectors)

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Results

## Analysis of current monitoring structures

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Monitoring in Long-Term Care
Pilot Project on Elder Abuse

- Inspection bodies in all countries also have a documentation system -> might assess indicators of elder abuse (in Germany and in the Netherlands: standardized assessment instrument) -> but goal is not to assess elder abuse, but e.g. quality of care
- There are less monitoring structures in the informal and formal home care setting than in the institutional care setting:
  - In particular informal care setting is problematic when no care allowances are received



Results

## Analysis of current monitoring structures

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Monitoring in Long-Term Care
Pilot Project on Elder Abuse

- Advisory structures specialized on elder abuse, if existing, are only in single regions (exception the support office for domestic violence in the Netherlands)
- There are less monitoring structures in the informal and formal home care setting than in the institutional care setting:
  - In particular informal care setting is problematic when no care allowances are received

Results

## Analysis of current monitoring structures

milcea
Monitoring in Long-Term Care
Pilot Project on Elder Abuse

### Main deficiencies of existing structures:

- Responsibilities concerning elder abuse are not clearly defined and communicated
- There is in general no institution that is specialized on elder abuse (in the Netherlands, in construction)



Results

## Analysis of current monitoring structures

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Monitoring in Long-Term Care
Pilot Project on Elder Abuse

### Main deficiencies of existing structures:

- Professionals in long-term care system are in general hardly sensitized on elder abuse, indicators and risk factors
- ➢ In general lack of education of professionals in LTC
- ➢ No recommendation to use screening tools (exception Spain)
- ➢ There is no defined chain for actors in LTC concerning actions in the case of elder abuse suspicion

**Results**

## Framework of Monitoring in European countries

milcea
Monitoring in Long-Term Care
Pilot Project on Elder Abuse

### Four main prerequisites for monitoring:

- There has to be an awareness and knowledge of elder abuse on general society level and particularly along professionals of long-term care system
- Validated screening/assessment instruments of elder abuse have to be available and incorporated into the monitoring system
- Risk factors of elder abuse must be controlled and reduced
- The responsibilities of actors in the prevention of elder abuse must be clearly defined



## Aims

GEWALTFREIE PFLEGE
PREVENTION OF ELDER ABUSE

- Transforming the MILCEA-recommandations in practice (Stuttgart, Fulda, Potsdam and Dortmund)

  Development and implementation of strategies for prevention ea for outpatient care and nursing homes.

  How do these strategies work in daily living? Which barriers and obstacles can be observed?

- The activities of the municipalities as good-practice-examples?
- all participants are senitized for the topic?
- The quality of life of persons in LTC shall be improved.

## Step 1: preparatory phase

**Developing a prevention approach**

1. **Identification of key actors**
2. **Founding a steering committee**
3. **Survey of the actual structure in the municipalities**



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## Development phase– Results: Action plans

- **Action plans** (e.g. as PDCA-circle) should be handled flexible („every case is different“).
- The responsible for the **case-management** should be
  - Well connected locally and
  - Well qualified and
  - Well known by profesionals and caring relatives, persons in need of care, volunteers.
- The „round table“ leads to reinforcement of the **relationship of cooperation**



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## Development phase – more results

- Actions on the **organizational level** are preconditions for prevention of ea:
  - flexible action plans
  - Defining responible persons on organizational and municipial level
  - Systematical use of screening-instruments
  - BUT: unbinding voluntariness ➜ need of action of the §§-legislator
- **Public relation** needed:
  - Information about elder abuse in care-relations; De-tabooization
  - Place to go is announced
- **Training** of caring relatives an professionel care-givers

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## Transformation phase in the municipalities

- Optimizing of von **Nursing consulting visits** acccording § 37 section 3 SGB XI (Potsdam)
- Development of a **Training concept** (Städt. Seniorenheime Dortmund & MDS)
- **performance of training courses** by local training institutions (District of Fulda, offered in Dortmund, Stuttgart, Potsdam)
- Integration of the topic in training-sets of caring relatives (Dortmund-Scharnhorst)
- **Control committes** guarantee sustainability

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## First Resumee, stimulating/handicapping factors

- The developping-process and the exchange in the control committees leads already to sensitivity of the local actors ("the journey is the reward ", Project nature).
- Flexible case-manangement is preferred; no strict algorithm in acting
- Development-process based on voluntariness are longsome or impossible.
- „Moving spirit" on the local level is needed, the higher the political influence the better for the topic
- Real problem: data protection must be solved

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Schlagen, Schütteln, Kratzen, mechanische Fixierung, z.B. Einsatz von Gurten, Entzug von körperlichen Hilfsmitteln z. B. Wegnahme des Rollators, Medikamentenmissbrauch, z. B. nicht indizierte oder nicht ärztlich verordnete Medikamentengabe, meist zur Ruhigstellung, sexueller Missbrauch, z.B. Missachtung der Intimsphäre, sexuelle Andeutungen, Aggression, emotionale oder psychische Gewalt, z. B. verbale Aggression, Schreien, Schimpfen, Missachten, Ignorieren, soziale Isolation, Handeln gegen den Willen, Androhung körperlicher Gewalt, Demütigungen und Beleidigungen, Manipulation, Missbrauch der Machtposition, Missachtung der Privatsphäre, Überredung / Nötigung zu Geldgeschenken, Entwenden von Geld / Wertgegenständen, Vernachlässigung, z.B. Unterlassen von notwendigen Hilfen im Alltag, unzureichende medizinische Versorgung, z.B. mangelhafte Wundversorgung, mangelhafte Pflege, schlechte Hygiene, Nahrungs- und / Flüssigkeitsentzug, Pflege ohne Gewalt gegen ältere und pflegebedürftige Menschen

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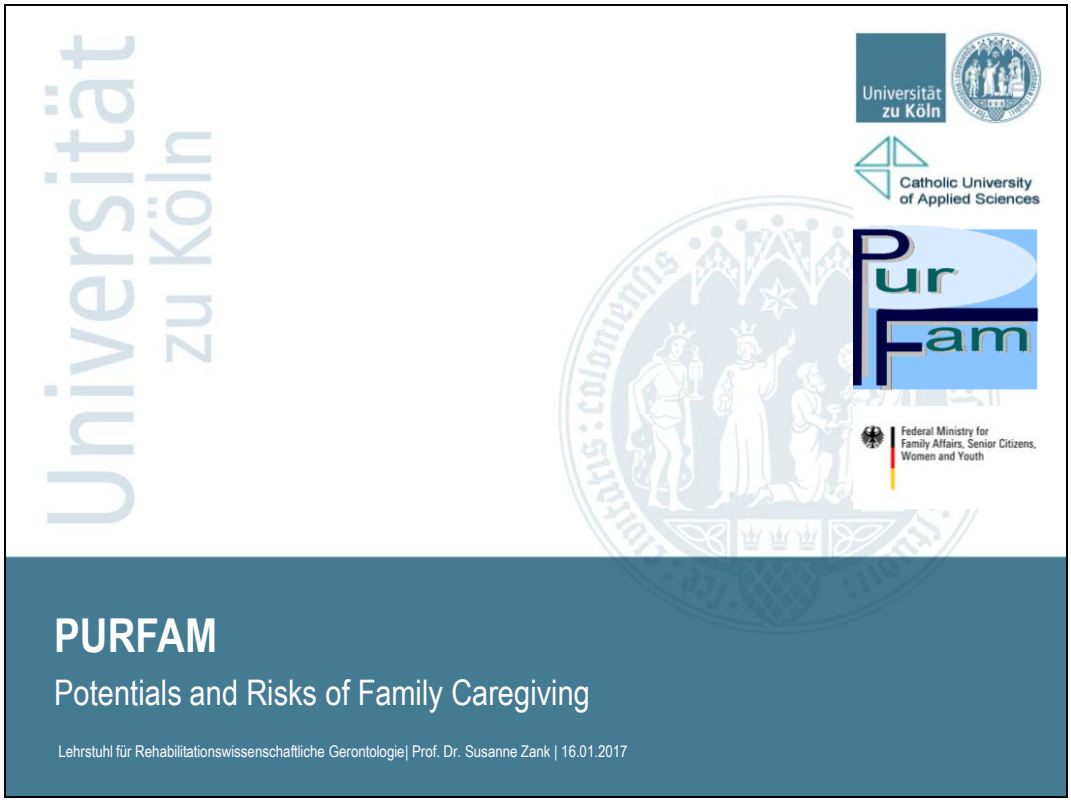
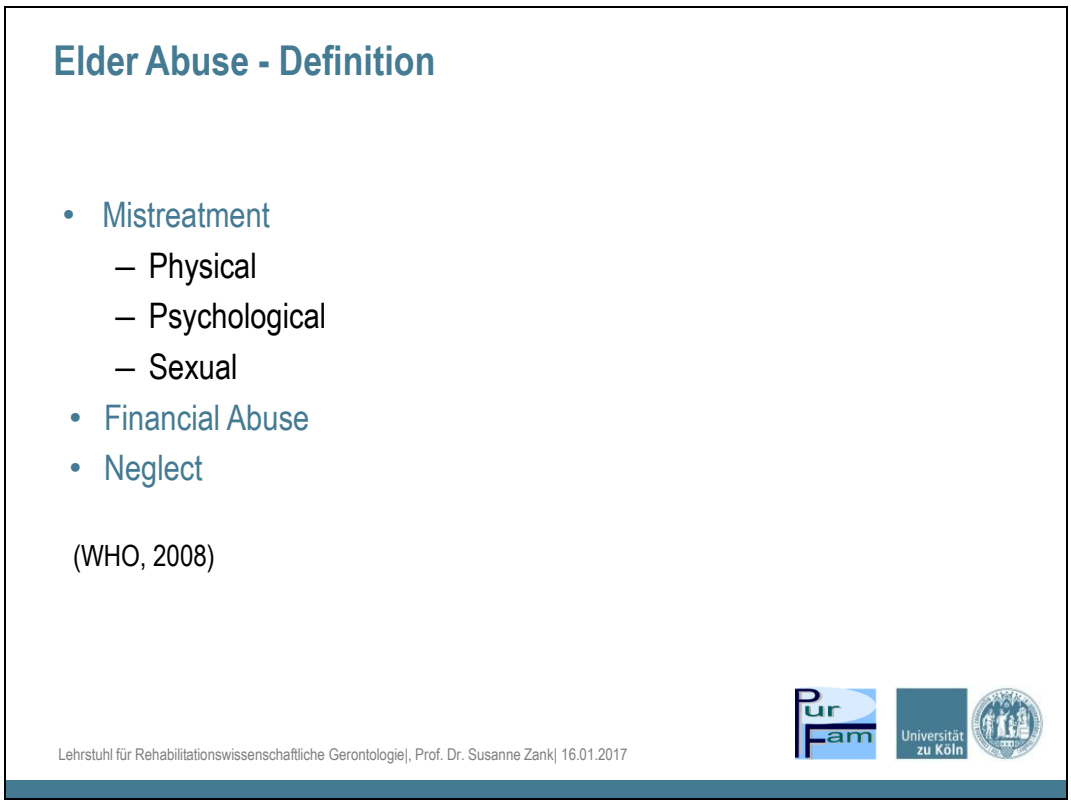
GEWALTFREIE PFLEGE | 16.01.2017 | 18 MDS

