



**Observatory for  
Sociopolitical Developments  
in Europe**

## **Documentation**

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

**8<sup>th</sup>/9<sup>th</sup> December 2016**

**Berlin**



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## 1 Introduction

On 8 and 9 December 2016, the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) and the [Observatory for Sociopolitical Developments in Europe](#) extended an invitation to be in Berlin within the scope of an Expert Meeting to discuss the topic of "Avoiding elder abuse in the home care of people with dementia – Prevention and intervention measures in European countries".

According to the World Health Organization (WHO 2015), one out of every ten of the elderly experience violence every month. In the public discussion, the prevalence of domestic violence against the elderly is still underestimated and the topic is strongly tabooed. In particular, people with dementia are at risk of suffering violence in care. The majority of people with dementia in Europe are cared for at home by family members who care for them informally and/or by formal outpatient care services. Care behind closed doors allows very limited possibilities of control. The causes of (intra-family) violence are varied – usually they are a sign of a lack of knowledge about the illness, hopelessness, exhaustion, anxiety about the future or being overburdened.



Ministerial Counsellor Petra Weritz-Hanf,  
Maike Merkle

The Expert Meeting dealt with the question of effective measures of violence prevention and intervention measures. The focus was therefore on the following questions: How can family care givers be informed, supported and relieved, and thus, among other things, be protected against being overburdened, which can lead to violence? And how can signs of violence, mistreatment and abuse be recognised and prevented without stigmatizing?

A total of 19 participants from Switzerland, Scotland, France, Austria, Belgium and Germany took part in the Expert Meeting. Experts from science, practice and politics were represented for this European exchange.<sup>1</sup>

The present documentation summarises the individual inputs and gives an overview of the most important results of the Expert Meeting. The presentations are to be found in a separate annex.

Many thanks to all participants for their active participation, the exchange and for the successful Expert Meeting. In particular, we would like to cordially thank the Ministerial Counsellor, Ms. Weritz-Hanf from the BMFSFJ for the good preparation and cooperation in the development and progress of the Expert Meeting.

For the Observatory: Maike Merkle

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<sup>1</sup> A list of the participants and the organisations represented can be found on pages 40 to 41.

## 2 Program

<b>Thursday, 8.12.2016</b>	
<b>13:00 – 13:15</b>	<b>Registration and welcoming snack</b>
<b>13:15 – 13:35</b>	Welcome & introduction Dr. Matthias von Schwanenflügel, Head of Department, German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany
<b>13:35 – 14:45</b>	<b><u>I. Session: Introduction to the topic</u></b>  Abusive Care Ao. Univ.-Prof. Dr. Andrea Berzlanovich, Department of Forensic Science, Medical University of Vienna, Austria  Dementia as a risk factor – understanding the causes and risk factors of abuse and violence Heike von Lützu-Hohlbein, German Alzheimer Foundation, Germany
<b>14:45 – 15:15</b>	<b>Coffee break</b>
<b>15:15 – 17:00</b>	<b><u>II. Session: Prevention – European perspectives</u></b>  Dignified ageing and the fight against elder abuse at European level Borja Arrue, AGE Platform Europe, Belgium  Presentation of the projects Monitoring in Long-Term Care (MILCEA) and Prevention of elder abuse (GfP) Uwe Brucker, The Medical Advisory Service of Health Insurance (MDS), Germany  Conclusions of the European perspectives Heike von Lützu-Hohlbein, German Alzheimer Foundation, Germany
<b>17:00</b>	<b>End of day 1</b>
Leisure activity after 17:00	Visit of the Christmas Market at the Gendarmenmarkt

<b>Friday, 9.12.2016</b>	
<b>09:00 – 9:15</b>	<b><i>Welcome coffee</i></b>
<b>09:15 – 10:45</b>	<p><b><u>II. Session: Prevention – National perspectives</u></b></p> <p>Presentation of the project Potentials and Risks of Familial Care for the Elderly (PURFAM)  Prof. Dr. Susanne Zank, University of Cologne, Germany</p> <p>The Austrian national dementia strategy <i>Living well with dementia</i> and measures to support family care givers  Sabine Schrank, Federal Ministry of Labour, Social Affairs and Consumer Protection, Austria</p> <p>Prevention and intervention against abuse: a brief overview on the French perspectives and policy measures  Dr. Marion Villez, University of Paris-Est Créteil, France</p>
<b>10:45 – 11:15</b>	<b><i>Coffee break</i></b>
<b>11:15 – 12:45</b>	<p><b><u>II. Session: Prevention – National perspectives II</u></b></p> <p>Adult Support and Protection in Scotland  Jim Pearson, Alzheimer Scotland, Scotland</p> <p>Protecting the elderly in home care arrangements  Barbara Baumeister, Zurich University of Applied Sciences (ZHAW), Switzerland</p> <p>Prevention of elder abuse in individual counselling  Marianne Wolfensberger, Swiss Alzheimer's Association, Switzerland</p>
<b>12:45 – 13:30</b>	<b><i>Lunch</i></b>
<b>13:30 – 14:00</b>	<p><b><u>III. Session: Identifying abuse &amp; intervention measures</u></b></p> <p>Training and raising awareness of volunteers to identify violence and abuse and to act properly  Gabi Linster, Local-joint communities Bersenbrück, Germany</p>

<b>14:00 – 14:50</b>	<b><u>III. Session: Identifying abuse &amp; intervention measures</u></b>  Open discussion forum with: <ul style="list-style-type: none"><li>• Ingeborg Germann, Ministry for Social Affairs, Labour, Health and Demography, Rhineland-Palatinate, Germany</li><li>• Katrin Markus, German National Association of Senior Citizen's Organisations (BAGSO), Germany</li><li>• Susanna Saxl, German Alzheimer Association (DAIzG), Germany</li></ul>
<b>14:50 – 15:00</b>	Closing words Petra Weritz-Hanf, Head of Unit, Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany
<b>15:00</b>	<b>End of expert discussion</b>

### 3 Opening speech

Dr. Matthias von Schwanenflügel, Department Head of the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth opened the Expert Meeting. With introductory words, he outlined the importance of the topic as well as the political measures of the Federal Government, which are already implemented and planned for people with dementia in Germany.<sup>2</sup>

He greeted the Expert Meeting, and in particular the European, "learning from each other today and tomorrow".

Dr. von Schwanenflügel emphasised that violence in home care is a problematic subject encumbered with taboos with a large number of unreported cases and a high need for action. Among them, dementia is an important risk factor.

Violence in care has many facets. It starts with neglect, verbal degradation and extends to rough care treatment, physical mistreatment and liberty withdrawal measures even going as far as homicide.

The work definitions of the Council of Europe and the WHO are correspondingly wide ranging. A short definition comes from Professor Berzlanovich: "Any action that inflicts psychological or physical injuries on an elderly person or limits their rights is an act of violence."

Even when there is little knowledge of the actual frequency of violence, the available data suggest that it is (shockingly) high. For example, family care givers report in a survey (Professor Dr. Thomas Görden 2012) that 48 percent have used psychological abuse, 19 percent physical violence, but rarely care giving neglect. More recent epidemiological studies report a rate of about 10 percent. As these studies excluded people with dementia, a significant underestimation and number of unrecorded cases is to be expected.

The high relevance of the topic is also shown by the data of an important German initiative in the context of violence prevention in care, "Treatment instead of mistreatment", the Bonn initiative against elder abuse: Between 1997 and 2002, more than 1000 calls were received in which a violent act was described (Professor Dr. Rolf Hirsch et al., 2002). The most frequent forms of violence were psychological violence and neglect.

Since the beginning of the 1990s, the BMFSFJ has research results on the specific dangers for elderly people in home care.

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<sup>2</sup> Since the speech was given extemporaneously and the exact wording is not available, some important contents are summarised below.

Dr. von Schwanenflügel presented some projects in the field of elderly people in need of care and abuse on a national level:

- The "Care Round Table" was convened in 2003-2005 by the BMFSFJ and the then Federal Ministry of Health and Social Security to improve the life situation of people in need of assistance and care in Germany. About 200 experts from all areas of responsibility in the care of the elderly took part.
- By autumn 2005, recommendations for action were made to improve home and inpatient care and to reduce bureaucracy, and a "Charter of the rights of people in need of assistance and care"<sup>3</sup> was formulated as a central measure. The charter specifically describes the rights of people in Germany who need assistance and care.
- Action program "Live safely in old age" (SILIA): In cooperation with six care services and a care consultant, plans of action were developed to strengthen the potential for prevention of abuse in outpatient care services and tested them in practice. By means of training, the individual skills of the caregivers are further developed. On the level of services, a corporate culture should be strengthened which promotes the recognition of problematic care relationships and the taking over of responsibility by care providers.
- With projects like PURFAM: "Potentials and Risks of Familial Care for the Elderly": In the integration of international experiences and approaches regarding the optimisation of practical action, the BMFSFJ (German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth) has implicated itself very specifically regarding the protection of the elderly from violence in home care. Outpatient care services, which have direct contact with the group of elderly people in need of care and their families, received training on the assessment procedure developed by PURFAM. The procedure was implemented and evaluated nationwide in practice facilities. A manual was prepared which contains theoretical background information and practical guidelines for the prevention of violence as well as detailed instructions for using the PURFAM assessment. Professor Zank will provide more details on the project during the course of the Expert Meeting.
- In September 2016, a workshop discussion with the BMJV (German Federal Ministry of Justice and Consumer Protection), the BMFSFJ (German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth) and the BMG (German Federal Ministry of

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<sup>3</sup> The English version is available at: [https://www.pflege-charta.de/fileadmin/charta/pdf/Die\\_Charta\\_in\\_Englisch.pdf](https://www.pflege-charta.de/fileadmin/charta/pdf/Die_Charta_in_Englisch.pdf).

