

Dementia and self-determination

OPINION

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INTRODUCTION

“Since my father can no longer cross the bridge into my world, I have to cross over to him.”

(from: Arno Geiger, *Der alte König in seinem Exil*)¹

Our society is rightly concerned by the subject of dementia. The foreground issues for us are the perception of dementia as the loss of mental and physical strength and the suffering this entails for those affected and their families. This makes it all the more important to give consideration to new scientific findings and to the practical experience of carers and family members; these open up a different approach to the topic of dementia and direct attention to the potential of those affected.

The number of people with dementia is increasing and it presents all those directly involved and those around them with considerable challenges. In this connection, women are particularly affected, firstly because on average they live longer than men and therefore more often suffer dementia themselves, and secondly because it is the female family members who take on the majority of caring tasks. No effective remedies for dementia have yet been discovered; at present, it is only possible to alleviate symptoms and temporarily halt the progress of the disease.

Dementia is one of the great challenges to health and social policy of the present day. In recent times, there have been many improvements. Nevertheless, the individual, social and political problems associated with dementia are increasing, raising questions not only for health policy and social policy, but also for our self-perception as human beings and citizens. In future, there must be a large number of changes for the better and new

¹ Geiger 2011, 11. [Translator's note: Except when otherwise stated, all quotations from German sources have been translated by Margaret Marks.]

equipment, more appropriate financing and more competent coordination.

To date, political action has concentrated on diagnosis, using medication to put a temporary halt to the disease and giving support in the early stages. But less attention is paid to the long process of increasing loss of strength and cognitive decline, which often place enormous stress on the persons affected, their family members and their carers. Family members who are also carers make the greatest sacrifices and go beyond the limits of what they can endure in order to give help and support to the person affected even in the phases of advanced dementia.

The family members and the persons with dementia themselves experience dementia to a large degree as a social adversity; they experience increasing alienation from their previous lives and also removal from the public sphere and thus isolation and exclusion. It can be assumed that, above all in the intermediate and later course of the illness, persons with dementia suffer less from the illness itself than from the exclusion from and loss of emotional security and a sense of familiarity.

Cognitive deficiencies in people with dementia may lead others to assume that they no longer understand anything. In this sense, the public discussion about celebrities who have dementia is largely marked by the assumption that they have completely lost their personalities.

By contrast, recent scientific findings show that even those suffering from advanced dementia are capable of individual experiences and sensitive social perception and have personal desires. They are therefore certainly still able to act and be experienced by others as sentient beings. Depending on the possibilities which the course of the illness leaves to those affected, they are able to continue to live their lives and experience joy. Consequently it is not only a therapeutical but above all an elementary human requirement to interact with them in their individual personal nature and in the continuity of their

personal biography and to respect the self-determination still possible for them in their specific situation.

Thinking about dementia makes us question our own image of humanity. If we equate a person with his or her mental performance, we must see dementia as the destroyer of the person. But if we see a person not only as a thinking being, but also as one with feelings and an emotional and social component, it is easier to direct our attention to the resources that are still present.

This new perspective must be reinforced, because preserving the remaining independence and self-determination of persons with dementia, alongside medical, nursing, psychological and social support, may contribute to a greater quality of life, may have a positive influence on the course of the illness and may alleviate the emotional burdens on family members who are carers and on professional care workers. This is not intended to trivialize the illness nor to dramatize it.

Merely thinking about dementia gives rise to feelings of concern, insecurity and defensiveness. The thought of not being able to end one's life in a state of mental clarity, but instead being dependent on help and no longer able to understand one's situation is bound to unsettle us. But life does not end when dementia is diagnosed. Despite the restrictions, the remaining years have value.

The question of self-determination in dementia is an area of tension. Self-determination and dementia appear to be two opposing poles of human existence, and yet they can be considered together and combined in practice in care. Even if the possibilities of self-determination decrease in the course of dementia, the self of the person affected remains, and the attentive and empathetic care of all those involved and the solidarity of society must be directed to this. In so far as this creates claims for those affected, these claims have a variety of addressees. In addition to agents and custodians (*Betreuer*) in the legal sense, these are mainly family members who act as carers, and professional carers. It goes without saying that account must

be taken of the differences in the duties of professional carers working under a contract and family members acting as carers, friends and neighbours. It is the duty of society and the state to create the basic conditions in which the self-determination of persons with dementia can be respected and reinforced.

If persons affected by dementia today speak for themselves in public, they ask to be given the possibility of contributing their experiences and their world to the collective world and making it part of collective life. Against this background it is a particular requirement of the respect we owe to the individual for us to create a space for the self-determination each of them still has.

In its Opinion, the German Ethics Council wishes to contribute to a better understanding of the situation of people with dementia and to make recommendations to encourage us to interact with people with dementia more respectfully and to preserve their self-determination.

1 STAGES OF DEMENTIA: SELF-EXPERIENCE AND SELF- DETERMINATION OF PERSONS WITH DEMENTIA

The philosophical understanding of self-determination distinguishes several aspects which constitute the full meaning of this concept. If a person's life is to be described as self-determined, the person must have more than one possibility of acting ("be able to act differently") between which the person can choose on the basis of deliberations ("have reasons"). In addition, the full definition of self-determination requires awareness of oneself as originator ("I am doing this"), which makes a chosen behaviour attributable. Full exercise of self-determination requires the person to understand the nature and implications of the essential aspects which guide that person's decisions, and that in addition the person is capable of making value judgments against the background of his or her life situation and attitudes and can direct his or her actions accordingly. The person acts on the basis of his or her "own insight". These partial aspects of self-determined acting may vary in their intensity and may also influence a person's individual decisions in different ways.

The requirements for some of these elements of self-determination may still remain in existence in extremely advanced stages of dementia. In order to encourage and reinforce an understanding of dementia which places capabilities in the foreground without trivializing deficiencies, information on various forms of dementia and – despite the high degree of individual variety – on the development of the symptoms and the associated self-experiencing of those affected is necessary.

1.1 Outline of dementia syndromes

The concept of dementia has undergone many changes in the history of psychiatry. Today the dementia syndrome is understood in a quite general sense to mean the long-term loss of memory and cognition, combined with limitations of orientation, impairment of the activities of daily life and of emotionality. Changes of emotionality and of behaviour, such as social withdrawal, lability of affect, distrust, apathy or alternatively disinhibition, restlessness or nervousness may acquire the quality of changes of personality. But often, in the course of dementia, traits of the existing personality become more marked or less controlled. Dementia does not include acute states of confusion and disturbances of consciousness – sometimes as a consequence of taking medication or drugs (delirium).² In order for dementia to be determined, the symptoms must continue for a period of at least six months.

The losses of memory and cognition are gradual processes which old people often experience without this in itself indicating a pathological state.³ To define them more precisely, therefore, what is known as a threshold criterion is applied in order to determine the time from which medical literature generally accepts the beginning of a dementia process. In practice, a number of dementia screening tests are used for the first diagnosis, with the help of which cognitive disorders which exceed this threshold criterion can be recognized and quantified. For specific diagnosis, and in particular in very early stages of dementia, a detailed neuropsychological examination is necessary.

A large number of measuring instruments, usually standardized evaluation procedures, are available to assess everyday competencies, such as eating and getting dressed, or telephoning, shopping or using public transport. In order to differentiate

2 Cf. the ICD-10 Classification of Mental and Behavioural Disorders of the World Health Organization, published in 1993.

3 Cf. *inter alia* Lauter/Haupt 1993, 375 f.; also Saß et al. 2003, 91.

still further, both neuropsychological tests and neurochemical examinations (blood, cerebrospinal fluid)⁴ and also imaging procedures (computer tomography, magnetic resonance imaging, positron emission tomography) are used. If vascular dementia is suspected, further specific examinations are carried out. Particular combinations of laboratory tests with biomarkers and imaging procedures may make early diagnosis possible.⁵

At present, when the value of such early diagnosis is evaluated, it is assumed that if anti-dementia medication is given early, it is particularly effective. However, as yet there are no studies which prove this beyond doubt. The emotional effects of an early diagnosis on those affected can as yet scarcely be determined, in view of the fact that there is no cure, but at most a treatment which delays the progress of the disease.⁶