# 5 Vorstellung des Projektes Potentiale und Risiken in der familialen Pflege alter Menschen (PURFAM) – Prof. Dr. Susanne Zank, Universität zu Köln, Deutschland



## Prevalence of Elder Abuse

Representative Study with 2.111 Participants older than 66 :

- **2,6% including all forms of mistreatment, financial abuse and neglect**

(National Prevalence Study of Elder Mistreatment, UK: Biggs et al. 2009)



## Prevalence in Family Caregiving (N = 888 Caregivers)

| Item | often/ very often |
|---|---|
| I become louder | 21% |
| I get so angry I could shake my relative | 7,5 % |
| I don‘t know to help myself other than to limit my relative‘s mobility | 5,5% |

Data from LEANDER (Thoma, Schacke & Zank, 2004)

## PURFAM
## Potentials and Risks of Family Caregiving

### Purpose

- Enabling Staff Members of Home Care Services in Preventing Elder Abuse

### Method

- Facilitating an Assessment Instrument for the early Recognition and a Standard of Action
- Providing Training Sessions for Staff Members of Home Care Sevices



## PURFAM – Setting and TEAM

Time Frame: 12.2009 – 12.2012

TEAM Members and Locations

| Function | University of Cologne | Catholic University of Applied Sciences Berlin |
|---|---|---|
| Head of Project | Prof. Dr. Susanne Zank | Prof. Dr. Claudia Schacke |
| Project Management | Dr. H. Elisabeth Philipp-Metzen | |
| Staff Member | Sonja Heidenblut | Marion Bonillo |
| | Constanze Steinhusen | Susanna Saxl |
| | Inka Willhelm | |

## PURFAM-Intervention
### For Home Care Services

Intervention-Modules


### Training - Components

1. Basic Information :
2. Elder Abuse in informal Caregiving
3. Early Detection and Documentation (Assessment)
4. Legal Questions / Questions of Jurisdiction
5. Intervention

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## PURFAM-Assessment

**Development of the Itempool**

Based on:
- Interviews with National Experts in the Field
- National and International Literature
- National and International Elder-Abuse-Instruments

**Content-Validation of the Checklists**

- PURFAM-Team
- International Workshop
- PURFAM-Training (Pilot)

Purpose:
- Minimising False Positives
- Avoiding Role – Conflicts for the Operator
- Considering the Regulatory Framework
- Keeping the Information and Documenation clear and easy
- Guiding the Decision Process of the Home Care Team

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## PURFAM-Assessment

| When? | Who? | Which Instrument? | What for? |
|---|---|---|---|
| 2-3 Weeks after Begin of Care by Home Care Service | Head of Nursing Service/ Nursing staff | BIZA-D-PV-PURFAM | • Developing a personal Relationship with the Client<br>• Monitoring Risk Factors |
| 2-3 Weeks after Begin of Care by Home Care Service | Nursing Staff | PURFAM-Checklist: Nursing Staff | • Documenting difficult nursing Situations in an objective way<br>• Providing basic Information for Case-Management within the Team |
| Next Team-Meeting | Home Care Service-Team | PURFAM-Checklist: Nursing Team | • Estimating the Risk of the Situation<br>• Decision-Making |

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## BICS-D-PV / PURFAM*
### Subscales

A: Restrictions in Personal Needs

B: Lack of Social Support

C: Coping

D: Cognitive Decline

E: Aggressiveness and Confusion

* Based on the Berlin Inventory of Caregiver Stress Dementia (BICS-D, Zank et al., 2006)

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## BIZA-D-PV / PURFAM Example

**2. Behavior Changes in the Patient**

We would like to know whether and how often your relative currently reveals specific dementia-related behavior problems. We are also interested in learning how much of a burden these behaviors are for you.
If the behavior in question did not occur in the last 2 weeks or never occurred, please mark the "0" and go on to the next behavior. If the behavior did occur in the past 2 weeks, please indicate how often it occurred and also how much of a burden this was for you.

| | Frequency of behavior | | | | Amount of burden | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **The patient …** | Never / / not in the last 2 weeks | Once in the 2 weeks | Once/Week | Several times/Week | Once a day or more | Not at all | Somewhat | Moderate | Considerable | Heavy [Strong] |
| 1. repeats him/herself (e.g., asks the same questions, says the same things). | (0)---(1)---(2)---(3)---(4) | | | | | (0)---(1)---(2)---(3)---(4) | | | | |
| 2. does things that seem crazy to me. | (0)---(1)---(2)---(3)---(4) | | | | | (0)---(1)---(2)---(3)---(4) | | | | |
| 3. is restless. | (0)---(1)---(2)---(3)---(4) | | | | | (0)---(1)---(2)---(3)---(4) | | | | |
| 4. is not responsive to logical arguments. | (0)---(1)---(2)---(3)---(4) | | | | | (0)---(1)---(2)---(3)---(4) | | | | |
| 5. Scolds me. | (0)---(1)---(2)---(3)---(4) | | | | | (0)---(1)---(2)---(3)---(4) | | | | |



## PURFAM – Checklist Nursing Staff:
### Observing and Documenting

### Indicators of Mistreatment and Neglect

- Physical Signs
- Suspicious Behaviours of the Care Recipient
- Cospicous Behaviours of the Caregiver
- Cospicous Interaction between Caregiver and – Care-Recipient

### Observed Mistreatment and Neglect

- Psychological Abuse
- Neglect
- Restrictions of Freedom
- Physical Abuse
- Financial Exploitation
- Sexual Abuse

## PURFAM – Checklist Nursing Staff:
### Observing and Documenting

| Please check which forms of problematic behavior in caregiving were observed or reported |
|---|
| The following type of **physical abuse** was observed<br>☐ Hitting ☐ Shoving/Pushing ☐ Shaking ☐ Pinching ☐ Grabbing roughly<br>☐ Other physical abuse, namely: _____ |
| The following types of **restrictions** of **freedom** have been observed<br>☐ Restraints ☐ Restraint through medication ☐ Restraint through denial of therapeutic aids<br>☐ Barrier construction ☐ Confinement<br>☐ Other instrumental abuse, namely:_____ |

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## PURFAM – Checklist Nursing Team:
### Evaluating and Decision Making

- Documenting Sources of available Information
- Evaluating the Indicators
- Evalutating the Observations
- Evaluating the Protective Factors
- Planning the Cause of Action
- Planning the Evaluation of Action

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## PURFAM – Checklist Nursing Team:
### Evaluating and Decision Making

| Information available to assess the caregiving situation | | |
|---|---|---|
| Did you witness a caregiving situation during [your] work that you felt was questionable? | yes | no |
| Did the care recipient report caregiving situations that were questionable? | yes | no |
| Did the caregiving family member report caregiving situations that were questionable? | yes | no |
| Did some other person report questionable caregiving situations? | yes | no |

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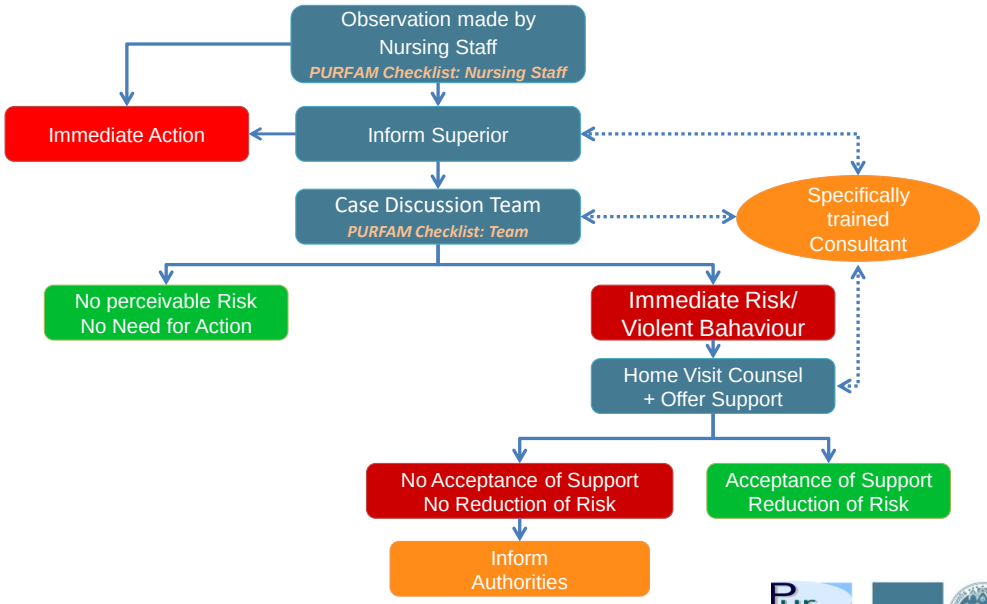
## Standardized Course of Action