Health) took place with experts and other participants with the aim of showing further options for action.

- The project ReDuFix outpatients (2009 – 2012), funded by the BMBF (German Federal Ministry of Education and Research), has investigated freedom restricting and withdrawing measures in home care and wanted to develop effective intervention measures. One of the most important results is that dealing with the legal issues affecting those measures, is an exceptionally defensive and inconsistent process, which causes uncertainty and ignorance in most of the parties involved.

Family home care remains essential and unaffordable – "the greatest care service in the nation" – but in the case of dementia over a possible period of about eight to ten years, it is linked with extreme burdening of the family care givers.

Approximately two thirds of the patients live long years in socially familiar environments, mostly with the family. Care and support in a familiar home environment is often the best solution for people with dementia up to the late stages of disease.

Dementia is a disease that affects the whole family. It not only changes the life of the patient, but also fundamentally changes the life of the family. They are in the front line and often manage to do incredible things. But often their own health also suffers, the social contacts dwindle, the financial situation can become difficult. We know: The well being and quality of life of carers and people in need of care are closely linked.

Violence does not appear out of the blue, it always has a previous history. And there are clearly identifiable risk factors on the part of carers and people in need of care. Dementia is an effective risk factor for both sides.

A central approach to improving the situation is therefore the continuous support of family care givers.

In the agenda "Together with people with dementia" that was developed with all the members of the Alliance for people with dementia,<sup>4</sup> which was signed on 15 September 2014, the field of action III is dedicated to the "Support for people with dementia and their families". It is the focus of the interim report, which was presented on 21 September this year, on the World Alzheimer Day 2016, and informs about the implementation up to now of the 155 commitments in all four areas of action.

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<sup>4</sup> <http://www.allianz-fuer-demenz.de/startseite.html>; the Agenda "Alliance for people with dementia" is available in English at: [http://www.allianz-fuer-demenz.de/fileadmin/de.allianz-fuer-demenz/content.de/downloads/Alliance\\_for\\_people\\_with\\_dementia.pdf](http://www.allianz-fuer-demenz.de/fileadmin/de.allianz-fuer-demenz/content.de/downloads/Alliance_for_people_with_dementia.pdf)

Effective prevention of all forms of abuse in the care of people with dementia is an important issue of the agenda. Lack of knowledge about alternative possibilities of action, overburdening and helplessness on the part of the people who care for the people with dementia are often causes for various forms of abuse. In addition to the objective of raising awareness of the problem, the agenda also arranges the implementation of appropriate measures for prevention and intervention.

In order to provide better support for caregivers, among other things the law on the reconciliation of family, care and work, which became effective on 01 January 2015, was adopted. Newly introduced were, among other things, the legal right to family care leave as well as a care support allowance as a compensation for families in order to be able to organise care in the event of a crisis. In addition, a care telephone hotline provides advice and assistance.

The work of the Alliance makes it clear that it is not enough to secure good medical and care provisions. Above all, social acceptance and understanding support play a role in the immediate context of life.

Understanding requires knowledge about the disease and the needs of the patients and their family care givers. With the Internet portal [www.wegweiser-demenz.de](http://www.wegweiser-demenz.de), the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth makes an important contribution to the transfer of knowledge, shows help options on site, but also enables the exchange between experts, patients and their families.

With the initiative "Dementia Partner", we are working together with the German Alzheimer Society and the Federal Ministry of Health for a new culture of coexistence, a social togetherness of citizens with and without dementia. Thus we become a member of the international movement "Dementia Friends".

And when all the participants work together in a coordinated way, effective support networks are created. This is also proved by the 500 Local Alliances for people with dementia which have been supported since 2012 as part of a BMFSFJ model program. The aim of the Local Alliances is to ensure that people with dementia, in the sense of sharing and participation, live as long as possible in their social environment and are able to cover their needs. The options on site should be better coordinated, jointly further developed and adapted to the needs of those affected. Important cooperation partners apart from the municipality are multi-generational houses, companies, welfare associations, church communities, colleges, senior citizen offices, volunteer agencies, self-help organisations, doctor's surgeries, hospitals, social stations and care support centres.

At two thirds of the sites, municipalities are the responsible parties or active cooperation partners of the Local Alliance. In the future it will therefore be a matter of giving municipalities more organisational freedom. With the third Care Support Law, the Federal Government wants to expand precisely this scope. The municipalities are to be more strongly reintegrated into care once again, and model municipalities will test new advisory structures.

As the best solution to avoid abuse, due to the complexity of the cases from a scientific viewpoint, the development and implementation of inter-professional teams at the municipal level are recommended.

The members are physicians (key persons: General practitioners), social workers, legal advisors, representatives of the judiciary, representatives of municipal services. They meet regularly and jointly develop a plan and introduce its implementation.

A similar life-oriented approach can also be found in the DelpHi-MV project of the German Centre for Neurodegenerative Diseases (DZNE), which is also a measure of the "People with dementia" agenda.



Dr. Matthias von Schwanenflügel, Petra Weritz-Hanf

The study shows new ways in the home care of people with dementia by means of Dementia Care Management: House visits by qualified counselling staff as effective support for people with dementia, their families and always with feedback to the consulting General practitioners. This is a forward looking approach with a view to the demographic induced increase in dementia diseases and the care infrastructure obstacles, especially in rural areas.

The results show that a better quality of life for patients and their families can be achieved, that problematic behaviour is reduced, and the care burden is lowered.

There are, therefore, usable approaches to avoid abuse in the home care of people with dementia. They must be strengthened and further developed.

I am looking forward to experiences from other countries and impulses from this Expert Meeting, which can help us all to contribute to the improvement of the situation.

## 4 Introduction to the topic

The introduction into the subject of violence in the home care of people with dementia designated Ao. University Professor Dr. Andrea Berzlanovich and Heike von Lützau-Hohlbein. Professor Berzlanovich gave input on the definition of violence, forms of violence, frequency, and securing or evidence as a possibility of intervention. Ms. von Lützau-Hohlbein then raised awareness about the problems of the subject in relation to people with dementia: What can be causes and risk factors for violence and abuse, and how is dementia itself a risk factor?

### 4.1 Abusive Care – Ao. University Professor Dr. Andrea Berzlanovich

Professor Andrea Berzlanovich from the Medical University of Vienna, Department of Forensic Science, Department of Forensic Gerontology introduced the topic with her lecture "Abusive care".

Firstly, Professor Berzlanovich gave the definition of abuse against the elderly of the World Health Organisation (WHO): "Elder Abuse is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person."<sup>5</sup> The WHO also lists the diversity of forms of abuse: physical, psychological/emotional, sexual, financial or simply reflect intentional or unintentional neglect.

However, according to Professor Berzlanovich, the forms of abuse are not always strictly distinguishable or they frequently occur combined.

According to Professor Berzlanovich, the figures published by the WHO on abuse against the elderly tend to be an underestimation of the real situation. In public, only the cases that are reported in the media with scandalous headlines get noticed. And these are mostly cases of mistreatment in care homes and, in particular, with death as a result.

She presented the respective manifestations and their (physical) characteristics – various types of injuries and the respective health consequences for the person in need of care. Omission or neglect is a very passive form of abuse that occurs more frequently than active forms.



Ao.Univ.-Prof. Dr. Andrea Berzlanovich

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<sup>5</sup> See Toronto Declaration on the Global Prevention of Elder Abuse, WHO (2002).

Violence is very subtle here, and therefore, Professor Berzlanovich estimated the number of unrecorded cases as being very high.

Sexualised abuse begins already when the margin of intimacy is ignored, for example if the patient is washed by a person of the opposite sex without wanting to be.

Freedom withdrawing measures can also lead to serious physical and psychological consequences. Here the speaker mentioned examples of injuries such as muscle wasting or pressure ulcers or also death due to the improper use of restraining straps, bed rails and the like.

Violent situations are seldom observed by third parties, so it is important to take note of the warning signals, the so-called "red flags," and to take them seriously. Examples of how violence can be detected include among others:

- Multiple injuries and multiple occasions,
- Chronic complaints (without a physical cause),
- Bruises and haematomas that occur in non-typical places and abrasions on the joints of the wrists and ankles.

In people with dementia it is even more critical to pay attention to the signs mentioned.

Psychological forms of abuse are very difficult to detect. Here in particular, it helps to observe the person in need of care, their behaviour and condition as well as to pay attention to changes and warning signals.