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- 4 At present, the diagnosis of Alzheimer dementia is still a diagnosis by exclusion, in which the neuropsychological findings, the ability to cope with everyday life and the case history on the one hand and the exclusion of other possible illnesses by neuroradiological and laboratory examinations on the other hand show that the diagnosis of Alzheimer's disease is probable. It is possible that in future combined biomarker tests, including tests of the increased concentration of tau proteins and decreased concentrations of amyloid-beta peptides in the cerebrospinal fluid will make it possible to diagnose Alzheimer's dementia with even more certainty and no longer solely based on the neuropsychological tests and the diagnosis by exclusion.
 - 5 In 2011 the U.S. National Institute on Aging and the Alzheimer's Association published a revised list of diagnosis criteria for Alzheimer's dementia, based on biomarker tests and imaging procedures; these are intended to make earlier diagnosis and a better differentiation from other forms of dementia possible (cf. Frisoni et al. 2011). If the validity of these criteria can be confirmed in large samples of patients, this will also enable early diagnosis.
 - 6 Research is now being directed to the question of prevention, which is repeatedly raised in public discussions; in essence, the findings are based on the assessment of risks arising from particular other illnesses and lifestyle factors. Thus, for example, a current meta-analysis cites diabetes mellitus, hyperlipidaemia and nicotine consumption as risk factors and five factors which reduce the risk (Mediterranean diet, folic acid supplementation, low to moderate alcohol consumption, cognitive training and exercise); in each case, the correlation strength is stated as small (cf. Daviglus et al. 2011). Similar results were reached by a study at the University of California which found that the risk factors are diabetes, high blood pressure, mid-life obesity, nicotine consumption, depression, cognitive and physical inactivity and a low level of education (cf. Barnes/Yaffe 2011). The evaluation of biographies by a team at the university of Pennsylvania found the following risk-reducing factors: resistance to stress, resistance to anxiety and low exposure to depression and trauma, collectively referred to as high resilience values (cf. Steinberg et al. 2011).

With a proportion of over 60 per cent, Alzheimer's dementia is the most common form of dementia.⁷ The disease is named after Alois Alzheimer, who in 1907 described both the symptoms and also, on the basis of post-mortem findings, the neuropathological changes; modern procedures have repeatedly confirmed his findings. Alzheimer's dementia is one of the neurodegenerative forms of dementia, in the course of which nerve cells are slowly and progressively destroyed and what are known as neuritic plaques and neurofibrillary changes appear; this is also mirrored by the development of the symptoms, but the strength of the symptoms and the duration of the course of the disease vary from individual to individual.

According to the current state of knowledge, the majority of those who suffer from Alzheimer's dementia are over 65 years in age, but it can also affect younger people. Depending on the age at which it appears, the words "early-onset" or "late-onset" are therefore added. In addition, a distinction is made between sporadically occurring cases of Alzheimer's dementia (approximately 95 per cent) and cases of familial predisposition (approximately five per cent).⁸ Mean life expectancy after the first symptoms appear is stated as eight years, but individual cases vary greatly.

A further group of neurodegenerative dementias whose progression is equally irreversible are the frontotemporal

7 On this, cf. in particular Lieb 2005, 125; but also Lauter/Haupt 1993, 376 f.

8 In a small subgroup of cases of Alzheimer's dementia with familial predisposition there are gene mutations on chromosomes 1 (E5-1 gene or STM-2 gene) and 14 (S 182 gene); defined mutations here result in a familial form of dementia. To date, this is regarded as the only connection between genetic make-up and Alzheimer's disease that has actually been proved. A predictive genetic test could theoretically also be used for this subgroup of familial dementia, but ethically this would raise the same critical questions as arise, for example, in the case of Huntington's disease. In addition, it has long been known that in the case of a particular gene variation of apolipoprotein E there is a higher risk of developing Alzheimer's dementia. But since in fact only a minority of ApoE4 carriers develop dementia, but on the other hand a large number of Alzheimer's patients are not ApoE4 carriers and furthermore this genetic variation is also a risk predisposition for coronary heart disease and for cerebrovascular diseases, this cannot be described as a genetically determinable cause of Alzheimer's disease.

dementias (for example Pick's disease). Memory function is retained for a relatively long period, but there are early changes in personality and behaviour (for example disinhibition, apathy). Today, this form of dementia can largely be diagnosed with the help of psychopathological findings, the determination of particular behavioural abnormalities, imaging procedures and biomarkers. But these cases are only a small percentage of dementia (approximately five per cent of all forms of dementia).

The second most common form of dementia is vascular dementia as a result of vascular disease (for example widening of blood vessels) or disturbances of the blood circulation in the brain (for example several small strokes). The proportion of vascular dementias to all dementias is stated as approximately 15 per cent. The severity of the dementia depends on the location and volume of the areas of the brain affected. In contrast to Alzheimer's dementia, the development of the symptoms is usually marked by a sudden commencement. The further progression varies greatly and depends on vascular events. The mean life expectancy after the first symptoms appear is highly dependent on the underlying vascular processes, but on average it is four years.

In addition, a large number of secondary forms of dementia should be mentioned, which result from organic, infectious, metabolic, toxic or traumatic causes. This also includes dementias which may arise as a result of neurological illnesses, such as Parkinson's disease. Approximately 30 per cent of persons with Parkinson's disease develop dementia at a late stage of the disease.⁹ But this constitutes only 1.3 per cent of cases of dementia.¹⁰ Dementia resulting from chronic alcohol

9 Cf. Brunnhuber et al. 2005, 137 ff.

10 Lewy body dementia occupies a special position, with characteristics of Parkinson's disease and of Alzheimer's disease at the same time. The symptoms include progressive cognitive impairments, a fluctuating progression, visual hallucinations and parkinsonism. Diagnosis is made by finding what are known as Lewy bodies, that is, intraneuronal inclusion bodies. In the literature, 20 per cent of dementias are sometimes attributed to these Lewy bodies. Other writers dispute the existence of Lewy bodies as evidence of a separate form of dementia.

consumption is more widespread and has a proportion of approximately 4.6 per cent. Some of these dementias can be treated and even reversed. But here too, in the majority of cases there is progression, in particular where the toxic damage to the brain is combined with Alzheimer's disease.

The treatment of dementia syndromes usually has three aims: the improvement of the disturbed brain function, the strengthening of everyday competencies and the reduction of behavioural abnormalities.¹¹ For treatment with drugs, a number of antidementive drugs are available whose effectiveness has been proved by the criteria of evidence-based medicine in the areas of cognition, everyday activities and emotional and behavioural symptoms. At present their overall effect is a temporary delay of progression and to some extent also the improvement of individual symptoms.¹² In addition, emotional attendant symptoms, in particular anxiety, depressive symptoms and restless or aggressive behaviour, but also psychotic symptoms can be treated symptomatically with specific psychotropic drugs, although because these have particular side effects and increased interaction with other medicinal products particular care must be taken to ensure close supervision.

Particular importance attaches to the approaches to treatment without drugs. These may be subdivided into cognitively activating processes (for example memory training, orientation training) and socio-emotional approaches (for example ergotherapy, milieu therapy changes of environment, music

11 A good summary is given by Frölich et al. 2012.

12 Hopes are repeatedly expressed of a treatment of the causes of neurodegenerative dementia and at the same time of the development of a vaccine intended to inhibit the underlying metabolic processes, such as amyloid formation, by immunization. To date, however, these approaches have not been shown to be effective. The latest research results assume that it is increasingly unlikely that Alzheimer's dementia can be cured with one single substance, and instead a network of factors must be assumed, which is all the more difficult to influence. What is known as the beta-amyloid cascade hypothesis, which assumes that clumped protein fragments set off the loss of neurons in the brain, is sometimes questioned today.

therapy, self-maintenance therapy¹³ and validation¹⁴). The majority of these procedures and approaches, which normally contribute to the stabilization and improvement of the quality of life of those affected, directed attention to the individual competencies and potential which the person affected still has.¹⁵

The following observations relate essentially to Alzheimer's dementia.

1.2 Development of the symptoms of Alzheimer's dementia and their effect on the persons affected

Alzheimer's dementia begins slowly and insidiously, usually with disturbances of retentivity, and often also slight changes of behaviour, such as decreasing activity or social withdrawal. The processing of the first personal fears, the slowly developing awareness of symptoms, the decision to undergo an examination, and finally coming to terms with a diagnosis and directing one's own life to the associated new prospect of one's future life, which has been anticipated with fear for some time but has now become a certainty: persons with dementia often describe this as a very difficult stage of their lives.¹⁶ The fear of the imminent burden they will be to others and of the dependence

13 In self-maintenance therapy, the self of dementia sufferers is reinforced, as is their knowledge of their own past, their own strengths, weaknesses and preferences and their awareness of what they have acquired during the course of their lives. With the help of daily training, their own resources are trained at an early date and their own identity and the possibilities of self-determined decisions are strengthened. Strengthening the self which in this way can be activated even in late phases and after crises makes it possible to minimize negative emotions and to have positive self-experience as the basis of personal involvement in decisions (cf. Romero 2004).