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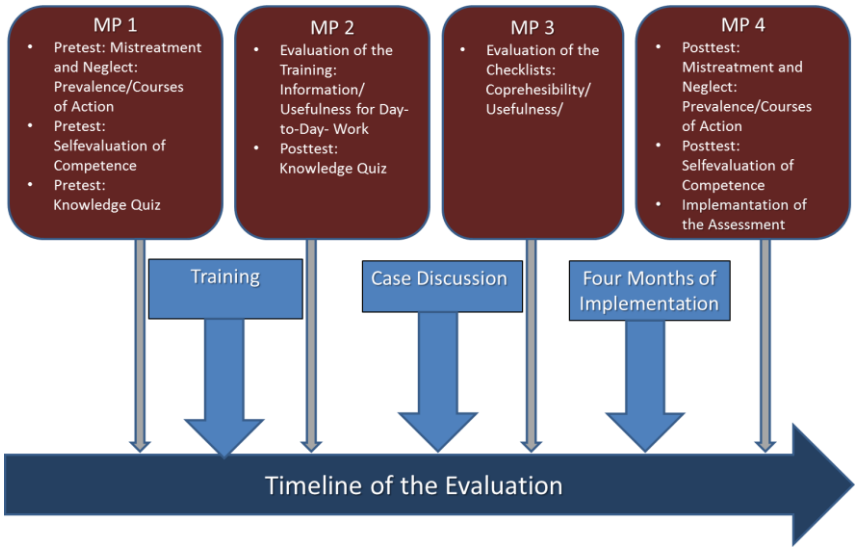
## Evaluation

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## Sample

Participants Training (N = 374)

| Participants characteristics | Data Sets | n | % | M(SD) |
|---|---|---|---|---|
| Age | 365 | | | 45 (11) |
| Sex | 365 | | | |
| male | | 47 | 13 | |
| female | | 318 | 87 | |
| Position in nursing service | 360 | | | |
| Skilled Nurse | | 107 | 30 | |
| Skilled Elderly Care Nurse | | 63 | 18 | |
| Healthcare Assistant | | 59 | 16 | |
| Nursing Management | | 49 | 14 | |
| Others | | 82 | 23 | |
| Work Experience (Years) | 363 | | | 16 (11) |
| Region of Nursing Service | 349 | | | |
| City | | 155 | 44 | |
| Country | | 194 | 56 | |

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## Prevalence of Violence and Strategies of Action

| | N | n | % | M (SD) |
|---|---|---|---|---|
| Evaluation of Topic for Everyday Work | 374 | | | |
| Important Topic | | 279 | 75 | |
| Often encountered in Everyday Work | | 123 | 33 | |
| Prevalence last four months | 179 | | | |
| Observed Cases | | | | 2 (2) |
| Types of Violence | | | | |
| Psychological Abuse | | 138 | 77 | |
| Neglect | | 89 | 50 | |
| Physical Abuse | | 87 | 49 | |
| Financial Exploitation | | 49 | 27 | |
| Sexual Abuse | | 10 | 6 | |
| Strategies of Action on last concrete Case | | | | |
| Further Observation | | 139 | 78 | |
| Discussed in Team | | 139 | 78 | |
| Documented Case | | 96 | 54 | |
| Other | | 58 | 32 | |
| Existence of Norm in Nursing Service | 374 | 32 | 10 | |

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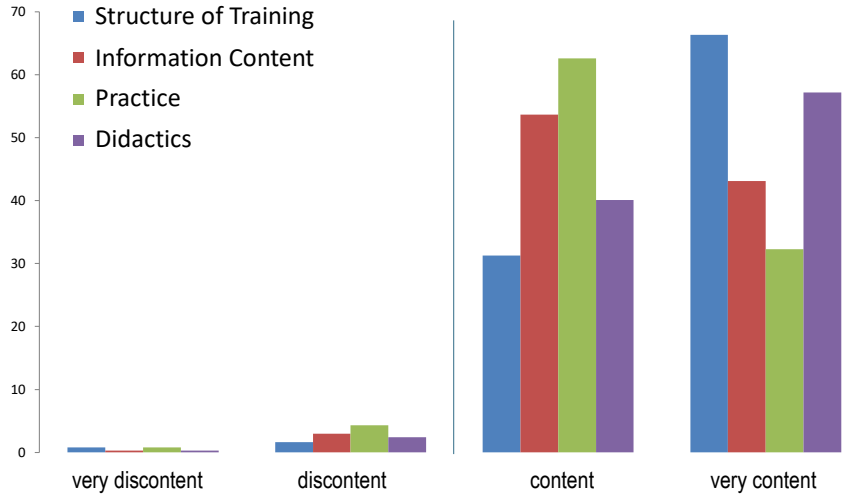
## Participants Evaluation of Training

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## Change of Knowledge
## Knowledge Quiz Scale

| | | | |
|---|---|---|---|
| 15. | If Care Recipients and Family Caregivers live together in one household, the Risk of Mistreatment in Family Caregiving is increased. | R | F |
| 16. | If a caregiving Relative doesn't leave Care Recipient and Nurse alone, this can be a Sign of Mistreatment in Family Caregiving. | R | F |
| 17. | "Mistreatment" describes only active Acts. | R | F |



## Change of Knowledge
## Results

Participants Increase of Knowledge from MP1 to MP2 (21 Points max.)

| | n | M (SD) | T | df | Sig. (2-tailed) |
|---|---|---|---|---|---|
| MP 1 | | 17 (2) | | | |
| MP 2 | | 18 (3) | | | |
| MP2-MP1 | 374 | 1 (2) | 11 | 373 | > .001[1] |

[1] T-Test

## Change of Decision-making and Responsibility (Self-assessment) Scale

**I have the Feeling that I can estimate "Mistreatment in Family Caregiving" accurately.**

| Don't agree at all (1) | Rather don't agree (2) | Rather agree (3) | Totally agree (4) |
|---|---|---|---|

**I know how I can proceed if I suspect "Mistreatment in Family Caregiving".**

| Don't agree at all (1) | Rather don't agree (2) | Rather agree (3) | Totally agree (4) |
|---|---|---|---|

**I have the Feeling that I can act adequately in cases of "Mistreatment in Family Caregiving".**

| Don't agree at all (1) | Rather don't agree (2) | Rather agree (3) | Totally agree (4) |
|---|---|---|---|

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## Change of Decision-making and Responsibility (Self-assessment) Scale

Participants self-assessed Increase of Decision-making and Responsibility from MP1 to MP2 (16 Points max.)

| | n | M (SD) | Sig. (2-tailed) |
|---|---|---|---|
| **MP 1** | | 10 | |
| **MP 2** | | 13 | |
| | 335 | | > .001[1] |

[1] Wilcoxon-Test (Z = -14,6)

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## Discussion

Difficulties

- Knowledge Quiz
- Problem of “Practice vs. Research“

Further Questions

- Long-term Effect of PURFAM Training?
- Was PURFAM-Assessment applied in the Nursing Services?
- Are there Subgroups that particularly benefited from PURFAM-Training?

# 6 Die österreichische Demenzstrategie Gut leben mit Demenz und Maßnahmen zur Unterstützung pflegender Angehöriger – Sabine Schrank, Bundesministerium für Arbeit, Soziales und Konsumentenschutz, Österreich

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## The Austrian Dementia Strategy *„Living well with dementia“* and support measures for caregiving relatives

*Vermeidung von Gewalt in häuslicher Pflege von Menschen mit Demenz – Präventions- und Interventionsmaßnahmen in europäischen Staaten*

Berlin, 08.- 09.12.2016 Bundesministerium für Familie, Senioren, Frauen und Jugend

Mag.ª Sabine Schrank
Sekt. IV/B Provision for long-term care
Federal Ministry of Labour, Social Affairs and Consumer Protection

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## Overview Austrian long-term care system

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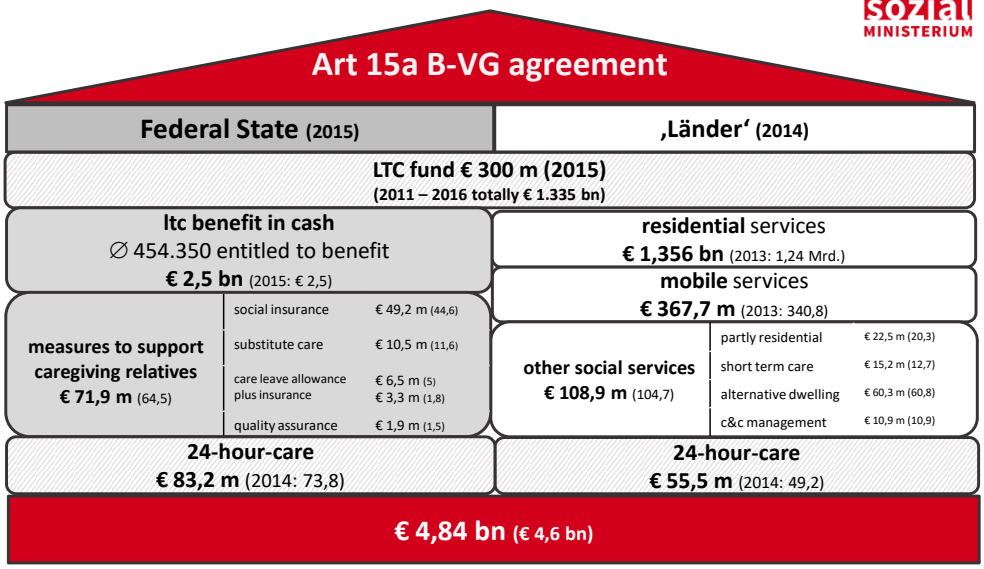