In order to underline the lecture, Professor Berzlanovich showed video examples from practical experience. In one of the videos, a caregiver mistreats a resident with dementia during physical care. Without the hidden video recording, this use of force could not be demonstrated afterwards because the caregiver left no physical signs of violence.

Professor Berzlanovich reported that she had prepared an examination questionnaire for the Austrian Federal Criminal Police Office in order to document the injuries.<sup>6</sup> Securing of evidence by medical examination is possible, if physical and/or sexual assaults have occurred in the last 24 to 96 hours.

**PLENUM:**

Ms. Weritz-Hanf then asked whether the examination questionnaire for documentation could also be used by volunteers. Professor Berzlanovich confirmed, that also volunteers could describe and document matters and indicators. The second question was aimed at the

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<sup>6</sup> This is shown in her sheets in the annex and can be seen at <https://oeggm.com/oeggm-service.html> (available only in German).

recognition of the hidden recorded video as encroachment in courts. According to Professor Berzlanovich, the videos are often admitted in court proceedings.

Mr. Brucker adhered to the fact that reliable studies and figures on victims of violence in Germany are lacking. The international studies, which are available, arrive at different results by means of different approaches.

#### **4.2 Dementia as a risk factor – understanding the causes and risk factors of abuse and violence – Heike von Lützau-Hohlbein**

In a graphic overview from a newspaper that Heike von Lützau-Hohlbein showed at the beginning of her presentation, the frequency of violence is shown by age group, gender, and by the type of attack. The low number of victims of the over 60s suggests a high number of unreported cases.



Heike von Lützau-Hohlbein

According to Ms. von Lützau-Hohlbein, violence is understood as a complex situation and a mixture between neglect, insult, power, abuse and empowerment. The importance of power is central and the person with dementia is always the weakest.

People with dementia are cared for in about two thirds of the cases in their home environments. 50 per cent of them without any care allowance, which means without additional support from outpatient care services. Ms. von Lützau-Hohlbein described precisely this outpatient care as the only control mechanism in home care. But it is also not clear how the employees react when they have observed a situation of abuse and how the service providers then deal with the information passed on to them by the employees.

Traces of violence could also be detected in hospitals. As a good example of the recognition of abuse and for low-threshold assistance, Ms. von Lützau-Hohlbein named the website WikiHow with the article "Detecting mistreatment of the elderly".<sup>7</sup> The vividly illustrated page is intended to facilitate the recognition of the various forms of abuse and to show warning signs. At the end of the page advice and help centres in Germany, Austria and Switzerland can be located, which the suspicion or the abuse can be reported to. The fact that the site is not visited too often is shown by the number of clicks, which is only around 1,500. According

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<sup>7</sup> Available at: <http://www.wikihow.com/Identify-Elder-Abuse>.

to Ms. von Lützu-Hohlbein, this is not due to the low numbers of cases of abuse in care, but rather to the taboo related with abuse and violence.

Risk factors, that make people with dementia victims of abuse, are among others:

- Behavioural changes,
- Compensation or ignorance of deficits,
- Shame,
- Feelings of guilt,
- Fear,
- Strength,
- Vulnerability and
- Helplessness.

Especially older women often think that they can care for their husband or partner without help and are then overwhelmed from a certain point onward. There are many support options that provide information on where and how assistance can be requested. These options should be made more well-known.

## 5 Prevention – European perspectives

The AGE-Platform Europe presented itself in the panel on European considerations, the projects "Monitoring in Long-Term Care" (MILCEA) and "Prevention of Elder Abuse" (GfP) were also presented. Both parties are committed to the prevention of abuse against the elderly at a European level.

### 5.1 Dignified ageing and the fight against elder abuse at European level – Borja Arrue

At the beginning, Borja Arrue introduced the AGE Platform Europe. AGE is a European network of 130 non-profit organisations. It represents the rights of people aged 50 years and over at a European level in order to tackle the common challenges of social security and financial burden in care systems.

Long-term care and elder abuse are two important issues for the AGE members, who continue to promote and increase a complete awareness. Mr. Arrue sees this as an important task, as he also emphasised a lack of data and a lack of awareness in the area. This concerns long-term care as a whole in Europe. As other common challenges in long-term care in Europe he mentioned among others:

- The lack of social recognition of care professionals,
- The lack of support to informal/family carers,
- Insufficient specific support and
- Care services for people with dementia.

Factors that lead to an increased risk of elder abuse are, according to Mr. Arrue, the overburdening and insufficient training of formal and informal carers. A human rights approach and a focus on prevention are needed to address this social challenge.

In order to tackle problems relating to abuse against the elderly, inhumane care and neglect at a European level, AGE calls for action and measures. Two reference documents are to be named in particular: on the one hand the "European Charter of rights and responsibilities of older people in need of long-term care and assistance" (2010) and on the other hand the "European quality framework for long-term care services" (2012).<sup>8</sup> The European Quality Framework has been developed as part of the project "WeDO: A European Partnership for the Wellbeing and Dignity of Older people." In this project, 18 partner organisations from 12 different Member States worked together on quality standards for long-term care in Europe.

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<sup>8</sup> Both reference documents are available in several languages online at: <http://wedo.ttp.eu/>.

Both publications aim to raise awareness about the dignity of elderly people in need of care. They should also have a preventive effect in order to prevent or inhibit abuse against the elderly.<sup>9</sup>



Borja Arrue, Uwe Brucker, Jim Pearson (from right to left)

Mr. Arrue introduced an implementation example: School children in Poland have learned with the help of the principles in the quality framework what it means to age with dignity and to be well cared for. Also, care staff and the general public are being trained with the help of the packages specially developed by the WeDO<sup>10</sup> project. In addition, the European quality framework

for long-term care has been cited by the European Commission as a reference document for the importance of good care.

At EU level, long-term care is currently also included as one of the in total 21 rights in the counselling of the European Commission on "European Pillars of Social Rights."<sup>11</sup> AGE had supported the inclusion.

The AGE Platform will continue to promote preventative measures, strengthen discussion in the area and report on elder abuse. An EU action plan on elder abuse is also on the AGE agenda.<sup>12</sup>

#### **PLENUM:**

Following his presentation, Mr. Arrue was asked whether he perceived cultural differences in images of old age and, if so, whether this is reflected in the members of AGE and their positions regarding care. In the respectful interaction with the elderly, Mr. Arrue sees

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<sup>9</sup> The ten articles of the charter as well as the principles and fields of action of the quality framework are listed in detail in the annex of the presentation of Mr. Arrue.

<sup>10</sup> The training packages are available in several languages at: <http://wedo.ttp.eu/quality-care-training-package>.

<sup>11</sup> See Principle no.18 in the published document: [https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles\\_en](https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en).

<sup>12</sup> For further information on the work of AGE Platform a position paper (22.02.2017) by Borja Arrue can be downloaded at <http://www.age-platform.eu/sites/default/files/AGE%20position%20paper%20protecting%20victims%20of%20elder%20abuse.pdf>.

differences between the EU Member States. The welfare state support in the individual countries is also greatly different. AGE is of the opinion that informal care must always be an option, but not an obligation. The state should assume responsibility here, for example as regards care leave.

## **5.2 Presentation of the projects Monitoring in Long-Term Care (MILCEA) and Prevention of Elder Abuse (GfP) – Uwe Brucker**

Uwe Brucker from the Medical Advisory Service of Health Insurance presented the two European Monitoring Projects in Long-Term Care (MILCEA) and Prevention of Elder Abuse (GfP).

According to Mr. Brucker, surveys have shown that the issue of abuse in care is recognised as an important issue in care facilities, but that no one can imagine that this takes place in their own facility. In order to tackle this problem, there was an awareness campaign in the Netherlands "If you don't believe it, you don't see it."

On the individual level, abuse against elderly people is heavily burdened with shame, is tabooed and existing respite services are not well known. At institutional level, on the other hand, knowledge and the taking on of responsibility are lacking. Existing assessment instruments do measure the risk of violence and abuse against the elderly, however they are not integrated into the structures of the organisations or the daily work routine. According to Mr. Brucker, plans on how to deal with suspected cases in the facilities are lacking.

He also considered the existing advice and support options as problematic, which are merely designed as "come-here" structures and not as an outreaching approach.

The police is not the right place to resolve conflict situations. A parallel institution, such as the Children and Youth Welfare Office does not exist for the elderly in conflict situations. Mr. Brucker highlighted the problem of access to the person cared for informally in the home. For example, in a case of long-term care, if a care allowance is not applied for, there is hardly any access to the potentially vulnerable person. One of the few parties who have access to the person is the general practitioner.

The aim of the European project "Monitoring in Long-Term Care – Pilot Project on Elder Abuse" (MILCEA) was to contribute to the prevention of elder abuse in long-term care. With the development of a monitoring system in long-term care, risk of violence should be revealed and abuse should be prevented. Within the project, framework recommendations were formulated to help the Member States of the European Union to establish strategies and a monitoring system for the prevention of abuse. The project was carried out with the

partner countries of Germany, Austria, Spain, the Netherlands and Luxembourg in the years 2009 to 2012 and was funded by the European Commission.<sup>13</sup>

In all partner countries there were already some monitoring structures before the start of the project. Criteria for key participants in a monitoring system were:

- There is regular contact with the client,
- (Legal) responsibility with regard to elder abuse lies with the actor,
- There is a power of intervention for the direct protection of the victim.