14 Validation is a method of not correcting the utterances of dementia sufferers, but instead dealing with them positively and incorporating them into everyday life, defining them as "valid" (cf. Feil/Klerk-Rubin 2005).

15 Cf. Woods 2002.

16 Cf. *inter alia* Taylor 2007, 6 ff.

on them, of loss of autonomy and being patronized are in the foreground at this time.¹⁷ In this connection, the individual's reaction to the diagnosis is often determined by fearful images of Alzheimer's disease which are prevalent in society.

It may therefore be regarded as a standard in medical practice not only to adapt and structure the communication of the diagnosis individually to the requirements and level of understanding of the patient, but also to inform the patient with empathy but also realistically of the need for assistance he or she may need and of his or her possibility of living a largely independent and self-determined life as long as possible.¹⁸

In the following, the different phases of development of dementia are described symptomatically and are summarized with regard to coming to terms with them emotionally and the resulting possibilities of self-determination and self-directedness. The division into three phases, which is widespread in the literature, is followed.¹⁹ Subdivisions over and above this, down to seven levels²⁰, may give a more complex account of the gradual process, but for the purpose of this Opinion, that is, considering questions of self-directedness and self-determination, they are not necessary.

Early phase of dementia development

Symptoms, while motor function and affective sensation are otherwise unremarkable:

- >> Poor short-term memory
- >> Difficulty in learning new things
- >> Disturbed orientation in unfamiliar environments (tendency to lose one's way)
- >> Absentmindedness
- >> Speech disorders, trouble finding the right word, reduced vocabulary and declining speech comprehension

17 Cf. *Demenz Support Stuttgart* 2010.

18 Cf. Alzheimer Europe 1999, 7 ff.

19 Cf. Lang 1994.

20 Cf. Reisberg et al. 1982.

- >> Distorted sense of time and space (limited ability to copy pictures)
- >> Lack of drive
- >> Difficulties with complex activities previously mastered (for example cooking)
- >> Restricted judgment
- >> Declining self-sufficiency

Possible forms of emotional processing:

- >> Denial of illness
- >> Glossing over with jokes and empty phrases
- >> Anxiety and depressive moods
- >> Social withdrawal

It can generally be stated that forming intentions and being able to make decisions for all areas of life are in principle possible and not subject to legal restrictions in this stage of the illness, although both fluctuate greatly and may be influenced by emotional elements such as anxiety and depressive moods. This may lead both to overadjusted decisions wishing to please everyone and be a burden to no one, and also to a state of denial and fixed ideas. But in principle, decisions on the basis of the person's own system of values and made by weighing a number of points of view are possible. Here, a supportive atmosphere and enough time are helpful for the person concerned to form intentions, in particular where it is a case of forming intentions with regard to new or fundamental questions and where complex constellations call for detailed statements. Decisions on activities of everyday life, such as remaining in one's familiar domestic environment, going out alone, driving, using public transport or restrictions of smoking and alcohol consumption are described in the literature as typical topics of this phase, with regard to which the opinions of the persons affected and of those around them may differ, but on the whole it is possible to rely on the persons' understanding

if communication is conducted carefully and with enough time.²¹

Family members are recommended to discuss all areas of decisions at an early date and openly with the person involved. In contrast to the above areas of everyday life, dealing with money and managing financial affairs are described as the areas which may result in profound conflicts. The advice is therefore given to think of arranging for legal custodianship or a power of attorney with similar effect at an early date.

Middle phase of dementia development

Symptoms:

- » Severe disorder of short-term memory (extreme forgetfulness)
- » Memories of early events are lost in inverse proportion to the distance in time, that is, the longer ago the events took place, the longer they are remembered
- » Disorientation even in familiar surroundings
- » Temporary failure to recognize family members, home, familiar items
- » Increasing disturbances of speech comprehension and oral expression (for example trouble finding the right word, confusing words, saying syllables out of sequence, creating individual new words, decay of language)
- » Accumulation of situations in which the person with dementia is helpless
- » Disturbance of day-and-night rhythm

Possible forms of emotional processing:

- » Behavioural problems (for example wandering, running away/running towards, aggressivity, panic states)
- » Wakefulness, restlessness
- » Irritability and mistrust (sometimes hallucinations and delusions)

21 Cf. Alzheimer Europe 1999, 9 ff.

- » Living in the past, living in one's own world which can scarcely be communicated to others
- » Emotional sensitivity (for example joy, shame, grief, pain), in particular intuitive identification with a situation is possible, albeit with fluctuations)
- » Intensive experience of the moment possible

With regard to the question of self-determination, it can be established that the forming of intentions is increasingly restricted to acts based on opinions, to decisions in the immediate experiential sphere and to the direct satisfaction of needs. Things must either be directly visible or easy to imagine, must correspond to old patterns of perception and be assessable by the person's remaining value orientations, which are applied using a yes/no pattern.

Decisions linked to language and outside the person's immediate experiential sphere are more difficult, utterances often clichés. Since short-term memory is particularly affected in this phase, decisions often have no stability, or decisions made by the person are forgotten a short time afterwards. Sequences of action must be short or may consist of only a few steps. But in some cases there may be sudden interruptions of these as a result of forgetfulness.

Decisions on matters that are unknown or no longer available to memory cannot be made by the person alone, but he or she can share in them. This relates in particular to decisions on financial expenses, change of residence and other long-term plans.

Late phase of dementia development

Symptoms:

- » Very severe mental degeneration
- » Stereotypical repetitions of sentences and words
- » Continuing failure to recognize situations and people
- » Physical disorders (for example incontinence, difficulty swallowing, difficulty walking, bedsores)

- » Complete dependence for food, hygiene and everyday tasks

Possible forms of emotional processing:

- » Agitation, hallucinations
- » Apathy
- » Delusional reactions

The persons with dementia act in order to satisfy their immediate needs, to ward off unpleasant sensations and negative feelings, from intuition or in line with habitual behaviour patterns. Decisions based on opinions which do not serve the direct satisfaction of needs or warding off negative stimuli are usually no longer possible, unlike in the second phase. In some cases behaviour occurs whose motivation and objective cannot be understood by others, although if they know the history and personality of the person with dementia well they may be able to interpret it in part. To the persons close to the person with dementia, he or she appears to live in a world which is largely inaccessible to others and often incomprehensible, and is no longer able to adjust to the perspectives of other people. But even in this stage the person with dementia is certainly able to experience positive emotions and (as a rule) to express them non-verbally, and thus to make yes/no decisions in the area of what he or she directly experiences, on an emotional basis (cf. section 1.3).

When speaking of the self-determination potential of people with dementia, it is important also to mention their substantially increased vulnerability as a particular dimension of the development of dementia. This applies to all phases of the development of dementia. People with dementia are often well able to sense genuineness and authenticity and have a need to be seen and respected as persons. In many cases they are highly sensitive to behaviour which calls their self-respect into question or prevents them from living in their world in their own way. The changes in memory and cognition in particular

result in a great strengthening of the competence to perceive situations intuitively and an increase of sensitivity to interpersonal relationships, to the feelings of others and to nuances.²² The vulnerability of people with dementia also stems from the fact that these emotions are spontaneous and unfalsified, but may also be very strong and uncontrolled. Like the somatosensory, visual and verbal information, the emotional information too is not integrated, that is, it does not appear inherently consistent. Learned social behavioural patterns are often now scarcely present. Persons with dementia increasingly live in a world of their own, in which sensitivity, empathy and respect shown to this world by others have great importance for those affected.

1.3 Current state of research into quality of life as the basis of an understanding interaction which facilitates self-determination

Research into the quality of life, which in Germany is conducted in particular by the Institute of Gerontology at Heidelberg University, assumes that the quality of life of many persons with dementia is low as a result of failure to communicate with the persons with dementia and the consequent lack of understanding of those around them for the lifeworld of people with dementia.²³ The confrontation with the illness dementia reminds the person of a dimension which has often become forgotten in the striving for independence and self-determination: the dimension of dependence. The recognition and acceptance by the person with dementia himself or herself and by professional carers and family members of this need for the solidarity and help of others represents the foundation for a

22 Cf. Kitwood 2008.

23 Cf. Kruse 2010.

form of contact with the person which is free of prejudice.²⁴ In practice, cognitive deficiencies may often create the mistaken assumption that persons with dementia no longer understand anything and are incapable of interaction. In their 2005 research, Kruse and the representatives of the Heidelberg Institute already countered this when they established that even in advanced stages people with dementia are perfectly capable of reacting in a nuanced way to social situations.²⁵ Even in the advanced stage of dementia, the ability to experience positive emotions and express them nonverbally is present.