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## Dementia Strategy

- ✓ part of the **Work Program of the Austrian government 2013-2018**
- ✓ on the basis of '**Austrian dementia report**' **2014** (= investigation of status quo)
- ✓ The **Austrian Dementia Strategy *"Living well with dementia"*** provides a framework of objectives, recommendations for taking action to improve the lives of people with dementia as well as their families and carers
- ✓ **6 working groups** (stakeholders, science, concerned persons, social insurance agencies,…) to develop aims and recommendations to improve situation of people affected by dementia and their carers
- ✓ **online consultation** (more than 300 organisations and people replied)

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## Dementia Strategy

- ✓ Dementia Strategy aims at creating a system in which people affected by dementia and their carers
  - live in community that promotes **participation and autonomy**
  - get **information** they need as early as possible
  - know where to go for **help** and which services are available
  - get **high-quality care** irrespectively of place of residence
  - are **actively involved** in decisions about their care
- ✓ Everyone should develop **better understanding** of dementia and defeat the stigma attached to it.

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## Dementia Strategy - 7 objectives

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**Objective 1**

**Promote participation and self-determination/ autonomy for people with dementia and their caregivers**

**Public and professionals should become more aware of dementia and should better understand dementia →**

- removing the stigma of dementia in communities
- creating a dementia-sensitive living environment (e.g. check list communities, improving technology, close-to-home services)

**Participation of people with dementia in social and community life →**

- improving community support services
- improving and promote self determination (self-help groups, support networks), involving them in planning their care and by ensuring legal representation
- involving people with dementia in applied research

**Objective 2**

**Ensure high-quality knowledge on and raise awareness of dementia in public and in special target groups**

**People with dementia, their caregivers and the public should have access to good-quality information on dementia and relevant services through**

- broad information and media campaigns,
- supplementary information for special target groups
- easily accessible information on diagnosis and care services
- the development of a code of good practice for media information

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## Dementia Strategy - 7 objectives

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**Objective 3**

**Improve knowledge, skills, and expertise of formal and informal caregivers**

**Health care + social care staff as well as informal caregivers should acquire the necessary skills to give the best care to people with dementia →**

- providing the appropriate training and
- supporting the caregivers to keep on learning about dementia

**Objective 4**

**Create consistent framework conditions for coordinated care**

**(Political)decision makers + health care + social care service providers should cooperate in developing systems of coordinated services, by**

- establishing a cooperation between the health the social sector on national and regional level
- developing quality standards
- creating a platform for all stakeholders to plan and work together in a coordinated way

**Objective 5**

**Ensure and improve health care and social care services**

**All people with dementia should have access to the support and care they need →**

- ensuring integrated care by multi-professional teams on a local basis with treatment, care and support as needed after the diagnoses, esp. mobile support services for people living at home, intermediate care, and residents with dementia in nursing homes
- improving the quality of care for people with dementia in general hospitals

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## Dementia Strategy - 7 objectives

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**Objective 6**
**Improve cooperation and coordination between different care services**

**All people with dementia and their families should have access to**
- near-to-home contact points and drop-in centers where multi-professional teams give information, provide services for early diagnosis and support, and coordinate care according to the specific need of the person affected.

**Objective 7**
**Improve and ensure quality of care by research on dementia**

**A clear picture of the research on the causes of dementia and the needs of people with dementia will be provided by**
- communicating the recent state of research on dementia
- identifying the gaps in information and data,
- undertaking coordinated research to close the gaps and
- disseminating the findings to (political) decision makers, the public and people with dementia.

→ **21 recommendations**



## Current Implementing Measures

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- **creating a platform for all stakeholders to plan and work together in a coordinated way → website: www.demenzstrategie.at** (online since October 2016)

- **Folder *"Living well with dementia"***

## Support measures for caregiving relatives

I. Financial support for substitute care

II. Paid care leave/ paid family hospice leave for caregiving relatives

III. Care leave allowance

IV. Quality assurance in home care

- Free home visits by request
- Free dialogues between psychologists and caregiving relatives

IV. Free social insurance (pension/ health) for caregiving relatives



## Financial support for substitute care

- **Main caring person** for 1 year
- Long-term care benefit in cash of at least **level 3** (more than 120 hours need of care/month)(or level 1 [more than 65 hours/month] for minors or people with dementia)
- **Inability to provide care** (holiday, illness, other reasons) **for at least 7** (4) **days**
- Private or professional substitute care
- Allowance of **€ 1.200 to € 2.200** (depending on care stage) for maximum 28 days/year (2017 an increase of € 300 in each care stage)
- **Income limit**

## Paid care leave for caregiving relatives

- ✓ **arrangement** employee - employer for
  - ➢ care leave (no wage or salary is paid)
  - ➢ part-time care leave (reducing working time, prorated payment)
- ✓ **1 – 3 months**
- ✓ **to care** for a close **relative** who
  - receives a ltc benefit in cash of at least of level 3 (level 1 for minors or people with dementia)
- ➢ legal title on **care leave allowance**
  - as high as the unemployment benefit (**55 % of daily net income**)
  - **free pension- and health insurance**
  - **no** subject to **income tax**

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## Quality assurance in home care

- ✓ 20.000 annual free and voluntary home visits
- ✓ **Total home visits** between 2001 – 1. half-year 2016: **189.855**
- ✓ **Information, support** and **consultation**
- ✓ **locating the concrete care situation**
  - ✓ standardized report (with 6 domains)
  - ✓ (if necessary) inducing further measures
- ✓ **Since 2015**
  - ✓ free home visits by request
  - ✓ Free dialogues between psychologists and caregiving relatives

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# 7 Prävention und Intervention gegen Gewalt: ein kurzer Überblick über französische Perspektiven und politische Maßnahmen – Dr. Marion Villez, Université Paris-Est Créteil, Frankreich

« Prevention and intervention against abuse of people with dementia living at home : a brief overview on the French perspectives and policy measures »

Marion Villez, Senior lecturer in sociology
University Paris Est Créteil, UFR SESS-STAPS. LIRTES
marion.villez@u-pec.fr

**Expert Meeting :** ***Avoiding elder abuse in the home care of people with dementia - Prevention and intervention measures in European countries.*** **8th and 9th December 2016 - Berlin**

**As introduction :**

At the national level : No specific initiatives nor measures on abuse of people with dementia, but a common framework with elderly people and more widely with people with disabilities

For a long time :
-abuse against elderly people - and even more against people with dementia - is a complete taboo and hidden topic,
-thought as : institutional or "family" abuse and as « active abuse » (physical violence, aggression, theft …).
**Step by step** abuse was thought in a more balanced way and as a diverse (multiform) phenomenon, we have to treated without a caricatural view, in a sensitive way.

- The general movement to describe the French perspective can be summarize in the following shift :
  From "fight against abuse" to "promotion of what is called in France : "well-treatment"

## Main issues:

**A better understanding on what elder « abuse » is:**

***The abuse process***

In France : The topic appears for the first time in the middle of the 80's. Especially with the gerontologist R.Hugonot.

Since that, more and more works and studies are done, to:

- develop a "systemic approach"
- have reflexion and a view on :
  - when abuse begins on when abuse of power… begins (especially in case of people with cognitive disorders) …
  - what are the main risks factors, and the causes
  - what is abuse

Ex: Classification based on the different kind of acts of abuse (Physical ; psychological : financial and medical abuses / negligence (active and passive)/ rights violation) - European council, in 1992.

Ex: Classification based on victims's point of views, on the different kind of damage generated by abuse (Integrity / dignity / autonomy and citizen right) – France : Hélène THOMAS, Claire SCODELLARO, Delphine DUPRÉ-LÉVÊQUE, Etudes et résultats N°370, DREES, 2005).

➢ Beyond the "offensive" kind of abuse (violence, neglict…), the surrounding ageism / the negative social representation / and the truly discrimination against People with dementia and elderly people, are abuse, socially dominant and accepted …

***Statistic datas***

- 15% of the people under 75 years old suffer a form of abuse.
- 80% of the known situations of abuse are at home:
  - The victims are often women (75% of the cases), in average they are 79 years.
  - The person who abuse are often relatives (not only family but also close shopkeepers, commercial visitors at home, neighbourhood …) :
    - family (68% of the case) /
    - shopkeepers, commercial visitors at home, neighbourhood (17% of the case)
  - At home and in family context, abuse concerns financial or "power" aspect.
  - When the medical situations of the victims is known, 30% of them have cognitive troubles.

(Source: Fédération 3977. Alma France. 2016 and 2014)

**Main issues:**

**Intervention and prevention measures : Some key references points :**

- Abuse (especially in home context) : a difficult topic to deal with but very important because:
  - It happens in "closed places" where still few interactions with the outside exist.
  - The "victims" don't complain, sometimes don't are in capacity to complain.
  - "Report" abuse or alarming situations can have risky consequences for the one who denounces.
  - Professionals, volunteers are more isolated than in nursing home, have a structural lack of reference points, of appropriate trainings, and are often in precarious situations.