Uwe Brucker

The result of the analysis is: There are no parties with immediate legal responsibility to recognise and prevent elder abuse. However, there are parties with an indirect order (among others providers of care services, legal guardians). Powers of intervention are available in all countries (among others by means of the police); in Germany and in Austria there are supervisory bodies for inpatient care facilities. There are only a few counselling centres specialising in elder abuse, for example, the advisory service "support office for domestic violence" in the Netherlands.

The four prerequisites for a monitoring system mentioned by Mr. Brucker are:

1. Existing awareness at societal and professional level in long-term care.
2. Assessment instruments must be integrated into external quality controls.
3. Risk factors must be regularly checked and binding responsibilities must be established.
4. Violence and risks of elder abuse can be identified and prevented using regular data evaluation and reporting in monitoring systems.

Informal care is a focus of a total of three care arrangements.<sup>14</sup>

In the follow-up project "Prevention of Elder Abuse" (GfP), the results from MILCEA at a national level are to be implemented in four model municipalities in Germany. The aim is to counter against elder abuse and people in need of care with a systematic approach to prevention. The project was run until the end of 2015 and was funded by the German Federal Ministry of Health. Summing up the GfP project, Mr. Brucker mentioned stimulating and aggravating factors. As an aggravating factor he mentioned the data protection problem

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<sup>13</sup> A results brochure of the MILCEA Project is available at: <http://www.milcea.eu/pdf/Milcea-englisch-Internet.pdf>.

<sup>14</sup> Others are professional home care and institutional care.

in Germany. As a stimulating factor, he named the presence of the driving force that is needed at a local level. The higher the political influence, the better it is for the consideration of the topic.<sup>15</sup>

The Health Insurance Medical Service (MDK) in Germany now wants to advance the qualification of its own employees, so that they can recognise elder abuse better. The MDK has access to around 1.5 million households to determine their care level. In the future, the assessments prepared will be handed over to the applicant – and thus the information on possible abuse in the domesticity.

**PLENUM:**

Ms. Weritz-Hanf praised the approach at the local level of the GfP project, which addresses the living environment of the affected people. The Delphi-MV study in Mecklenburg-Western Pomerania also had an outreaching approach. In the innovative care concept, approx. 130 participating General practitioners are supported by specially qualified care staff, the so-called Dementia Care Manager (DCM). The DCMs visit patients and their families at home every six months and they record the personal care situation. As a result, care can be improved and families can be unburdened.

Ms. Markus also stressed the importance of the municipality, which is also responsible for the well being of children and adolescents within the framework of the Youth Protection Structure Law, and pleaded for an adult protection authority for all over 18 years – in the sense of an Adult Protection Structure Law.

According to Mr. Brucker, a similar structure to that of women's shelters would also be conceivable, in that "emergency rooms" could be maintained at nursing homes.

Ms. Saxl stressed that a diagnosis – which exists in only about 50 percent of the cases – is extremely important in order for the family members to understand the sometimes strange behaviour of people with dementia and to be able to make use of the assistance available. At the same time she stressed that a call to the Alzheimer telephone is a way to get help when overburdened.

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<sup>15</sup> For more information on the Prevention of Elder Abuse Project see: [http://www.milcea.eu/en/index\\_en.html](http://www.milcea.eu/en/index_en.html).

### **5.3 Conclusions of the European perspectives – Heike von Lützu-Hohlbein**

Ms. von Lützu-Hohlbein summarised the European considerations, discussions and approaches of the first day as follows – it is still applicable,

- to strengthen public relations work and public debate,
- to break the taboo and expand the perception of the subject of abuse and violence in care,
- not to proceed with criminalisation, but to provide support and assistance,
- to create new structures, for example, with a responsible body for vulnerable groups (comparison with the Youth Protection Structure Law),
- to ensure a good transfer of project results into practice,
- to ensure the best care for people with dementia (not only according to the principle of outpatient care to decide before admission as inpatients),
- to establish comprehensive prevention strategies for inpatient as well as for home care,
- to create clarity in the responsibilities and
- to provide the necessary (financial) resources.

## 6 Prevention – National perspectives

In the section "Prevention – National perspectives," national efforts regarding the subject of preventing abuse and violence against the elderly in care from Germany, Austria, France, Scotland and two measures from Switzerland were presented. The prevention measures covered a wide range:

- Measures in which employees of outpatient care services and also volunteers have been trained,
- Measures for the support of family carers,
- Measures for the protection of the elderly in home care as well as
- Prevention in the individual counselling,
- Also the transferability of the results from science into practice was taken into account.

### 6.1 Presentation of the project Potentials and Risks of Familial Care for the Elderly (PURFAM) – Prof. Dr. Susanne Zank

At the beginning of her input, Professor Susanne Zank referred to two studies on the frequency of elder abuse, which she used to underline the problem with reliable figures: On the one hand, a representative study<sup>16</sup> from the United Kingdom, which states that 2.6 percent of respondents are affected by one of the forms of abuse. In this study, however, no patients in care facilities were questioned. On the other hand, the longitudinal study LEANDER<sup>17</sup>, which has measured the burden of family care givers on the basis of "carefully" formulated questions. The answer "I become louder" was chosen by 21 per cent of the interviewees with often to very often, the answer "I become so angry that I could shake my relative" was chosen by only 7.5 per cent.

In the project Potentials and Risks of Familial Care for the Elderly (PURFAM), the focus was on the prevention of violence in family caregiving settings. The project, carried out from 2009 to 2012, had the following aims:

- Early detection and strengthening of resources,
- Inclusion of international experiences,
- Development and testing of a screening and assessment procedure,

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<sup>16</sup> Biggs, S. (et. al.) (2009): Mistreatment of Older People in the United Kingdom: Findings from the First National Prevalence Study. In: Journal of Elder Abuse & Neglect Vol. 21 , Iss. 1.

<sup>17</sup> Thoma, J.; Zank, S.; Schacke, C. (2004): Gewalt gegen demenziell Erkrankte in der Familie. Datenerhebung in einem schwer zugänglichen Forschungsgebiet. In: Zeitschrift für Gerontologie und Geriatrie, 37(5), S. 349-350 (available only in German).

- Training for the staff of outpatient care services.

Staff in outpatient care services, who have direct contact with elderly people in need of care and their families, received training on the assessment procedure developed by PURFAM. The training consisted of three modules: 1. Information session; 2. The training consisting of five elements; and 3. Case discussions. Caregivers should learn to recognise and act on signs of violence and abuse.



Prof. Dr. Susanne Zank

A total of 170 care giving services participated and 455 employees were trained. According to Professor Zank, it was not easy to find outpatient care services willing to participate in the study and the training. This suggests that only those outpatient care services which participated in the training courses, are already sensitive to the issue of abuse and violence. Also the optional case discussion offered several months after the training met with little demand.

A PURFAM checklist for care giving staff was developed as a practical aid to document signs of violence.<sup>18</sup> On the checklist, the following signs of neglect and abuse are listed:

- Physical signs which can be perceived on the person in need of care (for example, haematomas on the body),
- Signs in the behaviour of the person in need of care (for example, if they seem to be anxious or distressed),
- Signs in the behaviour of the family (for example, showing inadequate knowledge about the disease or acting aggressively),
- Signs in the interaction between the person in need of care and their families (e.g. insults or roughly taking hold of),
- Listing various areas where problem situations have been observed (for example, neglect, freedom withdrawing measures, financial area).

It is provided that the checklist should be completed by the care giving staff, then discussed together with the care giving team, and to evaluate the signs. The “Team” checklist was

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<sup>18</sup> The checklist for care giving staff is available online at: [https://www.hf.uni-koeln.de/data/gerontologie/File/PURFAM\\_Checkliste\\_Pflegekraft\\_aktuell.pdf](https://www.hf.uni-koeln.de/data/gerontologie/File/PURFAM_Checkliste_Pflegekraft_aktuell.pdf) (available only in German).

developed for evaluation as a team.<sup>19</sup> Subsequently, it is considered whether an intervention is necessary or what needs to be done, and how the family care givers may be offered support. The decision is taken in the team so that the responsibility does not lie with one person alone.

The project developed a standardised approach to the monitoring of abuse (see sheet 16 of the presentation in the annex). The survey of a total of 374 employees of the outpatient care services showed that only ten percent of the outpatient care services have a standardised procedure. The relevance and importance of the subject of the prevalence of violence and action strategies have been confirmed by 75 per cent of the respondents. Here, a discrepancy becomes clear between the highly assessed relevance of the topic by employees and the too few existing standards of action in practice.

In order to examine the usefulness of the training, employees were given a knowledge quiz to answer before and after the training. However, the evaluation revealed no significant difference.