The quality of life of persons with dementia depends considerably on how successfully the persons close to them and carers perceive the emotional situation of the persons with dementia and respond to it. Scientific investigations show that this can be shown by the analysis of facial expressions, which was originally developed in research into schizophrenia.²⁶ On this basis, individually determined everyday situations which contribute to experiencing positive emotions can be identified and systematically created. According to the available investigations, this increases the quality of life of persons with dementia and their possibilities of having a lifestyle as self-determined as possible. They state that even if creating self-determined life situations does not always succeed in improving the emotional state in the long term, at least it alleviates symptoms, such as restlessness, agitation and many aspects of what manifests itself as aggression. In this way, not least, it is made easier for carers to carry out their tasks, and in particular their motivation and job satisfaction increases.²⁷

Against this background, the *Bundesministerium für Familie, Senioren, Frauen und Jugend* (Federal Ministry of Family Affairs, Senior Citizens, Women and Youth) called for a

24 Cf. Kruse 2009.

25 Cf. Becker et al. 2005; also Kruse 2005.

26 The method of Facial Action Coding System (FACS) goes back to Ekman/Friesen/Ellsworth 1972.

27 Cf. Bär/Böggemann/Kruse 2005.

comprehensive study to record the quality of life of persons with dementia with the aim of systematically improving this.²⁸ This took into account not only the individual competencies and characteristics such as emotionality, activity and experience of pain, but also elements of the environment, such as health care and the person's spatial environment and social network. It can be established as the essential result of the study that persons with dementia, irrespective of the stage of their illness, can experience everyday situations in an emotionally nuanced way and can express their emotional state non-verbally. Even in the late stage of dementia, therefore, reactions on the level of emotional perception and differentiation are possible which contain elements of understanding, assessment and intention, and these may also be expressed in the form of a situatively authentic cooperation.²⁹ In addition, the authors emphasise that even in extremely advanced dementia the emotional state shows great variability, which is reflected in the pattern of facial expressions.³⁰ Only if carers and family members interpret the wishes and communications of the person with dementia in a nuanced way will they be able to support the person in particular ways and give the person possibilities of self-determination or behaviour appropriate to needs. But with the help of the analysis of facial expressions, carers and family members can recognize emotions of joy, wellbeing, irritation, anger, sadness or shame and thus react positively to the wishes and impulses of the person with dementia, support the person's remaining self-determination or self-directedness, depending on the stage of the disease, and increase the person's quality of life.

28 782 care homes with 64,588 care home places took part in the study (cf. Becker/Kaspar/Kruse 2010).

29 Cf. Kruse 2012.

30 Cf. Becker/Kaspar/Kruse 2010.

1.4 Personal testimonies of persons with dementia

Only a few years ago it was customary to say nothing about the lives of celebrities with dementia, but now there are extensive reports and discussions in the media in some cases. Newspapers and magazines, radio and television report on the lives of celebrities, whether they are academics like Walter Jens or footballers like Rudi Assauer. This is accompanied by a broad journalistic echo which encourages public discussion on dementia.

The world of experience of those affected by dementia, in particular the experience of possibilities of self-determination and of their limits, is most graphically shown in their own accounts. There are now a number of impressive and self-assured personal accounts by persons with dementia³¹ and reports by partners or by children directly involved in companionship³².

The personal accounts show that the first symptoms, in particular disturbances of memory and inability to find the right words, often elicit shame and lack of understanding, but also uncertainty and confusion. Some also report that they tried to play down or cover up the situation: “At first I thought I was just very worn out”, “I am just very tired.” The personal accounts also show how difficult it is to admit one needs to go to the doctor to be examined. The period of waiting for the diagnosis is also hard. The American psychologist Richard Taylor, who speaks openly about his Alzheimer’s disease in public and has published on it, calls the period between the suspicion that one has Alzheimer’s disease and the certainty that one has it the time of “purgatory”.³³ For many persons with dementia, even more burdensome is the memory of the situation when they were told the diagnosis, when their fears became reality

31 Cf. *inter alia* Rohra 2011; Taylor 2007; Zimmermann/Wißmann 2011; *Demenz Support Stuttgart* 2010.

32 Cf. *inter alia* Braam 2007; Geiger 2011.

33 Taylor 2007, 13.

or when what they thought was improbable suddenly became real. Shock and numbness, but also grief and despair are described as reactions. “In that moment, I felt as if I were falling into a hole. I was completely incapable of continuing to listen,” Helen Merlin describes this situation.³⁴ She later revealed that she is Helga Rohra, and since 2010 she has been a member of the board of the *Deutsche Alzheimer Gesellschaft* (German Alzheimer Society), the only person with dementia in that position. James McKillop, a person with dementia from Scotland and an activist in the Scottish Dementia Working Group there, says: “When I was given the diagnosis, I was thunderstruck [...]. [...] So I fell into a deep depression [...]. I sat in a dark room, spent the whole day staring at a blank television screen and didn’t talk to anybody.”³⁵

But how do persons with dementia overcome this first reaction? “You must not give anxiety and terror too much space,” writes Christian Zimmermann, who has dementia and who in the last years has often spoken about it, in the dementia support project and elsewhere.³⁶ He says that Alzheimer’s disease is like a partner which accompanies him in his second life. It is only important not to let it become too powerful. And Rita Dechant, who also has dementia and is active in the dementia support project, reports: “The first weeks after the whole process had finished and the doctor had told me that I have dementia, I simply cried the whole time. Then I said to my husband: ‘Now I would like to know what kind of a disease that is and how it will continue.’ And then I read everything [...]. [...] I can’t do anything but accept it. Reaching this stage simply takes a few days, or actually, it was several weeks. Since then it has been part of my life [...].”³⁷

Many persons with dementia are driven back and forth between despair and accepting the inevitable, according to their

34 *Demenz Support Stuttgart* 2010, 13.

35 *Demenz Support Stuttgart* 2010, 82.

36 *Demenz Support Stuttgart* 2010, 52.

37 *Demenz Support Stuttgart* 2010, 109.

personal accounts. For many, part of accepting the situation is making it public. “Above all it is important for me to talk about it [...]. [...] Till now I have not yet found that anyone reacted negatively to it,” says Wolfgang Krüdwagen, who also has dementia, and many others in the dementia support project agree with him.³⁸ But those who are still in working life have had different experiences and tend to recommend keeping it to oneself.

Many concern themselves intensively at an early stage with the disease. How do you feel if you know that you have dementia and are afraid of losing your identity? “I race up and down the corridors of my mind, frantically seeking to make sense of what’s going on around me. Sometimes this process makes me even more lost, and I become lost about why I am lost!” writes Richard Taylor.³⁹ And yet, even when he reports of many states of despair, he finds new insights and qualities: “I enjoy the process of doing things, and most of my feelings of accomplishment come from the middle, not the end, of projects.”⁴⁰ The fact that he knows that he is ill, he says, makes him focus on “actively making today better than yesterday, not hoping tomorrow will be better than today.”⁴¹

The terror of the disease disappears for many persons with dementia who speak about it when they speak or write about it or in the exchange with other persons with dementia in a support group. “When I realized that I can still do things for myself and can help others in a dark stage in their lives, I began to enjoy life again,” McKillop answers the question as to how he coped with the diagnosis and gave his life meaning again.⁴² The personal accounts are evidence of a multitude of reflections on the persons’ own situation, in which anxiety about the future admittedly appears again and again, but which usually

38 *Demenz Support Stuttgart* 2010, 96.

39 Taylor 2007, 35 f.

40 Taylor 2007, 79.

41 Taylor 2007, 88.

42 *Demenz Support Stuttgart* 2010, 83.

contain many wishes and needs and clear ideas for the future and the things they intend to do in the future. The personal accounts are also often characterized by humour and quick-wittedness. Many also report new discoveries and developments in themselves. These include painting pictures by people who have never held a brush in their hand before, or acting by people who have never dared to do so before. So it is not the case that only familiar things are preserved or continued (those who could sing well before can often still sing well as persons with dementia), but new things are discovered or things long since abandoned are taken up again.