In that context:

- The objectives of associations, public authorities, providers ' approaches converge towards 6 key goals :
  - Raise Public awareness
  - Prevent (staff recruitment, long term support and training…)
  - Promote the "well traiting"
  - Promote victims'support and protection
  - Facilitate the report procedure and also the control and penalty of the facilities and home care services (to fight against individual or structural organizational abuse)
  - Reinforce Legal protection and ensure rights ' access of the people cared for

***" In France, a system combining : non profit organisations, public authorities in order to better fight abuse"***

Geneviève Laroque.

***Non profit organization initiatives (1/2)*** *(not an exhaustive view)*

- In 1994 : A non profit organization dedicated on abuse against elderly people is created by Pr. R.Hugonot: **ALMA FRANCE** : "Allo miss-traitment" FRANCE. (with the government's support).

Its missions are to develop and federate local phone-listening (at the department level) and counselling center :

Listeners and counsellers (professionals or volunteers) are trained and supported.

They are Linked, when needed, with judicial and administrative authorities if its needed. But, the experience shows that often, in family case, it is listening and mediation that are requested.

At the begining, 7 departments are covered, now 80% of the departments have this relays.

- In 2002, a similar non profit organization was created (**HABEO**) for people with disabilities.
- In 2007, as government action, one single contact phone number at the national level is created : **3977** (to achieve equality of access and nationwide coverage).

This National platform (the listeners are professionals) linked with the local listening and counselling centers managed by the FEDERATION 3977 (with volunteers). FEDERATION 3977 is a fusion (done in 2014) of the 2 non profit organization : ALMA FRANCE and HABEO.

The Federation 3977'missions are : to improve the system, to develop training and prevention.

Nb: Others non profit organizations are also involved on abuse (FNAPAEF, AFPAP…)

***Non profit organization initiatives (2/2) (not an exhaustive view)***

- In 2006, an initiative was taken by the French **society of geriatrics and gerontology (SFGG), launched** (with the support of public authorities) :

MobiQual program : « **Mobilisation to improve quality of care » :**

- ○Proposes scientific and pedagogic reference tools to inform, raise awarness and train those who take care for elderly people, at home or in nursing homes …
- ○One of the 7 topics covered is : « well treatment ». the main idea is that a "well-treated team" becomes a "well-treating team". In this topic, special tools concern people with dementia.

- In 2007, publication by the *Fondation Nationale de Gerontologie*, of the « charte des droits et libertés de la personne âgée en situation de handicap ou de dépendance » which is an actualisation of the 1987' and 1997' versions (with the support of the government).

***Government initiatives (not an exhaustive view)***

- An acceleration at the beginning of 2000 … at the begining most measure concerns facilities context
- **In 2002** (the "2002-2" law) :
  - Creation of the "Comité national de vigilance et de lutte contre la maltraitance des personnes âgées » ("national comittee for vigilance and fight against elder abuse »)
  - Improvement of intervention measures on abuse and sexual abuse especially in nursing home
  - Publication of the "charte des droits et libertés de la personne accueillie"
- **In 2007:**
  - A national plan in order to develop the « weel-treatment » and to reinforce fight against abuse (for elderly people and people with disabilities… 10 measures : one announced a better ratio of professionnals in the facilities and services and improve their recognition.
  - The « Comité national de vigilance et de lutte contre la maltraitance des personnes âgées » is extended to the people with disabilities.

NB: **In 2009**, a guide « give references points on how manage risks of abuse within home care services" was established. Inactive for 2009, the "Comité national de vigilance et de lutte contre la maltraitance des personnes âgées » was **substituted in 2013** by the « national comittee for weel traitment and rights » (CNBD). Formal entry (by law) of the word « well-treatment ».

- A new « agency » was also created : ANESM : sometimes called « weel traitment agency » : National agency for health and care best pratices …
  - ❖ publication by ANESM of guidelines for best practices dedicated on the managers'mission in case of abuse in home care
- Measures are taken to facilitate "report", to improve living conditions and work conditions, to promote people'rigths …

- **In 2015**
  - A new law was adopted(December), : "adaptation of the society to the ageing process"

Some measures concern elder abuse :

-« Report obligation » is extended (concerns the home and nursing homes context). New tools to protect for punishmnent those who report an abuse….

- The Prohibition on receiving money from the users is extended to volunteers and to the care at home … (in the context of the fight against financial and patrimonial abuses, which is an important topic in France)…

- In a more general way : new measures are taken, and existing measures are reinforced to promote people' rights

  - Though the umbrella of the *3rd Alzheimer Plan (2008-2012)* and of the current *Plan on Neurodegenerative diseases* the *national ethics center* has conducted reflexion on ethics, on respect for rights :
    - Publication of a charter to give reference points for carers of people with dementia at home (sept 2016)

      This document insists on the importance of the « obligation of the report » but precises that collegiality is required and that the « victim » has to be informed …

**<u>As conclusion:</u>**

- Others institutions exist. For instance : The « Défenseur des droits » can help individuals to defend their rights.
- All the measures taken for informal carers (respite, training, public awarness, conciliation between care and jobs…) are also a kind of prevention against abuse (The relatives frailty can lead to inapropriate attitude and abuse)

## 8 Unterstützung und Schutz von Erwachsenen in Schottland – Jim Pearson, Alzheimer Scotland, Schottland

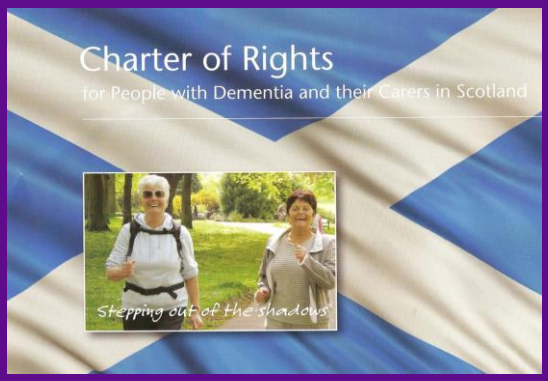
Alzheimer Scotland
Action on Dementia

# Adult Support and Protection in Scotland

Jim Pearson, Director of Policy and Research, Alzheimer Scotland

## Charter of Rights: Human Rights principles and values

- **P**articipation
- **A**ccountability
- **N**on Discrimination
- **E**mpowerment
- **L**egality

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## Scottish Human Rights Commission

- Scotland's National Action Plan for Human Rights (SNAP)
- launched on International Human Rights Day, 10 December 2013
- sets out a bold roadmap towards a Scotland where everyone can live with human dignity.

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## Scrutiny, inspection, improvement

- The Care Inspectorate
  - regulates and inspects care services in Scotland
- Mental Welfare Commission for Scotland
  - monitors - mental health and incapacity law, visiting & investigations
- Health Care Improvement Scotland
  - scrutiny and improvement support health environments
- Professional Bodies
  - Scottish Social Services Council
- Adult Protection Committees (APC): multi-agency committees in every local authority

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## Adult protection

- Three key pieces of legislation which work together to provide a framework for adult protection in Scotland
  - Adults with Incapacity (Scot) Act 2000
  - Mental Health (Care & Treatment) (Scot) Act 2003
  - Adult Support & Protection (Scot) Act 2007
- This is complimented by the Protection of Vulnerable Groups (Scotland) Act 2007 - national disclosure scheme for people who work with vulnerable groups.

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## Adults with Incapacity (Scot) Act 2000 (AWIA)

- Established the **Office of Public Guardian**
- Defines “Incapacity”
- Establishes fundamental principles
- Makes provision for range of welfare and financial interventions
- Establishes statutory responsibilities for **Local Authorities** and **Mental Welfare Commission**

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## Adults with Incapacity (Scot) Act 2000

- The law of Scotland presumes that adults (aged 16 or over) are legally capable of making personal decisions for themselves and of managing their own affairs.
- Only where there is evidence of impaired capacity can this presumption be overturned
- The act allows for intervention in a wide range of property, financial or welfare matters where an adult lacks capacity.
- Intervention is only permitted where an adult is incapable of making decisions in relation to the issue relevant to that intervention

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## Incapacity definition

- Adults over 16
- Incapable, by means of mental disorder, or inability to communicate because of physical disability of
- Acting, or
- Making decisions, or
- Communicating decisions, or
- Understanding decisions, or
- Retaining memory of decisions

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## Principles

- Benefit
- Least restrictive (minimum) intervention
- Take account of past or present wishes of the adult
- Consultation with relevant others
- Encourage the adult to exercise skills he/she has

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## Provisions of the Act

- **Financial**
  - Powers of Attorney
  - Guardianship Orders
  - Intervention Orders
- **Welfare**
  - Powers of Attorney
  - Guardianship Orders
  - Intervention Order
  - Medical Treatment

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## Investigations under adults with incapacity legislation

- Office of Public Guardian - powers to investigate concerns and take steps to safeguard the property and financial matters of an adult with incapacity, where it appears they are at risk of misuse or abuse
- Local Authorities have a duty to investigate circumstances where the personal welfare of an adult appears to be at risk

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## Adult Support & Protection (Scot) Act 2007

- The act creates
  - Statutory duties on Local Authorities (and other bodies), and
  - Statutory powers
- To intervene and prevent harm

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## Who is covered by the ASP Act?