Professor Zank stressed at the end of her presentation that it is not easy to research in this area, because researchers are perceived as being a "disturbing factor" in everyday work. Therefore, the question of sustainability and the benefits of training cannot be fully answered yet in practice.<sup>20</sup>

#### **PLENUM:**

Ms. Saxl, who also worked in the PURFAM project, pleaded to oblige care service providers to document violent occurrences. Currently in Germany there is no obligation to do so and all additional tasks mean a lot of effort. The time for this is usually not available in the daily working routine. The question of suitable instruments and contact persons (apart from the police) in cases of abuse remained unanswered in the project. Mr. Brucker added that it takes a long time to put new knowledge into practice. It isn't a problem of knowledge itself, but rather of its transfer.

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<sup>19</sup> The Team checklist is available online at: [https://www.hf.uni-koeln.de/data/gerontologie/File/PURFAM\\_Checkliste\\_Team\\_aktuell.pdf](https://www.hf.uni-koeln.de/data/gerontologie/File/PURFAM_Checkliste_Team_aktuell.pdf) (available only in German).

<sup>20</sup> The final report "Potentials and Risk Factors of Family Caregiving for Older People" is available at: [https://www.hf.uni-koeln.de/data/gerontologie/File/PURFAM%20Abschlussbericht%20Onlinefassung\\_2015.pdf](https://www.hf.uni-koeln.de/data/gerontologie/File/PURFAM%20Abschlussbericht%20Onlinefassung_2015.pdf) (in German) a summary is available in English at: [https://www.hf.uni-koeln.de/data/gerontologie/File/Summary%20PURFAM\\_english.pdf](https://www.hf.uni-koeln.de/data/gerontologie/File/Summary%20PURFAM_english.pdf).

## 6.2 The Austrian national dementia strategy *Living well with dementia and measures to support family care givers* – Sabine Schrank

At the beginning of her presentation, Ms. Schrank gave a brief overview of the Austrian care system, in particular the services and responsibilities included in it. The care system is based on three pillars: 1. The personal care allowance, 2. Measures to support family care givers; and 3. Care services.

The national dementia strategy "Living well with dementia" developed for Austria was already published in November 2015. In a joint process, seven key objectives and 21 recommendations for action were developed with all key parties (affected parties, decision makers, experts):<sup>21</sup>

1. Promote participation and self-determination of those concerned
2. Expand the information widely in the public but also in special target groups
3. Strengthen knowledge and skills
4. Create consistent framework conditions for coordinated care
5. Ensure and improve health care and social care services
6. Improve cooperation and coordination between different care services
7. Improve and ensure quality of care by research on dementia

The aim of the dementia strategy is to improve the life situation of people with dementia and their families as well as to strengthen the recognition of the work of the family care givers.

The challenges in dealing with people with dementia are, on the one hand, that specific knowledge and interaction forms are needed and the family care givers often lack sufficient knowledge and skills. On the other hand, the family care givers are exposed to considerable and multiple physical and psychological burdens. This circumstance leads to the following problem: Individual relief strategies are not sufficient and this leads to an overburdening and thus to withdrawal behaviour, disagreement, aggression and can subsequently lead to all forms of



Sabine Schrank

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<sup>21</sup> The Austrian dementia strategy "Living well with dementia" is available at: [http://www.bmgf.gv.at/cms/home/attachments/5/7/0/CH1513/CMS1450082944440/demenzstrategie\\_abschlussbericht.pdf](http://www.bmgf.gv.at/cms/home/attachments/5/7/0/CH1513/CMS1450082944440/demenzstrategie_abschlussbericht.pdf) therein a executive summary in English on the pages 3-5.

violence. In this context, the objective “Improve knowledge, skills and expertise” is particularly important for the dementia strategy. In this objective, measures are included that are intended to provide information and qualifications both for professional groups in the health and social areas as well as for families.

Among other things, measures are planned to raise awareness, to develop and strengthen skills, to qualify medical and non-medical participants in health care and social facilities and to strengthen the skills of dependants and family carers. The aim is that the educational and training opportunities for dependants provide dementia specific skills, so that they can recognise individual burdens and challenges and thereby achieve a better quality of care in the informal sector.

Since October 2016, there is a platform at [www.demenzstrategie.at](http://www.demenzstrategie.at), which links together all parties, lists regional projects and thus promotes the transfer of knowledge from projects.

Among the already established support measures for the reconciliation of care and work, the emphasis is on care leave and part time care. Since 1 January 2014, employees have been given the option to arrange an exemption for care, the so-called "care leave", or part-time care for a period of one to three months for the care and support of close relatives entitled to a care allowance from level 3 (level 1 for people with dementia). These measures provide income compensation for the duration of the hindrance and serve to assist the organisation of the care of a close relative. The amount of the care allowance is income dependent (55 per cent of the daily net income) and can be paid for a maximum of 12 months for the same person in need of care.<sup>22</sup>

Within the framework of "Quality Assurance in Home Care", nationwide since 2001 the Austrian Ministry of Social Affairs has been conducting free of charge and voluntary home visits to persons receiving care allowances (PGB), who are cared in their home setting. Licensed health and nursing staff contact the person receiving care allowance and their caregivers and assess the actual care situation by means of a situation report. If required, the necessary information and counselling is provided, also with regard to 24 hour support, in order to ensure the necessary support and the best possible conditions for daily care. Since 1 January 2015 there is the possibility that house visits can also be carried out at the request of the person receiving care allowance or their families.

A further measure is the supporting family discussions, which family caregivers can benefit from free of charge. By means of these discussions, psychological burdens are intended to

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<sup>22</sup> See also Hoyer/Reich (2016): Leave and financial support for family caregivers in EU member states, available at: [http://www.sociopolitical-observatory.eu/uploads/tx\\_aebgppublications/2017\\_Report\\_Support\\_family\\_caregivers\\_EN.pdf](http://www.sociopolitical-observatory.eu/uploads/tx_aebgppublications/2017_Report_Support_family_caregivers_EN.pdf).

be reduced, individual course of action options are explained, and access to relevant support options is facilitated. This consultation option is well received, according to Ms. Schrank, but is still relatively new.

**PLENUM:**

Ms. Weritz-Hanf was impressed by the abundance of measures implemented in Austria by the Ministry of Social Affairs. When asked about the support of the online platform, Ms. Schrank replied that this is done by *Gesundheit Österreich GmbH* (GÖG), an external service provider.

The question of Ms. von Lützau-Hohlbein about existing strategies for the implementation of the dementia strategy was affirmed by Ms. Schrank.

Mr. Brucker commented positively on the financial benefits, which are adopted in a preventive period<sup>23</sup>. The question of whether the payment was linked to some kind of proof, was negated by Ms. Schrank, only the contact data of the person who takes over the care has to be indicated.

Ms. Markus asked how the family talks were accepted. Ms. Schrank informed that those who accepted the offer were highly satisfied and that some were even willing to make use of a second consultation. To make the offer known to the family caregivers, on the other hand, is not easy. Currently, the Ministry of Social Affairs faces the challenge of networking the offer and making it more low-threshold.

Ms. Weritz-Hanf asked if there were online training courses on the subject of dementia in Austria. In the course of this question, she mentioned the initiative of the German Alzheimer Society "Dementia partner", launched half a year ago.<sup>24</sup> By participating in a course on dementia, the participants become Dementia partners who are informed about the disease. Ms. Schrank reported that in Austria there is nationwide online training for the police in dealing with people with dementia, and also training for employees of public transport.

Ms. Wolfensberger added that there is a project in Switzerland of the Alzheimer Association, which uses an infomobile, where experts are available to answer the questions of those interested.

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<sup>23</sup> Up to 28 days per calendar year and with a maximum benefit of up to 2,200 Euro.

<sup>24</sup> More information about the Initiative Dementia partner available (only in German) at <https://www.demenz-partner.de/startseite.html>.

### 6.3 Prevention and intervention against abuse: a brief overview of the French perspectives and policy measures – Dr. Marion Villez

Dr. Marion Villez first gave a general introduction on the subject of elder abuse in France. On a national level, there are neither specific initiatives nor measures to combat abuse against people with dementia. However, there is a common framework for the elderly and people with disabilities.



Dr. Marion Villez

In France, the issue of elder abuse, especially abuse against people with dementia, has long been tabooed. Moreover, abuse was long understood and perceived only as active violence (physical violence, aggression and theft). Step by step, the perception is changing and the subject is being treated as a wide ranging phenomenon.

Ms. Villez spoke of a change of perspective in France, away from the interventional approach and the fight against abuse and violence towards a preventive approach and the focus on "good care" of the elderly – a positive approach which is concerned with people's well-being.

Ms. Villez mentioned some figures on the incidence of elder abuse in two studies of ALMA France (2014 & 2016): 80 percent of the known cases of abuse occur in the domesticity. 75 percent of these cases are women affected and they have an average age of 79 years. The known cases of abuse are carried out in 68 percent of cases by family members. If the health condition of the victims is indicated, 30 percent of them suffer from a mental disorder.

She identified six objectives, in which associations, authorities and service providers orient themselves in their work to prevent abuse or to intervene:

1. Raising public awareness,
2. Improvement of prevention (through staffing, support and training),
3. Strengthening the "good care" of the elderly,
4. Promote support and protection of victims,
5. Facilitating the reporting and control as well as the sanctioning of facilities and home care services,
6. Strengthening the legal framework and ensure the rights of people with dementia.