Those who make their situation public constantly emphasize that they can speak for themselves and do not need anyone to do this for them. One of the most upsetting experiences of people with dementia is the frequent reaction of medical staff, who after diagnosis often begin to treat them as mere objects and even in their presence often conduct the conversation only with their family members.⁴³ Taylor describes dementia as a social illness. He says that he came to the conclusion that people with dementia do not need pharmaceuticals but “socioceuticals”.⁴⁴ Being seen as ill and no longer capable of making decisions is a negative experience which accelerates the disease: “I want and need the same things, and Alzheimer’s does not make my need to love and to be loved by others any smaller. Dementia does not mean that I no longer need any purpose in my life. Dementia does not mean that I cannot any longer learn anything new. Dementia does not mean that laughter is no longer important to me. Dementia does not mean that I no longer need a social network of friends and family members with whom I interact every day.”⁴⁵

Persons with dementia repeatedly describe the following as important for their lives: their connection to their family or to

43 Cf. Rohra 2011, 103.

44 *Demenz Support Stuttgart* 2010, 69.

45 *Demenz Support Stuttgart* 2010, 67.

friends, the knowledge that they belong, the feeling of being needed and, of particular importance in this connection, the possibility to make free decisions and to have self-determination. Very often they decidedly protest that they want and are able to decide something themselves and do not have to be told what to do by others. Again and again one reads statements like this: “We can do more than you think we can”, “We can speak for ourselves”, “We must influence what our lives are like”.⁴⁶ “I want others to listen to me” is Richard Taylor’s heading for one of his contributions.⁴⁷ “I want to be treated as if I had the same potential as you do, but that it is only more difficult for me to put it into practice.”⁴⁸

“Regrettably, when people have Alzheimer’s disease, attention is mainly given to what has changed and what has worsened. This mistaken emphasis on people’s deficiencies rather than their strengths begins very early, at school. We should above all look at what we can do and cultivate these strengths,” says Zimmermann when describing his experiences.⁴⁹ He does not want to be equated with his memory or understanding. Like many others, he wants to be experienced as a complete person.

Taylor deplores the fact that too much weight is attached to the diagnosis and too little to the person behind it.⁵⁰ He says that the illness does not mean that the personality disappears. It is often only accessible in new ways and presents itself differently. “I am certainly more than merely memory or abstract thought,” says a person with dementia self-assuredly. Another: “It is true that with Dr. Alzheimer a new life began for me, but that does not mean that the old life disappeared from sight without trace.”⁵¹ “I am still me” and “I have still remained

46 Zimmermann/Wißmann 2011, 114.

47 *Demenz Support Stuttgart* 2010, 66.

48 *Demenz Support Stuttgart* 2010, 127.

49 Zimmermann/Wißmann 2011, 84.

50 Cf. Taylor 2007, 12.

51 Zimmermann/Wißmann 2011, 83.

myself, with and without dementia!”⁵² But they say that it depends on how others treat them whether they can feel that they are persons who can decide about themselves.⁵³

A mirror image of this dependence of persons with dementia on the reactions of the family members directly accompanying them is also shown in the accounts of the family members. Stella Braam’s book on the last three years of her father René van Neer, who had Alzheimer’s disease, shows her own process of learning and adjustment as she came to terms with the various stages of her father’s illness, but also her attempt to see her father as the person she was familiar with. But he had changed so greatly that she had to develop a new, different relationship to him in order not to put too much stress on him. “Persons with Alzheimer’s disease have a lot to say about their own situation. We must take them seriously. We must listen to them,” Braam writes.⁵⁴

52 Rohra 2011, 15.

53 This statement, which is encountered again and again in the personal reports, is also confirmed in the person-centred approach. Kitwood (2008, 73 ff.) speaks of a “malignant social psychology” if those around the person with dementia react only impersonally to persons with dementia and treat them as objects, and pathologize and devalue their statements. In such cases, he writes, the symptoms always deteriorate (cf. Morton 2002, 180 ff).

54 Braam 2007.

2 THE SOCIAL REALITY IN GERMANY

2.1 Persons who are directly affected by dementia

At present it is not possible to give precise figures on how many people in Germany have dementia.⁵⁵ There are precise studies for individual regions⁵⁶, but they are not yet available for the Federal Republic as a whole⁵⁷. However, the increasing frequency of the illness (prevalence) can be estimated on a reliable basis and compared with international experience, which shows that similar developments can be observed in other industrialized countries too.⁵⁸

At present, experts assume that there are up to 1.2 million people in Germany who have a medium to severe form of dementia; the statistical data on the milder forms are not very reliable.⁵⁹ Between the ages of 60 and 90, the prevalence within one age group appears to be doubling at intervals of about five years, as Table 1 shows. It rises to over one-third of those over 90 years old.

55 Detailed report in *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002.

56 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002, 152 f. and 167 ff.

57 Cf. *Deutsche Alzheimer Gesellschaft* 2008.

58 Cf. Nuffield Council on Bioethics 2009, 4 f.

59 Cf. also Weyerer (2005, 11 ff.), who estimates that there are from 900,000 to 1.2 million people with dementia.

Estimation of prevalence of moderate and severe dementias in Germany

Age group	Average prevalence (%)	Estimated numbers affected	
		1999	2007
65 to 69	1.2	50,000	66,000
70 to 74	2.8	94,000	111,000
75 to 79	6.0	136,000	184,000
80 to 84	13.3	225,000	288,000
85 to 89	23.9	253,000	256,000
90 and older	34.6	142,000	197,000
65 and older	7.2	900,000	1,102,000

Table 1: Estimation of prevalence of moderate and severe dementias in Germany⁶⁰

Since the number of older citizens is growing both relatively and absolutely and in the coming decades, because of increasing life expectancy, is certain to continue growing, experts expect that as a result of the new cases (incidence) every year of between 200,000 and 300,000 the absolute number of persons with dementia will rise in the year 2020 to approximately 1.4 million or – according to other estimations – 1.7 million and more than 2 million in the year 2050, unless a treatment to remove the causes is developed before then.⁶¹

Approximately two-thirds of persons with dementia are women. There are several reasons for this: On the one hand, women usually have a greater life expectancy than men; on the other hand, particularly when advanced in age they statistically have a greater risk of Alzheimer's disease. In addition, women with dementia live more than two years longer after the first diagnosis than men with dementia.⁶²

60 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002, 167; *Deutsche Alzheimer Gesellschaft* 2008, 1. The data on the course of the average prevalence in the sources deviate from each other only slightly.

61 Cf. Bickel 2005.

62 Cf. Ostbye/Hill/Steenhuis 1999.

Age- and gender-specific prevalence of dementia		
Age group	Average prevalence (%)	
	Men	Women
65 to 69	1.6	1.0
70 to 74	2.9	3.1
75 to 79	5.6	6.0
80 to 84	11.0	12.6
85 to 89	12.8	20.2
90 to 94	21.1	30.8
Total	4.5	7.3

Table 2: Age- and gender-specific prevalence of dementia on the basis of meta-analyses⁶³

There is a particular difficulty in the diagnosis and treatment of concomitant diseases of persons with dementia, because among other things the communication between patients and treating doctors is difficult. Thus, for example, clinical symptoms in the moderate and severe phase of dementia are more easily overlooked because it is so difficult to interpret the communications of those with dementia, but also because of lack of time and experience on the part of doctors, and they often do not receive appropriate treatment.⁶⁴

2.2 Persons indirectly affected

Those indirectly affected by the consequences include above all the closest family members, spouses, brothers and sisters, children, other relations and friends. They have to cope with the process of the change of a relationship, which is often conflict-laden and painful, in which they have to adjust to the

⁶³ Cf. Lobo et al. 2000, S5.

⁶⁴ Cf. Bundesministerium für Familie, Senioren, Frauen und Jugend 2002, 174 f.

perspective of the person with dementia and must increasingly accept that the family member they are caring for no longer recognizes their own feelings and needs.

The families bear the greatest burden, emotionally, physically and financially, in the care of family members with dementia. They often assume the tasks of direct supervision and domestic care in the awareness that there is no cure but at best alleviation of an illness which in the last instance is fatal. Family members are usually those who by reason of their personal relationship and long-term familiarity with their relation can best recognize or interpret the person's utterances, wishes and interests, which are often difficult to understand.⁶⁵ Even if supporting self-determination means that the family member carers are burdened even more, it can in the long term reduce the emotional pressure which many family members repeatedly report.