– "Adults at Risk of Harm"; Adults aged 16 years or over, who are
  - unable to safeguard their own well-being, property, rights or other interests;
  - at risk of harm; and
  - because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected *(this may include people who have dementia).*

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## Scope of the ASP Act

– Investigations

– Cooperation

– Protection Orders

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## Adult Support and Protection (Scot) Act 2007 - Principles

Any Intervention must:

- benefit the individual
- be the least restrictive option of those that are available to meet the purpose of the intervention
- the wishes and feelings of the adult at risk (past and present);
- the views of other significant individuals
- the adult's abilities, background and characteristics

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## Investigations

- A duty on Local Authorities to:
  - Make Inquiries and investigations about any known or suspected case of harm to an adult at risk wherever the local authority believes the harm is taking place or likely to take place
  - Powers of entry to any place where adult at risk is present to facilitate investigations

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## Cooperation

The Act sets out statutory duties of co-operation for the following public bodies and their office-holders:

- all councils
- the relevant health board
- Police Scotland
- Care Inspectorate
- Healthcare Improvement Scotland
- Mental Welfare Commission for Scotland
- the Public Guardian
- any other public body or office holder specified by the Scottish Ministers

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## Protection Orders

- The Act gives powers to Local Authorities to apply to a sheriff court for a **Protection Order**
- These take one of three forms
  - Assessment Order
  - Removal Order
  - Banning Order

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## Public information and awareness

http://www.actagainstharm.org/

## Types of harm

The act does not specifically define “harm”

It describes harm as including

- Neglect and acts of omission
- Financial or material
- Psychological/emotional
- Physical
- Sexual

Harm is not limited to the above

## Mental Health (Care and Treatment) (Scot) Act 2003

- The act prescribes
  - when a person can be detained in hospital against his/her will
  - when a person can be given treatment against his/her will
  - what an individual's rights are
  - safeguards to make sure an individual's rights are protected

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## Mental Health (Care and Treatment) (Scot) Act 2003 – Principles

- Non-discrimination
- Equality
- Respect for diversity
- Reciprocity
- Informal care
- Participation
- Respect for carers
- Least restrictive alternative
- Benefit

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## Protection of Vulnerable Groups (Scotland) Act 2007

- Introduced a Protecting Vulnerable Groups Scheme (PVG) for people who work with vulnerable groups.
- To ensure that those who have regular contact with children and protected adults through paid and unpaid work do not have a known history of harmful behaviour.

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## PVG Scheme - Disclosure

- A Disclosure is a document containing impartial and confidential criminal history information held by the police and government departments Disclosure information could include:
  - Details of criminal records
  - Information about a persons inclusion on children's or adults' lists
  - Other relevant information held by Police Scotland or Government Body
- Or state that there is no information
- This information is used by employers (including individuals) to make safer recruitment decisions

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- http://www.gov.scot/Topics/Health/Support-Social-Care/Adult-Support-Protection
- http://www.actagainstharm.org/
- http://www.careinfoscotland.scot/topics/your-rights/adult-support-and-protection/statutory-powers-and-duties/
- http://www.disclosurescotland.co.uk/index.htm
- http://www.publicguardian-scotland.gov.uk/investigations
- http://www.healthcareimprovementscotland.org/
- http://www.careinspectorate.com/
- http://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf
- http://www.scotland.gov.uk/topics/health/services/mental-health/dementia

Alzheimer Scotland

# 9 Schutz in der häuslichen Betreuung alter Menschen – Barbara Baumeister, Zürcher Fachhochschule für angewandte Wissenschaften (ZHAW), Schweiz

Zürcher Hochschule für Angewandte Wissenschaften

School of Social Work

## Institute of Diversity and Social Participation

### Protection in the home care of the elderly

Expert meeting:
Avoiding abuse in the home care of elderly persons with dementia

December 8/9, 2016
Barbara Baumeister

Zurich Universities of Applied Sciences and Art

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Zürcher Hochschule für Angewandte Wissenschaften

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## Research project


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## Violence, abuse, neglect in the home care of elderly persons

- **Abuse**
  Violence by intentional action, directed against the needs of an individual (physical, mental, financial abuse and restriction of a person's free will).

- **Neglect**
  Basic needs are neglected, necessary actions omitted
  - Active neglect entails actions where despite awareness of needs, these are consciously denied (leaving individuals alone, isolated, persistent silence, etc.)
  - Passive neglect entails unintentional neglect or refusal to respond to needs, due to a lack of knowledge, insufficient resources

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## Specialist units and professional groups: Overview

- Outpatient care (Spitex)
- Social counseling (Pro Senectute)
- Alzheimer Association of Switzerland (Alzheimer Vereinigung Schweiz)
- Socio-medical evaluation on site (SiL Zürich)
- Independent Complaints Board for the Elderly (Unabhängige Beschwerdestelle für das Alter, UBA)
- Agency for the Protection of Children and Adults (Kindes- und Erwachsenenschutzbehörde, KESB)
- General practitioner
- Social services in hospitals
- Police

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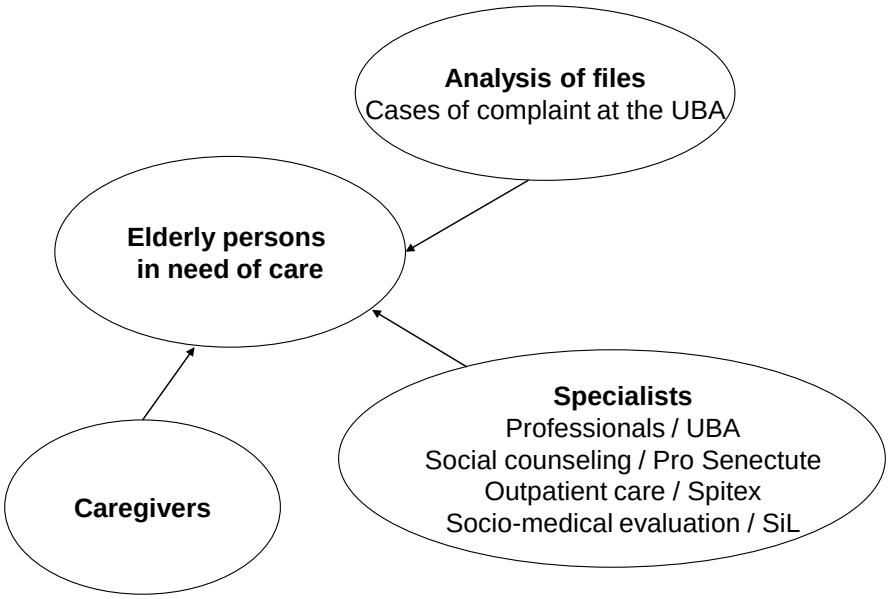
## Various approaches

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## Analysis of files
## Six conflict patterns

- Intergenerative entanglement: *care is performed unsatisfactorily*
- Partnership and development of dementia: *conflict is manifested through changes due to illness*
- Sibling conflict over care performance and financing: *conflict is manifested external to the setting of care provision*
- Social proximity and financial abuse: *care is not affected, but the conflict pattern leads to financial impairment*
- Social isolation and neighbors: *neighbors feel threatened or disturbed by the behavior of the person*
- Autonomy of action and need for protection: *greatest possible autonomy with simultaneous protection*

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## Findings from interviews with specialists
### Social counseling, outpatient care, socio-medical evaluation, professionals UBA

- All persons interviewed are confronted with the topic area ‘Protection for elderly persons in need of care’ in their professional sphere of activity.
- Conflict patterns in the analysis of files were confirmed by the description of cases by specialists.
- A distinct challenge for all specialist personnel consists in whether their assistance is in fact at all accepted.
- The possibilities for intervention in cases of abuse or neglect differ considerably depending on the specialist office and professional assignment involved.

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## Findings from interviews with specialists

- Importance of early recognition (Social counseling)
- Importance of observation ‘surveillance function’ (Outpatient care)
- Importance of longer-term accompaniment (Socio-medical evaluation [SiL])
- Importance of interdisciplinary interventions (UBA)
- Importance of voluntary work (Social counseling, Independent Complaints Board [UBA])

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## Findings from interviews with persons affected - caregivers and care recipients

Quality of relation:

- Appreciative
  *'I've received a lot, so I'm also giving something in return'*
- fulfilling duties
  *'I've always helped out and that's why now I have to do this'*
- requiring distance
  *'I didn't get much recognition, which is why I'm not ready to sacrifice myself either*'
- in need of help
  *'I help you and you help me'*

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## Conclusions

- When financial interests are the subject of the conflict, the complaint is issued directly by the affected or financially disadvantaged persons.
- In the case of mutual dependencies and isolated family systems, the abuse remains in the dark for a long time.
- A key challenge for all specialist personnel involved consists in ensuring their assistance is accepted.
- Outreach offerings that give advice and support to the system over a longer period of time are crucial in this context.
- The different relationship qualities allow conclusions to be drawn as to why the responsibility for the care was assumed (duty, preservation of the system and recognition) as well as with regard to the risk of escalation.