In France, efforts are being made to coordinate the work of non-governmental organisations (NGOs) and public authorities in the fight against abuse and violence. One of the most

important initiatives of one NGO (with the support of the government) is the helpline launched by Robert Hugonot in 1994<sup>25</sup> “*Hello, mistreatment of elderly people*” (ALMA France) with contact points at Department level. The trained specialists and volunteers are networked with the judicial and administrative authorities. However, experience has shown that callers are often already helped by being listened to and by mediating and receiving support. In 2007 the government set up a nationwide help telephone line. FEDERATION 3977<sup>26</sup>, founded in 2014 by a merger between ALMA France and HABEO<sup>27</sup> is a new structure and national platform that aims to improve the actions against mistreatment and violence. In addition to the helpline, FEDERATION 3977 develops training courses for the prevention of violence.

On a national level care facilities are often the focus of the measures and laws: For example, since 2002, the “Charter of the Rights and Freedoms of the Person in need of care”<sup>28</sup> has been displayed in every care home and is accessible for all residents. Likewise in 2002, a national committee was set up (*Comité national de vigilance et de lutte contre la maltraitance des personnes âgées*), which takes up the fight against violence and abuse against the elderly. In 2007, additionally a national action plan with ten measures was launched to strengthen the fight against abuse.

Another initiative of the national government is the law of December 2015 to adapt society to the ageing process. These include, among other things, measures relating to elder abuse, for example, the obligation of reporting was extended from care facilities to home care.

In the context of the current National dementia strategy “Plan Maladies Neuro-Dégénératives 2014-2019”, a publication was released in September 2016 dealing with the rights of the person in need of care in the home care sector.<sup>29</sup>

The possibility of care leave to look after a person in need of care was also made possible in France for neighbours and friends.

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<sup>25</sup> Robert Hugonot (1922 to 2010) is considered one of the fathers of gerontology and geriatrics in France. Since the 1980s he was a pioneer in the fight against abuse and violence against the elderly. Since then, many studies and research on risk factors and causes have been carried out and a systematic approach has been developed.

<sup>26</sup> Further information (only in French) at: <http://www.3977contrelamaltraitance.org/>

<sup>27</sup> HABEO is an NGO that was founded in 2002 to help people with disabilities and to offer help.

<sup>28</sup> «La charte des droits et libertés de la personne accueillie» is available in French at: [https://www.mgen.fr/fileadmin/documents/Etablissements/denis-forestier/2016/charte\\_personnes\\_accueillies.pdf](https://www.mgen.fr/fileadmin/documents/Etablissements/denis-forestier/2016/charte_personnes_accueillies.pdf)

<sup>29</sup> The publication „Réflexion éthiques et respect des droits de la personne malade au domicile” is available at: <http://www.espace-ethique.org/sites/default/files/CAHIER-5-031016.pdf> (only in French).

Ms. Villez has detailed in her presentation sheets further measures and programs from NGOs and the French Government (see annex).

**PLENUM:**

Ms. Weritz-Hanf was impressed by Ms. Villez's report from France on the abundance of government measures. Ms. Villez emphasised that it was important in France to focus not only on scandals in a stigmatising way, but rather to choose a positive point of view. Mr. Arrue also expressed favour regarding the positive approach of 'good care'.

#### **6.4 Adult Support and Protection in Scotland – Jim Pearson**

Mr. Pearson introduced his presentation with the overview of the "Charter of Rights for People with Dementia and their Carers in Scotland".<sup>30</sup> The Charter is guided by a human rights "PANEL approach". It underlined the following rights of each person:

- Participation in decisions which affect their human rights.
- Accountability of those responsible for the respect, protection and fulfilment of human rights.
- Non-discrimination and equality.
- Empowerment to know their rights and how to claim them.
- Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.

The charter also reflects other legal provisions and, in particular, the principles of Scottish law „Adults with Incapacity“ (2000), „Mental Health (Care and Treatment) (2003) and „Adult Support and Protection“ (2007). These three key pieces of legislation are inter-linked and form as a whole the framework for adult protection in Scotland.

The act "Adults with Incapacity" – legally incapacitated adults – dates from the year 2000. Legal incapacity is defined as follows: Adults (over 16 years of age) who are unable to make their own decisions or communicate them due to a mental disorder or physical disability, or to keep their own decisions in mind. The act allows a wide range of interventions in the fields of property, financial and welfare. Measures are only permitted if an adult is not in a position to make the decisions concerning the question relevant to this measure. A new office "Office of Public Guardian" was set up for the implementation of the act. This office, for example, intervenes in the event of a suspected financial abuse.

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<sup>30</sup> The „Charter of Rights for People with Dementia and their Carers in Scotland“ (2009) is available at: [http://www.alzscot.org/assets/0000/2678/Charter\\_of\\_Rights.pdf](http://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf).

The "Adult Support and Protection" act of 2007 aims to support and protect adults. The act creates legal obligations for local authorities (and other bodies) as well as powers to intervene and prevent damage. The act includes people who are not self-sufficient, who are unable to enforce their rights and interests and are unable to prevent damage. These can be, for example, people with dementia. Support and protection are brought together and cooperation between the different parties (including the police and the health authority) is necessary. All local authorities have the duty to investigate any suspicions, in the sense of proactive action. Alzheimer Scotland is also subject to the reporting obligation. The information provided by the various participants is intended to provide an overall picture and clarify whether a case of abuse exists. An awareness campaign was broadcast on television to support this process. The message of the campaign is „Seen something? Say something.“<sup>31</sup> The campaign also illustrates that there are different forms of abuse.



Jim Pearson

The act "Mental Health (Care and Treatment)" deals with the mental health of people with disabilities, mental illnesses and learning disabilities. The following areas are defined and bound in the act: Non-discrimination, equality, participation, informal care and respect for carers. Mr. Pearson mentioned bringing the three acts under one roof as the major goal.

Since 2010, there has been a national dementia strategy in Scotland. In particular, the improvement in the care of people with dementia in acute hospitals and the expansion of Post Diagnostic Support have been particularly promoted until now<sup>32</sup>. Scotland is currently on the brink of the publication of the third national dementia strategy.<sup>33</sup> The new strategy contains 21 commitments, which affect quality assurance among other things. The implementation and anchoring of human rights in everyday life is also a topic that should be addressed according to Mr. Pearson.

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<sup>31</sup> For more information about the campaign, see: [www.actagainstharm.org](http://www.actagainstharm.org).

<sup>32</sup> The Scottish government, in collaboration with Alzheimer Scotland, has introduced a "5 Pillar Model of Post Diagnostic Support" for the expansion of support services after diagnosis. Through the introduction of this model, all newly diagnosed people have a guarantee of support services after the diagnosis for a period of at least one year. This year they are entitled to the creation of a personalised support plan. Further information on this model can be found in the report by Jim Pearson in the Newsletter of the Observatory "National dementia strategies: Examples of good practice in Switzerland and Scotland" (2/2015). The Newsletter is available at: [http://www.sociopolitical-observatory.eu/uploads/tx\\_aebgppublications/Demenz\\_NL\\_Engl\\_01.pdf](http://www.sociopolitical-observatory.eu/uploads/tx_aebgppublications/Demenz_NL_Engl_01.pdf).

<sup>33</sup> Scotland's third National Dementia Strategy (2017 – 2020) was published in June 2017 and is available at: [http://www.alzscot.org/assets/0002/6035/Third\\_Dementia\\_Strategy.pdf](http://www.alzscot.org/assets/0002/6035/Third_Dementia_Strategy.pdf).

**PLENUM:**

Ms. Weritz-Hanf was impressed by the good networking of the legal framework in Scotland. Mr. Brucker noted that there is no spouse representation right in Germany (currently) and asked how this is regulated in Scotland. Mr. Pearson reported that it is useful to think ahead and prepare a power of attorney early on and not only when the time has come. Anyone who does not have any preventive power of attorney in Scotland will be assigned a caregiver by the municipality in case of needing care. According to Ms. Markus, the topic of preventive powers of attorney has not been sufficiently publicly debated in Germany, even if the patient decree in the context of medical care has been. She appealed that people should deal with it at an early stage.

**6.5 Protecting the elderly in home care arrangements – Barbara Baumeister**

Ms. Barbara Baumeister reported on the research project "Protection in the home care of the elderly" at the Zurich University of Applied Sciences. The project was conducted from March 2012 to May 2015.<sup>34</sup>

The aim of the project was to gain further knowledge about the conditions and challenges of home care.

The project included a file analysis and interviews with professional staff, caregivers and those needing care. For the file analysis, 31 complaints were analysed, which were received by the Independent Complaints Office for the Elderly in Switzerland (UBA).