Without the work of family member carers, it would no longer be guaranteed that people with dementia could be accompanied and cared for in their own domestic environment. But remaining in one's familiar surroundings is the predominant desire of those affected. Even in later phases of the illness and in care homes, many supporting activities which reinforce whatever self-determination the persons with dementia still have are possible only with the additional help of the family members. In addition there are a large number of persons largely illegally employed in private households, usually caregivers from states in Eastern Europe, without whom

65 In this connection, the risks of physical and mental maltreatment by family member carers must be kept in mind. This is the subject of the research project PURFAM (Potentials and Risks in the Family Care of Old People) sponsored by the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth. In addition to maltreatment, this also investigates neglect, financial abuse and restriction of free will. The prevention of violence and neglect is to be effected by measures of early warning and strengthening resources, and by information on best practice projects.

care at home would be impossible in many cases of advanced dementia.⁶⁶

According to surveys, which tend to be confirmed by examinations in other states, approximately one-third of the costs of necessary care are borne by health and long-term care insurance, and at present the families bear approximately two-thirds, mainly through their unpaid work, which is difficult to calculate.⁶⁷ This is shown by model calculations which take account of the time involved for care, which increases as the disease progresses. Within the family, approximately 80 per cent of those who care for their parents, parents-in-law or spouses are women. If men act as carers, this is usually for their wives.⁶⁸ However, the development towards smaller families, greater mobility and an increasing number of women in employment suggests that the present extent of care of people with dementia in their homes will not be possible in future.⁶⁹ This appears above all to affect the care of the older generation. Nevertheless, family members are and remain the safety net for persons with dementia.⁷⁰

Family members have to cope with the challenge of compensating as far as possible for the cognitive deficiencies and fluctuations of the persons with dementia, bearing their

66 The number of foreign caregivers working in private households for the supervision and care in particular of persons with dementia, mainly from states in Eastern Europe, is estimated to be between 50,000 and 100,000 (cf. *inter alia* *Deutscher Bundestag* 2006). At present the majority of them work illegally.

67 Hallauer et al. (quoted by *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002, 181) predict average annual costs of approximately 44,000 euros.

68 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002, 195 f. and 201.

69 Rothgang et al. (2010, 62 f.) show on the basis of the pensions insurance data of "carers" within the meaning of Section 19 of Book XI of the *Sozialgesetzbuch* (Social Code) that the number of women as "carers" on the one hand is up to fourteen times as many as of men, but on the other hand it has steadily decreased since 1999. In 1998 there were still 474,886 women with pensions insurance in this form, but in 2008 only 364,425. The number of men insured in the same way has been constant since 2000, between 38,000 and 39,000.

70 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002, 181 f.

rapidly changing moods and understanding the impulses and other utterances still present in order to negotiate appropriate activities in each case; this challenge only arises occasionally on the first signs of dementia, but it then increases and becomes increasingly burdensome. At the same time, the caring partners must come to terms with the loss of past essential times of understanding and of shared memories of their lives.

To combine all this with comprehensive care and at the same time to react to very different situations and disturbances is a highly demanding and burdensome task, in which as the severity of the disease increases the roles in a partnership increasingly turn into an asymmetrical relationship of caring and custodianship. At the same time, these caring family members are as a rule not trained to handle the problems with which they are confronted. Although they act as unemployed helpers, their attention and care are of great importance as a result of their familiarity with the person with dementia. They in turn need a great variety of assistance to support them in the concrete acts of care.

In view of their increasing cognitive weaknesses, people with dementia need not only technical and (varying) assistance from carers, but also social and emotional surroundings which make it possible to have access to persons with dementia and to take account of their present wishes on the basis of long-term familiarity. Such helpful assistance would be less common if in future caregiving by family members were to become less frequent.

Admittedly, the family members themselves run a great risk of becoming ill themselves, and they need to be aware that outside assistance is available.⁷¹ For physically and emotionally they are often challenged to go beyond their own limits. This also includes the conflict, which is difficult to resolve, between the customary desire of the persons with dementia to remain in their familiar surroundings at home, indeed, to

71 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2002, 198 f.

be able to die there, and the realistic possibilities of care by family members. Consultation and relief for family members becomes particularly important in the phase when they have to recognize that they have reached their own limits and it is impossible to continue care at home in the same way, and instead the person with dementia needs to be put in a residential care community, in a home or if necessary in a hospice.

2.3 Professional care of persons with dementia

In very many cases, persons with moderate and severe dementia can no longer be cared for by the family members alone, and often no longer at home either. For in view of behavioural disorders such as motor restlessness, verbal and physical aggression and difficulty of communication, persons with dementia need incomparably more help and attention than other patients, both in general nursing care and in the support over and above it.

The scale of professional help includes outpatient care, day-patient care, supervision and encouragement, short-term care, residential projects and inpatient care in a care home. The *Heimgesetz* (Care Home Act) provides that 50 per cent of the carers in these institutions are to be qualified personnel; this is only gradually being achieved in practice. All employees, including the geriatric care assistants (*Altenpflegeassistenten*) and companions, must have specific continuing training and further training in this area.

The involvement of voluntary helpers who take their citizenship seriously is one of the desirable and gratifying developments of recent decades. However, these too – like the committed family members – need their voluntary work to be recognized by ongoing communication, public recognition and possibilities of acquiring qualifications.

In the field of dementia care, the professional carers are subject to a particularly high degree of stress. At the same time

it is to be expected that by reason of the age shift in the working population as a whole and the future increase of the pensionable age, the care workers will on average be increasingly older.

A number of studies show that the nursing staff in hospitals and in inpatient and day-patient institutions are extraordinarily burdened, indeed, even permanently overburdened, both physically and emotionally.⁷² This is shown by fluctuation, frequency of leaving the occupation and strikingly high sickness figures.⁷³ These are all signs that limits of what carers can take have been reached and exceeded. If in addition there are calls for care which is targeted to the needs, reactions and emotions of persons with severe dementia and which as far as possible systematically involves family members and volunteers, this increases the demands on the professional carers even more. Such an improvement requires additional training measures and additional personnel. However, a number of studies and practical experience indicate that the burden on carers is reduced and their job satisfaction increases if persons with dementia are given appropriate surroundings, positive and respectful communication and appropriate care. In addition, person-centred caring work which integrates the communicative and emotional aspects also corresponds to the predominant self-image of the carers and contributes to increasing their satisfaction.

Violence in caregiving is a phenomenon which is becoming more frequent; it includes not only physical violence, but also forms such as neglect and molestation. Reasons often given include being overtaxed, lack of training, lack of communication within the profession and stress. Nevertheless, violence in care relationships arises not only from social and institutional circumstances. Violence in care also has to do with the emotional and mental state of the carers, with their feelings, with the loss of relationship to the person cared for and with dissatisfaction

72 On this, cf. Rothgang et al. 2010.

73 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2006, 72 ff.

with the work.⁷⁴ It should be noted that carers may not only become perpetrators, but also victims. For both sides of this difficult discussion, ongoing communicative exchange between the carers and other supervisors, counselling and further training, and also documenting all events of a violent nature, have proved to be particularly effective in preventing violence.

2.4 Care home and residential projects

In Germany, the number of persons needing care who can no longer live independently or with their families is increasing overall. Among them, the proportion of persons with dementia increases with the constantly increasing age of the patients to be admitted. In the year 2005, approximately 400,000 persons with dementia were already being cared for in old age homes and care homes.⁷⁵ In these inpatient institutions, therefore, the proportion of persons with dementia is currently further increasing both relatively and absolutely. Whereas in 1995 approximately 44 per cent of all inhabitants of inpatient old people's welfare facilities suffered from dementia, ten years later the figure was 60 per cent⁷⁶, other studies now put the figure at almost 70 per cent⁷⁷. This tendency is also confirmed by surveys in individual locations.⁷⁸ In this connection, the distribution between the exclusively domestic, day-patient and care home inhabitants varies considerably from region to region in Germany, as is shown by recent reports.⁷⁹ Such differences also arise from the still very uneven regional distribution of

74 Cf. Gröning 2004.

75 Cf. Bickel 2005.

76 Cf. Bickel 1995; Bickel 2005.

77 Cf. Schneekloth/Wahl (2008, 9), who give a figure of 69 per cent persons with dementia, on the basis of an in-depth study.

78 The prevalence of dementia cases in care homes is noticeably shifting. In fifteen Mannheimer nursing homes for the elderly, the prevalence changed from 53.8 per cent (1995/1996) to 58.6 per cent (1997/1998) and to 63.8 per cent in the year 2003 (cf. Weyerer et al. 2006).