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## Transfer of findings

- Short report by the specialists: ‘Schutz in der häuslichen Betreuung alter Menschen’ (Protection in the home care of the elderly)
- Information brochure for caregivers and care recipients **www.zhaw.ch/sozialearbeit/haeusliche-betreuung**.
- Baumeister, B. & Beck, T. (eds.), (2016). *Schutz in der häuslichen Betreuung alter Menschen: Misshandlungssituationen vorbeugen und erkennen – Betreute und Betreuende unterstützen*. Bern: Hogrefe AG. (**http://goo.gl/N1iZeP**)

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## Violence, abuse, neglect in the home care of elderly persons

### What cirumstances eventuate in violence in the home?

- Restricted cognitive abilities
- Pressures, burdens, to the point of excessive strains and demands
- Lack of support and social isolation
- Mutual dependencies
- Learned violence as a pattern for solving conflict situations
- Violence in care relationships is often interactive, leading to entanglement in reciprocal acts of violence

‘Assistance can turn to violence as a result of excessive strains and demands’ (Hirsch, 2010)

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# 10 Gewaltprävention im Beratungsgespräch – Marianne Wolfensberger, Schweizerische Alzheimervereinigung, Schweiz

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**Expert talk**
**Avoiding violence in domestic care**
**of people living with dementia**

## Prevention of violence by means of consultation

Marianne Wolfensberger
Swiss Alzheimer's Association

8./9.12.2016 Fachgespräch BMFSFJ, Berlin 1

Short profile

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## Swiss Alzheimer's Association

- National non-profit organisation founded in 1988 by a group of caregivers
- At present more than 10,000 members and more than 100,000 donors
- Umbrella organisation with 21 chapters in all Swiss regions

8./9.12.2016 Fachgespräch BMFSFJ, Berlin 2

## Short profile

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### Mission and services on offer

- Information, counselling and support for people living with dementia and caregivers
- Information, counselling for professionals, specific profession groups
- Services, e.g. respite care, support groups, dementia holidays, Alzheimer Cafés in the various chapters
- Advocacy for people with dementia and carers on a social and political level, while including the persons concerned wherever possible



## Counselling services on offer ("Alzheimer-Telefon" helpline)

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- An official offer by Swiss Alzheimer's since 2004
- 4 plurilingual staff members with specific training and a long experience
- Accredited and subsidised by the Swiss Federal Social Insurance Office for many years (service agreement)

## Content of consultations

- With the constant extension of the Internet and the access to written information, pure knowledge questions have become exceptional.
- Questions asked are increasingly complex and the duration of consultations is on the rise.
- Most frequent topics: How to take care of people with dementia, how to find respite offers
- Average duration of consultations: 20 minutes



## Topic “domestic violence” discussed during consultation

- Enhanced cooperation with UBA (Unabhängige Beschwerdestelle für das Alter / Independent complaint point for the elderly)
- Increasing attention is paid to the topic of violence
- Mutual exchange and forwarding of „situations”
- Advantage: specialised organisation having the possibility to act directly

## Referral to the Adult protection authority

- In Switzerland, the adult protection authorities have come into force in 2013
- Any person may notify the adult protection authority if a person appears to be in need of assistance (notification right). Restriction: professional confidentiality
- Persons acting in an official capacity are required to notify the adult protection authority (notification obligation)
- Counselling centre: generally no obligation to notify (but possibly notification obligations in some cantons)



## Case studies from our consultation service

Example 1

Husband looking for support on the helpline:

- Feeling his own latent readiness to resort to violence (“banging his fist on the table”, “shouting at his wife”)
- Spouse living with dementia (15 years older than husband), increasing cognitive impairment
- Conflicts, mutual verbal abuse, objects gone missing
- Temporary positive effect when the police is brought in
- Husband already attends support group for carers, on the lookout for on-site support: how to behave in difficult situations

## Case studies from our consultation service

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### Example 1

### Support offered:

- Information allowing a better understanding of the effects of dementia and the behaviour of the spouse and thus acquiring more appropriate reaction patterns
- Proposal of a personal meeting with the counsellor
- Bringing in a respite care service in order to grant some spare time for the husband's own needs
- Advice to involve the GP
- Presenting relevant addresses



## Case studies from our consultation service

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### Example 2

### Phone call of a worried niece:

- Aunt, i.e. the wife of an uncle living with dementia, doesn't cope with the situation
- Aunt locks up the uncle when she goes shopping
- This leads to aggression on his part
- Aunt feels overburdened, can see no other issue than placing her husband in a care home
- Uncle refuses

## Case studies from our consultation service

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### Example 2

### Support offered:

- Locking up a person is a form of violence. Explanations on the needs and the rights of the uncle.
- Pondering between allowing someone great latitude and taking risks
- Advice to rely on regular respite care
- Advice to use a GPS locator. This would allow the uncle to go out for walks.
- Setting up respite services provided by other family members
- Explanations on the moment when a care home might be the appropriate solution and on the legal requirements (adult protection law)



## Case studies from our consultation service

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### Example 3

### Phone call of a daughter:

- The mother has advanced Alzheimer's disease.
- The father provides care and assistance to the mother with external support and help from family members.
- The daughter is worried because the father can't cope with the situation any more and has also lashed out against the mother. The mother is afraid of her husband.
- An application for a place in an assisted living community for people with dementia is pending for the mother. However, admittance is not possible before next year.

## Case studies from our consultation service

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### Example 3

### Support offered:

- Explanations on the needs for dementia-specific care and protection in regard to the mother and the need for respite concerning the father/caregiver
- Alleviation of the problematic situation: e.g. medication given and personal hygiene looked after by external nursing service (“Spitex”)
- Advice to involve the GP
- Hint to the existence of UBA (Independent complaint point for the elderly)



## Case studies from our consultation service

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### Example 4

### Case involving our helpline and UBA:

- Other kind of violence: imposing a visiting ban in the care home to the partner of a woman with dementia by the children of this woman
- Both, woman and partner are suffering from this restriction
- Round table with all persons involved shows a lot of misunderstanding and leads to a solution
- Visits by her partner have a positive effect on the behaviour of the woman

## Support for caregivers in Switzerland: political plan of actions

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National Dementia Strategy 2014-2017

- Project 2.1: Individualised information and social counselling services
- Other projects in order to support the family caregivers

Action plan of the Swiss Federal Council:

- Framework conditions for relatives providing care and nursing allowing a long-term engagement without running the risk of overtaxing them.



## Conclusion

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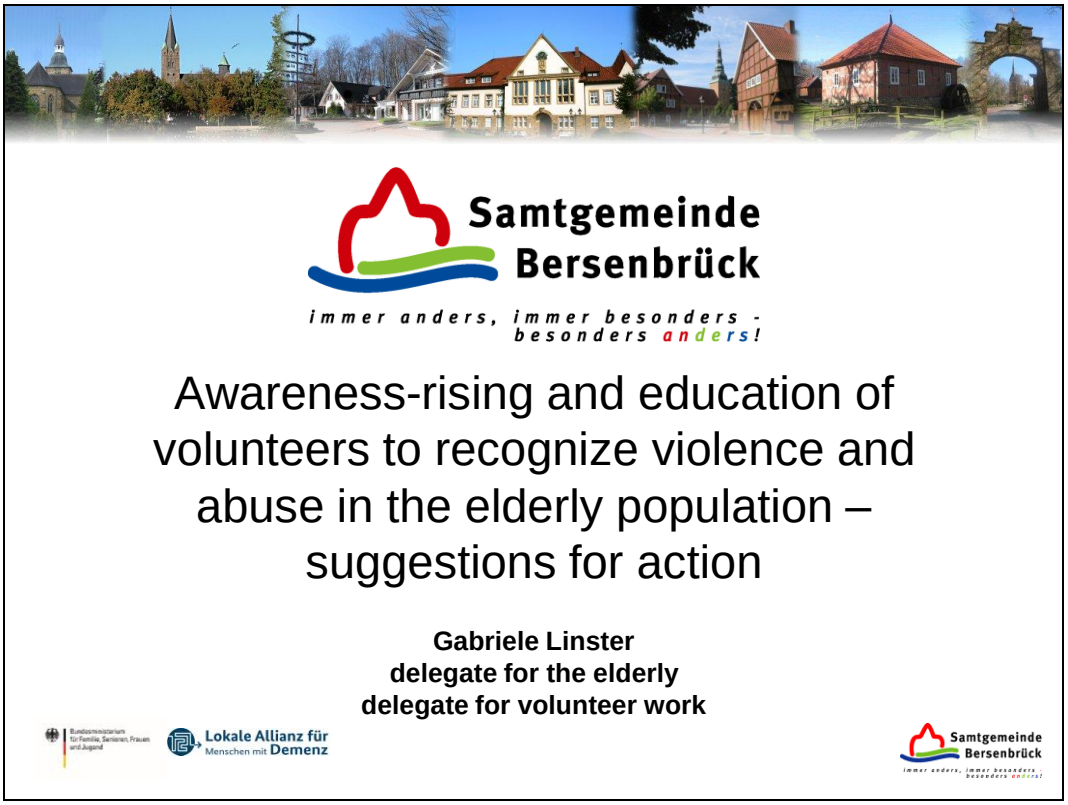
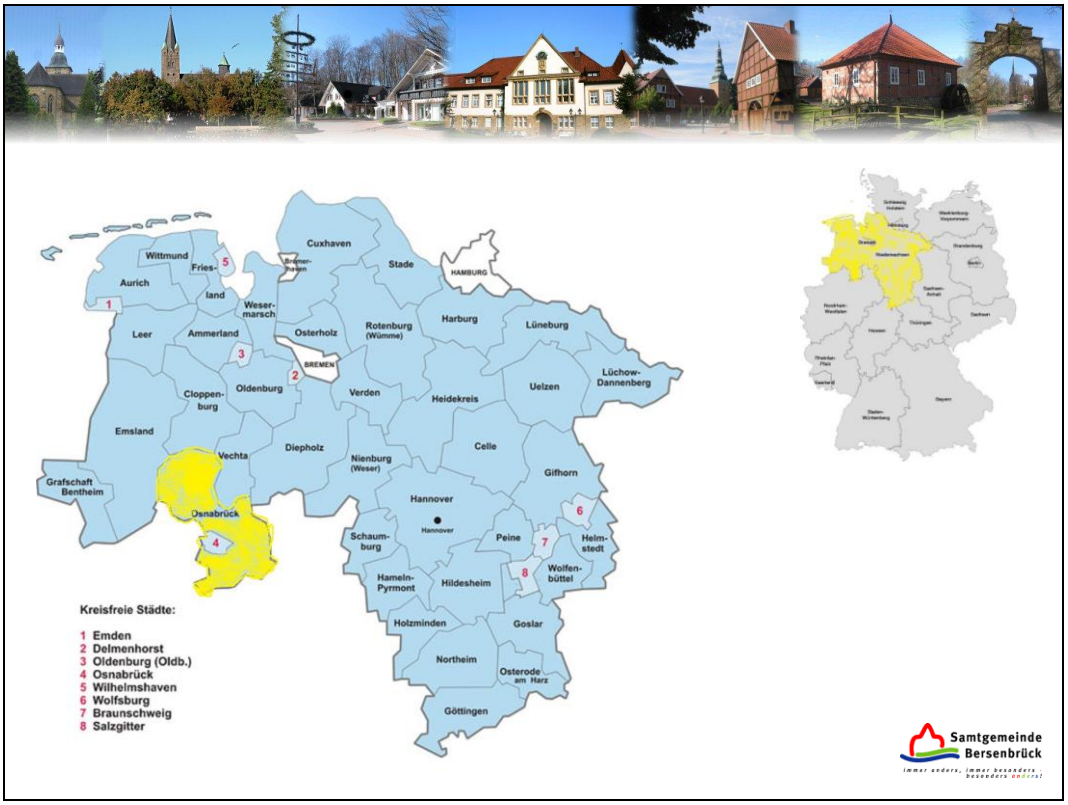
Frequent reasons for (latent readiness to resort to) violence within family members of people living with dementia:

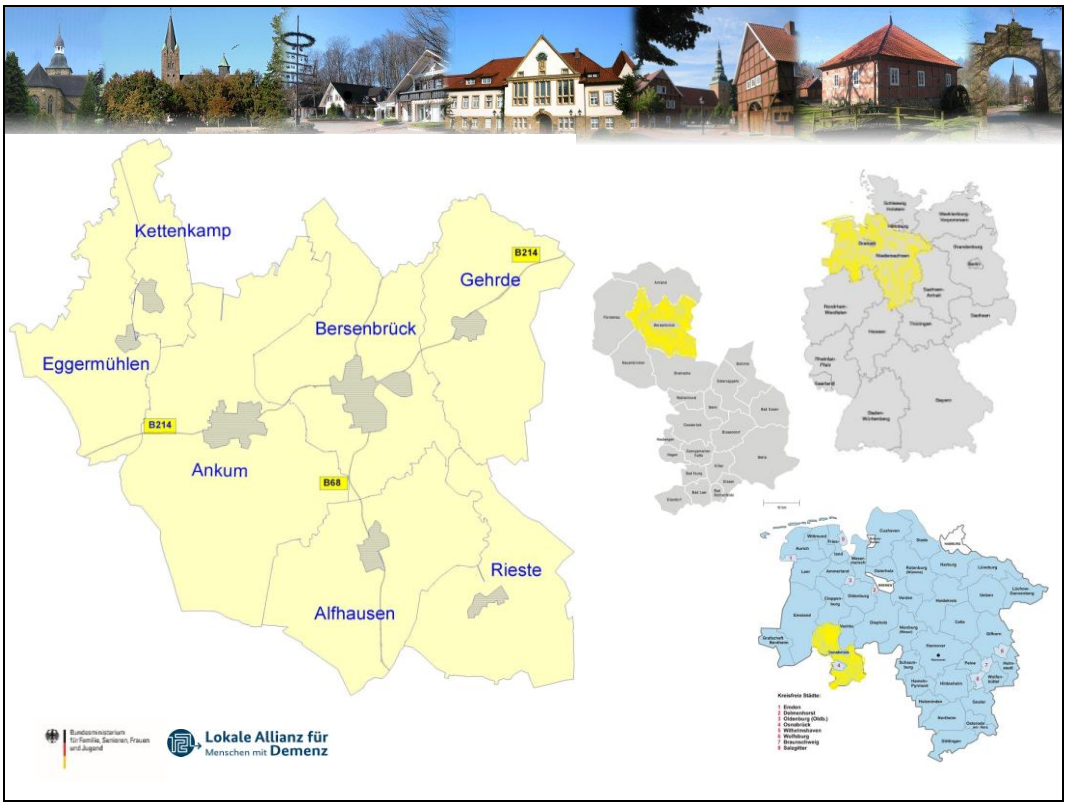
- Inadequate knowledge of the disease pattern
- Lack of understanding for the situation of the person living with dementia
- Overburdening due to nursing care
- Possibly also role reversal
- and many more

A phone call to the helpline is a first important step taken towards the support needed and towards an alleviation of the situation.

## 11 Schulungen und Sensibilisierung von Ehrenamtlichen, um Gewalt und Missbrauch zu erkennen und zu handeln – Gabi Linster, Samtgemeinde Bersenbrück, Deutschland

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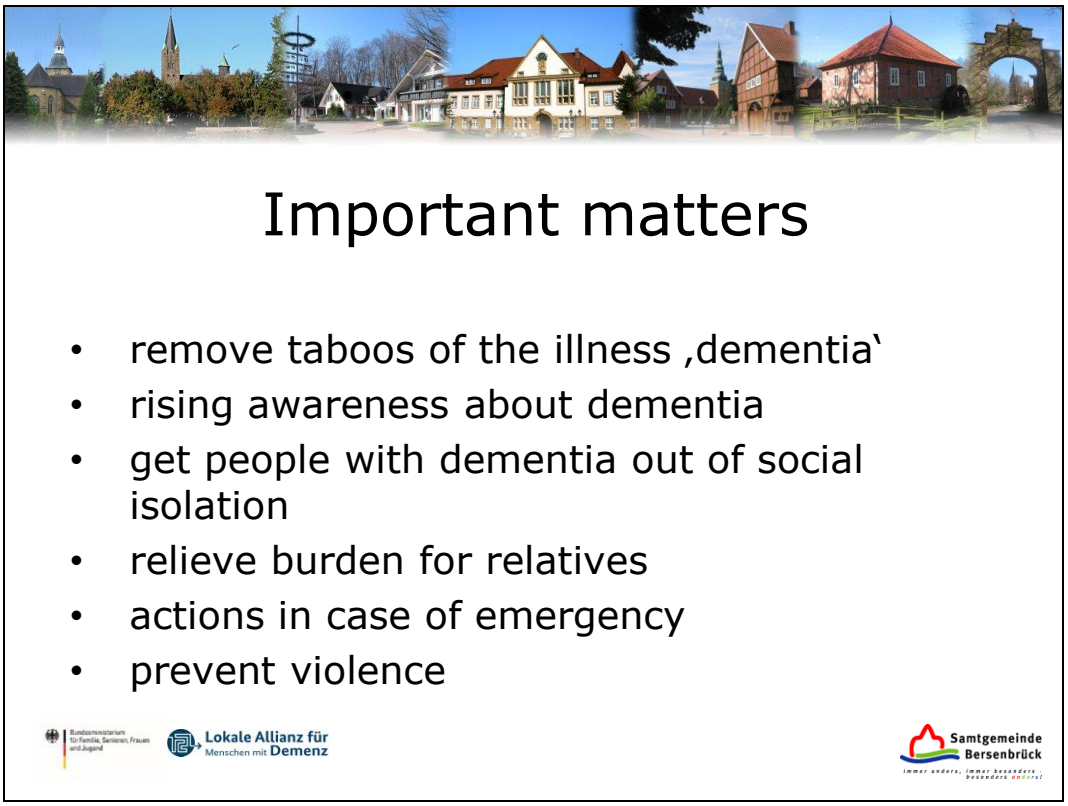
Rieste
Alfhausen
Lokale Allianz für Menschen mit Demenz


Important matters
• remove taboos of the illness ‚dementia‘
• rising awareness about dementia
• get people with dementia out of social isolation
• relieve burden for relatives
• actions in case of emergency
• prevent violence
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Samtgemeinde Bersenbrück

## Areas of action

- share knowledge and experiences among people dealing with dementia
- offer voluntary, mutual and professional support to people dealing with dementia
- offer information, advice and education in close proximity to the place of domicile of the senior citizen
- provide and intensify voluntary and professional mentoring, support and care
- education and information for retailers and service providers

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## Local alliances for people with dementia

- opening ceremony on the 4th Nov 2015
- acquisition of volunteers
- education of volunteers according to § 45 b SGB XI
- recognition of low-level offers of support, assistance and care according to § 45 b SGB XI
- public relations (press, internet)
- information events in local communities

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## Local alliances for people with dementia

- create a media box for the elderly communities in local municipalities
- cooperate with a local vocational school (BBS BSB) on a theater play
- establish a working group on dementia
- World Alzheimer Day:
  - cards, flyers, art exposition, church service, info events
- info-booth at a weekly local farmer‘s market
- yearly assembly of the ‚prevention council‘
- media forum BSB

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## Requests from people with dementia and their relatives (1)

- Information transfer
- Aid and support
- Affection
- More time
- Counceling
- Assistance


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## Requests from people with dementia and their relatives (2)


- Sympathy
- Creativity
- Companionship
- Attention and Security
- Place to roam
- Professional interdisciplinary care providers

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## Service from ‚dementia companions'

1. Team meetings, evaluation
2. Primary consultations in a team
3. Consultations via phone after first meetings
4. Range of voluntary education
5. Varying literature and educational media

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## How to deal with domestic violence

1. Hear → See → Suspect → Detect
2. consultation with team leader
3. house visit as a team
4. discussion with relatives
5. offer and initiate help
6. consultation of medical specialist

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## Future plans

- prioritize services for the public
- strengthening of municipalities to start counceling services
- appropriate support frameworks
- civic solidarity
- ‚altruistic society'
- dementia-friendly surrounding

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Samtgemeinde Bersenbrück


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