As a result of the file analysis six different conflict patterns were worked out:

1. Inter-generational entanglement: lack of care and/or support
2. Partnership and dementia: the conflict is caused by disease related changes
3. Conflict of siblings concerning care provision and financing: the conflict manifests itself outside of the care setting
4. Social proximity and financial exploitation: the quality of care is not directly affected, but financial interests are decisive for the conflict
5. Social isolation and neighbourly environment: People from the neighbourly environment feel threatened or disturbed by the behaviour of the person concerned
6. Autonomy of action and protection requirements: on the one hand, the autonomy of the persons concerned should be respected and, on the other hand, care giving assistance

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<sup>34</sup> The project report is available (only in German) at: [https://www.zhaw.ch/storage/shared/sozialarbeit/Forschung/Vielfalt\\_gesellschaftliche\\_Teilhabe/Soziale\\_Gerontologie/Projektbericht-Haeusliche-Betreuung.pdf](https://www.zhaw.ch/storage/shared/sozialarbeit/Forschung/Vielfalt_gesellschaftliche_Teilhabe/Soziale_Gerontologie/Projektbericht-Haeusliche-Betreuung.pdf).

is to be ensured (the only conflict pattern which the elderly person being cared for reports him/herself)



Barbara Baumeister

From the results of the interviews with the specialists, Ms. Baumeister reported that all persons who had participated in the study had had experiences with or observations of abuse in home care. The cases reported in the interviews could all be assigned to the six conflict patterns. The biggest challenge, which has been mentioned by the experts surveyed, is that the affected persons accept their help and advice.

The interviews of those affected – family carers as well as people in need of care – have shown that appreciative treatment is extremely important in the relationship since it is characterised by a high commitment (in the sense of: "I have received a lot, now I give something back"). In contrast, the burden of care is felt more strongly when the relationship to the person in need of care had already been affected. Likewise, the perception of the strain is high if the burden of care was taken on "involuntarily".

Ms. Baumeister also mentioned risk factors for elderly abuse in the care:

- Limited cognitive abilities of the person to be cared for (caregivers who have previously not shown such behaviour patterns, can act violently),
- Excessive demands on the caregiver (Especially in cases where the care was taken on involuntarily or a bad relationship exists with the person in need of care)
- Lack of support and social isolation of the caregiver,
- Dependency within a care relationship (studies show that abuse is often found in relationships characterised by massive dependency) and
- Violence as a learned pattern of conflict resolution or a long term relationship characterised by violence.

Ms. Baumeister mentioned the following conclusions from the project results:

- When financial interests are the subject of the conflict, the complaint is reported directly by the affected parties.
- In the case of interdependency and isolated family systems, the abuse usually remains undetected for a long time.
- A key challenge for all the specialists involved is that their support is received and accepted by the affected parties.

- The different relationship qualities allow conclusions to be drawn about why the responsibility for care and support was taken on (duty, maintenance of the system and recognition) and regarding the danger of escalation.

## 6.6 Prevention of Elder Abuse in individual counselling – Marianne Wolfensberger

Ms. Marianne Wolfensberger introduced various possibilities for intervention of abuse during individual counselling.

Since 2004, the Alzheimer phone has been available in Switzerland for information, advice and support. It is operated by the Swiss Alzheimer Association. Among other things, callers can find out where they can find self-help groups or how they can locate respite services. The multilingual staff has many years of experience and special training. The questions asked by the callers have become more and more complex with time. One reason for this could be the existing knowledge from the Internet. The average call duration is 20 minutes per call. Also, the routine documentation of the counselling deals with whether the subject of abuse directly or indirectly comes up in the consultations and in which context. However, this information has only been integrated into the documentation during the last few months and an exact evaluation has not taken place yet.



Marianne Wolfensberger

The Swiss Alzheimer Association agreed in 2016 with the national organisation *Independent Complaints Office for the Elderly* (UBA) that the UBA notes during calls if they are directly or indirectly made aware that a dementia disease may play a role in the consultation. In this way the issue of abuse is given more attention and a mutual exchange is promoted, even in individual cases. A clear advantage here is to benefit from the UBA, which is an organisation specialised in questions of abuse.

In addition to this complaints office, there has been a Child and Adult Protection Authority (KESB) in Switzerland since 2013. This specialist authority is under the authority of the cantons. The Adult Protection Authority intervenes and can order measures for assistance and protection, in cases where adults are unable to deal with their personal, property rights and administrative affairs themselves, or with the help of specialist agencies or persons of trust. Each person can submit a threat report as soon as a person appears to be in need of assistance or protection. Persons in official positions who are made aware of a risk are obliged to report it.

Ms. Wolfensberger presented some case examples from the counselling practice to illustrate the different forms of abuse and to show the appropriate assistance and interventions of the counselling centre (see her presentation in the annex).

The Swiss National Dementia Strategy 2014-2017 was published on 21 November 2013 (and extended in November 2016 till 2019).<sup>35</sup> The strategy is divided into four action areas, nine objectives and 18 related projects. Under objective number 2 „Affected persons and those closet to them have low-threshold access to a full range of information as well as to individual, appropriate counselling throughout the course of condition”, the project "Individualised information and social counselling services for affected individuals" was anchored, as well as other projects for the support of family carers. As part of the health policy priorities "Health2020", the Federal Council has set up an action plan for the support and respite of family carers, which also provides for improvements to labour laws.

As a summary of her presentation, Ms. Wolfensberger mentioned, among other things, the following reasons for abuse or the readiness to use violence of members of the family of people with dementia:

- Insufficient knowledge of the disease pattern,
- Lack of understanding of the situation of the patient,
- Excessive demands with the care role change within relationships.

In conclusion, she emphasised that a call to the Alzheimer phone would be an important first step to get help and to defuse the situation.

**PLENUM:**

Ms. Markus asked about the financing of the counselling centres in Switzerland. Ms. Wolfensberger answered, that the Old age and survivor insurance (AHV) – the compulsory pension insurance scheme in Switzerland – finances it. In addition, there is no support for people in need of care and no long-term care allowance in Switzerland.

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<sup>35</sup> The Federal Office of Public Health (BAG) and the Swiss Conference of the Cantonal Directorate General for Health (GDK) (2016): National dementia strategy 2014-2019. Information in English are available at: <https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie-2014-2017.html>.

## 7 Identifying abuse & intervention measures

Ms. Gabi Linster from the local-joint community Bersenbrück gave an insight into the practice and possibilities of acting and intervening in the field of home care.

### 7.1 Training and raising awareness of volunteers to identify violence and abuse and to act properly – Gabi Linster

Ms. Linster is senior representative and honorary coordinator of the local-joint community Bersenbrück (Lower Saxony). Her fields of activity in the area of dementia cover:

- Providing information, counselling and training for citizens, pass on knowledge and experience in dealing with people with dementia and free dementia from taboos,
- Offer voluntary, neighbourly and professional support for those affected and their families and relieve caregivers.

In the fourth phase of the governmental program, Local Alliances for people with dementia<sup>36</sup> Bersenbrück was selected and promoted as a Local Alliance. The main focus was on concepts that promote and develop networks in rural areas. According to Ms. Linster, low-threshold care options in rural areas are an important task. Moreover, the stigmatisation of people with dementia in rural areas is usually more pronounced than in urban areas.

Ms. Linster is very active in public relations and the recruitment of volunteers in her community. She organises, among other things, information events in all member municipalities, visits retailers, accesses groups with younger people (for example in schools or football clubs), or initiates an information stand on the weekly market. Regarding the latter, she reported that the interest in the information stand was greater when the mayor was present at the stand. This proves that community work needs people from public life as supporters, who are familiarising themselves with the topic. Ms. Linster also visits all the



Gabi Linster

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<sup>36</sup> Background: The Local Alliances are a central measure within the Alliance for people with dementia, which the Federal Government already launched as part of the demographics strategy in 2012. In the years 2012 to 2016 a total of 500 Local Alliances were funded as support networks for people with dementia and their families. The Local Alliances are linked with different responsible bodies, partly with regional dementia networks and have the goal that people with dementia can remain as long as possible in their usual social environment and thereby ensure their social participation. Further information is available at: <https://www.lokale-allianzen.de/startseite.html>. A fact sheet in English is available at: [http://www.lokale-allianzen.de/fileadmin/de.lokale-allianzen/content.de/downloads/Materialien/Faktenblatt\\_Lokale\\_Allianz\\_engl....pdf](http://www.lokale-allianzen.de/fileadmin/de.lokale-allianzen/content.de/downloads/Materialien/Faktenblatt_Lokale_Allianz_engl....pdf).

citizens who will become 80 years old in one year's time. On this visit, she brings along an "emergency portfolio", which contains educational materials as well as information on care advice. Ms. Linster's motto and self-understanding of her work: "You cannot sit in the office, you have to go out!"

In Bersenbrück, volunteer dementia companions are trained and employed. They take care of people with dementia and thereby relieve care giving families on an hourly or daily basis. Mediation between the dementia companions and the affected families as well as the training courses are organised by Ms. Linster. Ms. Linster accompanies the first visit of the dementia companions and holds a telephone consultation after the first care sessions. By means of this form of relief, Ms. Linster and her volunteers are given an insight into the households and can recognise emergency situations and act correspondingly. The dementia companions are trained how to recognise abuse and how to deal with domestic violence. The concept provides the following order of intervention:

1. Listen → See → Suspect → Recognise,
2. Consultation with the volunteer coordinator,
3. Joint home visit of the volunteer coordinator and the dementia companion,
4. Conversation with the family
5. Offer and initiate assistance and help,
6. Consult with a specialist physician.