79 Cf. Schneekloth/Wahl 2008; Rothgang et al. 2010, 10 ff.

residential projects or residential care communities⁸⁰, which present themselves as alternatives to care homes. Here, families concerned join together, rent a suitable home near where they live, large enough to accommodate their family members with dementia, and design and organize for the latter a mixture of professional care and their own support and companionship. It is regarded as particularly important that there is an active family members' committee, which should from time to time have expert support and advice.⁸¹ Such joint forms of residence and care offer a situation of everyday life which is a great deal more similar to the relations' previous domestic environment than a care home.⁸²

Since several persons with dementia (normally between six and ten persons) live together, they can be jointly supervised by permanent staff. Current experience indicates that in such surroundings everyday competences remain present for a long time and psychotropic drugs can be reduced, with further health benefits. In this form of supervised residence, family members who were overburdened by supervising at home or simply needed more space can be flexibly involved in the scheme decided on. The nursing staff seem to be less overburdened and to change their occupation less often than in other institutions.⁸³ The financial conditions of such residential communities are now made easier as a result of the *Pflege-Neuaustrichtungs-Gesetz* (Care Reorientation Act), which the

80 For example, a notice from the German Alzheimer Society dated 22 November 2011 gives the number of residential communities for people with dementia in Berlin as 180. The numbers in the other *Länder*, it states, are lower and vary greatly from *Land* to *Land*. There are no precise figures, since there is no obligation to register.

81 This must be distinguished from the residential care communities established by mobile nursing services or other organizations, for which the organization is responsible; these can offer a solution if the legal representatives of the people living there do not wish or are unable to be actively involved in organizing the residential community. However, without a community of persons commissioning the arrangement, there is no counterbalance to the organization responsible, which is then very strong.

82 Cf. Pawletko 2004.

83 Cf. Pawletko 2004, 45 f.

Federal government submitted in March 2012, although they are still insufficient.

In this connection it may be noticed that many care homes are now reacting to such needs for small-scale residential arrangements and are beginning to replace the classical ward system by small residential groups. Here too there is a trend towards smaller, simpler units with permanent nursing staff, avoiding the changes of staff which is common in practice and reduces standards.

But at present the Federal government is of the opinion that inpatient care of people with dementia is conducted in such a way “that nursing care tends to be conventional and not greatly based on new standards oriented towards prevention and rehabilitation and/or self-determination and independence.”⁸⁴ This is not surprising if it must be assumed on the basis of a long-term study that the staff, and in particular the qualified staff, are insufficient in numbers to satisfy the need.⁸⁵

84 Schneekloth/Wahl 2008, 164.

85 Cf. Schneekloth/Wahl 2008, 152 ff.

3 ENABLING AND RESPECTING SELF-DETERMINATION IN DEMENTIA: AN ETHICAL CHALLENGE

3.1 Self and self-determination

Self-determination is the elementary expression of human freedom. The term “determination” originally comes from analytical philosophy; it refers to the ability of human beings to describe the things in their world in a “determinate” way. Just as a person can “determine” one plant as “flower”, another as “bush” and a third as “tree”, the person can also – for example, in contrast to other living beings – describe or “determine” himself or herself as a “person”. “Determination” (*Bestimmung*) in this sense is the German word for “definition”.⁸⁶

In “self-determination” (*Selbstbestimmung*), this act of both description and definition acquires a practical meaning. If someone “determines” himself or herself by stating his or her name, gender, age or occupation, these descriptive statements relating to the speaker may also be understood normatively. The speaker wishes to be referred to by his or her name and also to be perceived and recognized in his or her individuality. It is then not enough for the speaker that the name, gender, age or other of his or her individual characteristics are known, but he or she must also be accepted in these.

In the emphatic use of self-determination, these descriptive and normative elements related to a person’s individual self lie close together. A person who “determines” himself or herself as “rational”, as “separate”, as “independent” or “capable” also wishes to be so and wishes also to be perceived in this way by others. The concept of self-determination therefore expresses all the factors of personal self-assertion. The person wishes to

⁸⁶ On this, cf. Gerhardt 2010a; Gerhardt 2010b.

be as he or she understands himself or herself, and expects to be recognized in this.

The independence of this claim to determine oneself and one's own existence was also the starting point of ethics in classical antiquity. Every virtue contains an element of self-knowledge and requires the self-control that is necessary in order to be prudent, rational, just, pious or wise.

The modern concept of self-determination, first introduced in German by Kant, has the advantage of linking self-knowledge with self-control. As a result of this weight is placed on the "autonomy" of the individual which understands itself in the knowledge of a given situation requiring action and in a realistic assessment of its own possibilities as the "legislator" of its own actions. In this the freedom of the individual comes into effect, the possibility of which encapsulates the dignity of the human being.

However, it would be a misunderstanding if self-determination were to be grounded on the self-knowledge of the individual in isolation. Even the authors of classical antiquity attached great weight to the fact that a self (*autos*) can only understand itself in its real relationship to the self of the other. This is why Socrates goes to the Agora, the market place in Athens, to talk to people in order to discover whether Apollo, the God of self-knowledge, is right in his judgment on Socrates' wisdom. When he himself is asked how one can know oneself, Socrates replies that this is only possible if one is reflected in the mirror of another person's eyes. One can therefore only meaningfully speak of a person's "self" when this is delimited against the self of other people. This relationship to one's equals also results in strong practical obligations, as is shown by the dominant position of the virtue of justice or the fine description of virtue as the ability to be one's own friend.

Self-determination directs attention to a person's "self". According to the dominant opinion in philosophy and psychology, this is determined by the characteristics of a person which are of fundamental significance for the person's experiencing,

discovering, recognizing, acting and behaviour. In agreement with a great tradition of thinking, the self can be seen as what a human being understands in himself or herself as a centre of sensing, feeling, recognizing and controlling. It is therefore not restricted to cognitions or thought processes, such as rational knowing, classification, logical operations and reasoning, but includes fundamental emotional and behavioural orientations and basic moods. The self must not be regarded as the unchangeable metaphysical substance of a person; it may be subjected to many changes in life without changing the legal and moral identity of the individual in any way. Nevertheless, every person remains at liberty to regard his or her self as the immortal personal core of the human being – a view which increases the weight of the arguments in favour of respecting the self-determination of the individual even in the case of dementia.

The concept of self-determination in Kant, largely acknowledged today, also originally related to the presence of other people. It is true that one may not permit one's assessment of oneself to be dependent on others; nevertheless, one can only ever understand oneself in relation to the possible effects on others. Only in this way can the conception of the categorical imperative be understood when it calls for the maxim of one's own actions to be measured by whether it is suitable to be a law for all human beings. It is still clearer that every self-determining human being must understand itself in such a way that it represents "humanity in its person". Kant called for "respect" of the moral law; this therefore includes respect of every other person, since the moral law has no other location than in the "breast" of every person. This self-respect, which includes respect for the other, demands, so we may conclude in our context, respect in interaction with that other. If one wishes to retain one's own self-determination, one must also desire the self-determination of one's equals.

Human beings are dependent on each other, and from this and from social solidarity there follows the ethical duty to use one's best endeavours to help one's fellow-humans towards

what each demands for himself or herself. This applies in the first instance to respect for every person's self-determination. But in the life situation, which includes helplessness at the beginning of life, weakness at the end of life and the innumerable forms of illness and need in the course of individual existence, respect for every person's self-determination also includes the expectation of supporting this self-determination, encouraging it or restoring it. It is therefore insufficient in ethical terms only to insist on the legally required respect for each person's liberty and not to prevent them from exercising their self-determination. Instead, it is ethically necessary to endeavour to attain the self-determination of one's equals.

Limits are placed on this, beginning with the priority of each person's own self-determination and extending to the limits of natural, social and individual powers. The lack of knowledge of another person's situation and state of mind may also impose limits on the ethical duty to help, although this prevents no one from endeavouring to understand the other. This applies not only generally to the social interaction between people, but also to those who are closely connected.

3.2 Accompanying changes, recognizing potential

Suffering from dementia presents the person affected and those close to him or her with problems and conflicts of a quite special nature. Not only health, wellbeing and ability are affected, but the person with dementia also faces the reduction of his or her autonomy, continuing as far as its effective loss. Persons with dementia become less and less able to make decisions for and about themselves and are more and more dependent on the solidarity and responsibility of others. They need active help and intelligent support.

Research in medicine and care and the accompanying practical experience attempt to achieve early diagnosis and

to alleviate symptoms. Despite intensive efforts, it has not yet been possible in this way to achieve substantial relief or to effectively halt the disease. It has only been possible to attain limited retardation of the course of the disease. The persons with dementia and the persons caring for them must at present settle for accepting the dementia.