On the basis of these measures, Ms. Linster described a case in which an overburdened family member had tied his wife to a chair in order to curb her tendency to walk around and thereby prevent unnoticed outings which, from the family's point of view, were dangerous. This case could be resolved by Ms. Linster in a conversation with the family, with the help of an outpatient care service and the help of a dementia companion. By temporarily relieving the care giving person with a dementia companion, overburdening could be prevented at an early stage. Tying up was no longer necessary due to the relief. Usually the cases of violence in home care are more complex and it is necessary to involve many parties in order to avert the abuse.

**PLENUM:**

Thanks to her commitment, Ms. Linster made a lasting impression on many of the participants at the Expert Meeting. She presented specifically and figuratively how training and awareness raising of volunteers at the local level can be implemented to recognise and deal with abuse. She also showed what can be achieved through the personal commitment of individuals.

## 7.2 Open discussion forum

### **Ingeborg Germann, Ministry for Social Affairs, Labour, Health and Demography in Rhineland-Palatinate, Germany**

After the last input and the abundance of measures initiated by Ms. Linster at the municipal level, it became clear that, the municipalities need support to cope with the activities resulting from this subject field.



Ingeborg Germann

Moreover, dealing with the issue of abuse in home care was a cultural question, as the European exchange had shown her.

The area of tension between "small abuse" and "large abuse" is important and, in particular, the question of what must be conveyed to people in order to find the right approach – where does violence begin? At this point Ms. Germann praised the campaign poster "Care without violence against elderly, people in need of care" of the MDS. It is necessary to create a social awareness, so that it is made clear what abuse against people in need of care is.

As a further important point, Ms. Germann mentioned the transfer of knowledge from research into practical work. According to Professor Zanks' input about PURFAM, the participants had learned that researchers "disturb" the work of the outpatient care services because the employees are under great pressure. Nevertheless, it is necessary to provide further knowledge, to close gaps and to promote awareness.

### **Katrin Markus, German National Association of Senior Citizen's Organisations (BAGSO), Deutschland:**

Ms. Markus also said that the relocation to the local level was very important and referred to the Seventh Report on Older People of the Federal Government. The importance and co-responsibility of municipalities is highlighted in the implementation and development of sustainable communities. She is particularly focused and concerned about questions of public services and the care of people with dementia, but also about their families who are in need of help and support.

The municipalities needed support in the building up of the necessary structures. This support should not only concern the funding, but rather the „Real people“, so that affected people also accept the support – here Ms. Markus referred to the extensive approaches of

Ms. Linster in Bersenbrück. With appropriate concepts and persuasive power, these persons can be found – also in the area of volunteers.

Ms. Markus spoke out against criminalisation if no offence exists. This is the case, above all, in the context of survival strategies and when members of the family create small spaces of relief. Here, Ms. Markus referred to the practical example of Ms. Linster. She can understand the tying up of the person with dementia by the relative as a small help, to catch their breath, but also sees the necessity for families to be shown other possibilities, so that such a tying up no longer occurs. All in all, it is necessary for the family members to be helped to find ways to escape and of being relieved.



Katrin Markus

She often thinks about the future potential of volunteers.

How much can younger people be used in the future? But also the developments in the professional care sector are concerning her.

### **Susanna Saxl, German Alzheimer Association (DAIzG), Germany:**

Ms. Susanna Saxl reported that the German Alzheimer Association has published a brochure on the subject of abuse in the care of people with dementia and has developed an e-learning course. A separate chapter on overburdening was also published on the website "Wegweiser Demenz" in September.

Ms. Saxl saw the excessive demand and overburdening of family caregivers as the main cause of abuse against people with dementia. From counselling, she knows the problem that many members of the family were not aware of or did not accept the excessive demand. Often the family carers have the feeling that it must work out somehow and that others are able to get by. To counter this, she recommended that counselling should encourage family carers to do something by themselves. In addition, Ms. Saxl also considers it a task of the counselling centres to inform the family carers in advance and to point out that the care of a person with dementia is extremely demanding and that caregivers also have to pay attention to themselves. This awareness is often lacking among family caregivers. However, it is essential to take time out in order to be able to take care good of themselves.

In this context, respite services are very important. Often, however, the problem exists, especially in rural areas, that the distances to the next day care offers are too far. That is why

Ms. Saxl stressed the importance of the further and comprehensive expansion of respite services.

In addition, she also advocated an adequate quality of the offers. She has often noticed that people with dementia with challenging, conspicuous behaviour are not included in day care.



Susanna Saxl

She suspects that even qualified staff is overwhelmed with the difficult care. The reason for this is given as the lack of group ability. Then, however, it would also have to be clarified how a care giving relative could take over this care around the clock. The quality of short term care services (up to eight weeks) is also a frequent topic in the counselling of the German Alzheimer Association. In the past, families often complained about the condition of the person in need of care after using a short-term care option.

In addition, Ms. Saxl called for the extension of the aid network and points of contact against abuse. These are frequented when they are known. This was also shown by the example of the LKA Berlin: After a poster campaign for an emergency call in the case of elder abuse, the counselling centre was overrun, so much so that the available capacities were not sufficient.

Finally, Ms. Saxl stressed that she found it very exciting to hear from other countries and their handling of and approaches to the prevention and intervention in elder abuse. She hoped that the issue would continue to be destigmatised.

## 8 Concluding words

For further action, Ms. Weritz-Hanf explained that she would continue to promote the interest and work on the issue of dementia and abuse in care – among other things, her department would work to ensure that the issue was included in the Coalition Agreements 2017, allowing it to flow into a National Dementia Strategy. The Alliance for People with Dementia has already taken up the issue, so that the prevention of abuse and the lifting of the taboo will continue to be pursued. In addition, the care phone is to be further expanded and advertised as a central point of contact. In this context, she mentioned the help line for abuse against women, which is now more and more well known nationwide and is used by women affected to receive help and support.

As mentioned at the start, in public discussion, the subject of elder abuse is still underestimated and tabooed. Ms. Weritz-Hanf emphasised that some events regarding this have taken place recently. Among other things, she mentioned the workshop discussion "Protection of elderly people from home violence", which was jointly carried out by the Federal Ministry of Justice and Consumer Protection and the Federal Ministry of Health and the BMFSJ in September 2016. In the follow up to this workshop discussion it was agreed to create a leaflet, which provides information on various counselling centres that can be addressed when one is confronted with the subject of elder abuse. And this year's German Care Day in March 2017 also included the issue of abuse in care in its program.

Finally, on behalf of the BMFSFJ, Ms. Weritz-Hanf thanked all participants. The Expert Meeting once again showed the importance of international exchange and the networking of participants across Europe. She has received many specific suggestions from other countries and would like to make use of them in view of the development of a National Dementia Strategy in Germany.

## 9 List of participating persons

Name	Organisation
Borja Arrue	AGE Platform Europe, Belgien / AGE Platform Europe, Belgium
Barbara Baumeister	Zürcher Hochschule für Angewandte Wissenschaften (ZHAW), Department Soziale Arbeit, Schweiz / Zurich University of Applied Sciences (ZHAW), Department Social Work, Switzerland
Ao.Univ.-Prof. Dr. Andrea Berzlanovich	Medizinische Universität Wien, Department für Gerichtsmedizin, Österreich / Medical University of Vienna, Department of Forensic Science, Austria
Uwe Brucker	Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (MDS), Deutschland / The Medical Advisory Service of Health Insurance (MDS), Germany
Ingeborg Germann	Ministerium für Soziales, Arbeit, Gesundheit und Demografie Rheinland-Pfalz, Deutschland / Ministry for Social Affairs, Labour, Health and Demography in Rhineland-Palatinate, Germany
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Benjamin Landes	Institut für Sozialarbeit und Sozialpädagogik e.V., Deutschland / Institute for Social Work and Social Education, Germany
Gabi Linster	Samtgemeinde Bersenbrück, Deutschland / Local-joint communities Bersenbrück, Germany
Heike von Lützu-Hohlbein	Deutsche Alzheimer Stiftung, Deutschland / German Alzheimer Foundation, Germany
Katrín Markus	Bundesarbeitsgemeinschaft der Senioren- Organisationen e.V. (BAGSO), Deutschland / German National Association of Senior Citizen's Organisations (BAGSO), Germany

Maike Merkle	Beobachtungsstelle für gesellschaftspolitische Entwicklungen in Europa, Deutschland / Observatory for Sociopolitical Developments in Europe, Germany
Jim Pearson	Alzheimer Schottland, Schottland / Alzheimer Scotland, Scotland
Susanna Saxl	Deutsche Alzheimer Gesellschaft (DAIzG), Deutschland / German Alzheimer Association (DAIzG), Germany
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Dr. Marion Villez	Universität Paris-Est Créteil, Frankreich / University of Paris-Est Créteil, France
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