It is all the more important to discover possibilities of perceiving, respecting and encouraging the self-determination of people with dementia, which deserve greater attention. This requires an attitude of attentiveness. On the basis of the closeness which once existed between the people involved, this attentiveness develops a consistent approach which is both practical and methodical. It results in an interaction oriented towards the concrete needs of the other, contains a perception of individual peculiarities and a caring thoughtfulness and helping actions even when mutual in talking and thinking is no longer possible.

In this connection the term “assisted self-determination” is also used: on the basis of person-centred attention the nature of the assistance is adapted and assessed depending on how far the remaining elements of independence and self-determination can be activated.⁸⁷ If the person with dementia can no longer express an opinion, this makes greater requirements on the perception. Attentiveness is an essential requirement for an individual companionship and concern which is oriented towards the subject’s life. It makes it possible for the self-determination of persons with dementia to be preserved for a long period of time.

This task is easier to carry out if, in particular in the early stage of the illness, self-determination can still largely be exercised. But self-determination must also be respected when greater disease-related limitations have commenced, the person is more dependent on support, care and supervision and self-determined actions are only possible in areas immediately

87 Cf. Graumann 2011.

concerned with everyday life. Experience shows that people in the stages of advanced dementia still have possibilities, above all in basic areas, to have direct influence on the organization of their own lives, for example in eating, mobility and personal hygiene.

The process of dementia has the cerebro-organic effect that the person loses the ability to associate somatosensory, visual and verbal information messages with each other and to integrate them. Many things therefore appear unstable, erratic and unregulated. Whereas the self is subject to an early change of its cognitive quality, it continues in existence in its qualities related to emotions, social communication, daily routine, sensations and aesthetics, even if these qualities become more difficult to address and recognize as the illness progresses.⁸⁸ Occasionally new characteristics also emerge in the course of the illness, and these may make it easier to interact with a person with dementia (on this, see section 1.4).

As the illness progresses, persons with dementia lose the conditions which make it possible to attribute the moral responsibility for actions to them. They remain the same persons and in their behaviour and memory they retain a large part of their individuality. But they can no longer be expected to present the consistent public image which normally controls our reactions to the behaviour of others. In addition, from a particular stage of the disease on, they can no longer be held responsible for their own actions. They “cannot help it” that they behave in this way and not otherwise. Their moral responsibility is reduced or absent in the final stage of the illness when they are not aware of the reasons for their actions. It is in this

88 Individual abilities, such as recognizing objects (“This is a bookcase”), realizing the significance of these objects (“This is my bookcase”) and the association of sensations and feelings with them (“I like this bookcase”) are often preserved for long periods of time. In the course of advanced dementia, there are merely no longer available in the communicative reciprocity which is usually expected and therefore cannot be used in reasoning at the same time. The rational explanation which is expected, “I like sitting here, because this is my favourite bookcase” is replaced by the statement – or sometimes the non-verbal signal – “I want to sit here because it is nice”.

decay of moral abilities that the particular tragedy of dementia lies; it imposes on us a duty of particular attentiveness.

With regard to the content of their actions, the basis of their judgements and the consistency of their decisions, marked changes may be observed in people with dementia. In the case of the content of their actions and the decisions on which they are based, a development from abstract topics to concrete physical and experiential things can be observed. The basis of judgment for actions, utterances or decisions changes from a cognitively penetrated value orientation to a needs-oriented preference orientation. In this connection, it is in particular the social and emotional qualities of the self that take effect. The consistency of decision changes from a stability of the direction of decisions supported by memory to more strongly intuitive spontaneous actions.⁸⁹

Despite the discernible restriction of the sphere of experience of those affected, and despite dwindling common ground in social experience, there may be a realization, and in part also a mobilization, of their own activities, which may be seen as acts of self-determination.

The ethical challenge of dementia consists in always respecting persons with dementia as subjects while caring for them, and to enable them as far and as long as possible to actively exercise their self-determination.

3.3 Enabling self-determination

3.3.1 Support as a human and social duty

Living one's own life is an elementary expression of human freedom. This freedom is proved in everyday decisions and supports the fundamental arrangements for or against a particular form of one's own life. In freedom, human beings keep

89 Cf. Wunder 2008.

their future open and preserve their dignity. It is said that human beings “by nature” have freedom and dignity. This means that they did not invent these rights, that they are the basis of human existence and all human actions and must be seen as “inalienable”. Nothing is capable of removing these rights, not even an illness that robs people of their mental and physical strength.

Respecting this inalienable dignity and permitting every other person to decide and act in liberty is the supreme maxim of human beings in their relationship to each other. It also applies to interaction with persons with dementia and to the organization of their lives.⁹⁰ Where persons with dementia lose their ability to make their own arrangements for their lives, the maxim imposes on us the duty to enable these persons as long as possible to have the chance of sharing in the organization of their existence. Even if ultimately this may only mean helping them realize their wishes, this too is subject to the requirement to grant the person affected the greatest possible freedom and to respect his or her dignity. It should go without saying that the appropriateness of purposes and the proportionality of means must be taken into account here. This includes the fact that there may be good reasons to place limits on one’s own willingness to make sacrifices. Renouncing one’s own freedom cannot and may not be expected of anyone.

The preservation of self-determination in the case of dementia may be realized all the better the fewer changes the person with dementia is expected to undergo. For this reason it is to be desired that the person can stay as long as possible in his or her familiar surroundings and can continue to have contact with persons with whom he or she is familiar. As a rule, everything which permits persons with dementia to maintain continuity with their habits is capable of reducing suffering and facilitating care. It is particularly important that the carers are

90 Cf. Helmchen/Kanowski/Lauter 2006, 203 ff.

also familiar with the background and preferences of a person with dementia.

The ethical precept of preserving and encouraging the possibilities of self-determination of persons with dementia presents a great challenge not only to caring and supervision but also to society as a whole. In order to realize their rights to participation and inclusion in society, persons who are in a position weakened by illness or disability, such as persons with dementia, need not only the enabling of their self-determination, but also protection and concern. Respect for self-determination and the concern and attention which respect and secure this self-determination are mutually dependent. The ethics of care⁹¹ developed in the USA and the United Kingdom also proceeds on this basis. The ethics of care emphasizes the oldest premises of European ethics, in particular the precepts of humanity, of charity, of helpfulness and of care for others and puts the more stringent methodological reasoning claims of recent ethics in second place. The concept of *care* covers the whole gamut of meanings which characterize this reciprocal relationship, from caring attention, concern and encouragement to instructive assistance and concern to providing for and assuming responsibility for the other. The ethics of care can therefore make a substantial contribution to practice.

In the centre of consideration is the particular quality of the interaction in dependency relationships. The human being is seen as a being capable of self-determination but also always vulnerable and dependent on others. The caregiver both gives and takes. The caregiver's inner attitude should be characterized by attentiveness, responsibility, competence and responsiveness.⁹² There is also a plea for destigmatizing the concept of dependence, which is otherwise associated with other-directedness, and interpreting it as a "characteristic of the human condition which is neutral as to values" which is more or less intensively

91 Cf. Gilligan et al. 1988; also Kittay 2004; Tronto 1993.

92 Cf. Tronto 1993.

marked in different phases of life and in illness or disability, and which is compatible with the potential for self-determination.⁹³

In the person-centred approaches to treatment too the social environment is seen as essential for the clinical picture of dementia. The recognition of the uniqueness and individuality of the person in question is essential to the well-being of the person with dementia.⁹⁴

For the person concerned, dementia means the progressive decay of his or her mental power. Corrections of behaviour on the basis of insight are often impossible or can be achieved only for a short time. Against this background it is necessary to understand the existing impulses of the person with dementia, to design his or her environment appropriately and to integrate his or her utterances, signals and habits into everyday actions. What is important is not shaping and educating, but accurately looking and listening, learning in every respect, intelligent shaping of the environment adapted to the person's needs, and also for the contact persons – both family members and professional caregivers – to share difficult processes and situations.

Treating behavioural abnormalities with medicinal products should not be the treatment of first resort, but at most the treatment of last resort for people with dementia. Higher priority must be given to responding to the individual occasions and personal triggers of the person involved. Such mindful attention can be a way of improving the subjective feelings of the person involved and make interaction with him or her easier.

3.3.2 Even limited self-determination must be respected

Approaches based on the preservation of and respect for the self-determination of persons with dementia relate above all to

93 Cf. Kittay 2004, 75.

94 Cf. Woods 2002.

gradations of the possibilities of self-determination and cooperation of the persons concerned.⁹⁵ Such approaches are also adopted in parts of the legal discussion where there is reference to the “partial autonomy being worthy of protection” which has to best possibly be guaranteed in the given circumstances.⁹⁶

The gradations extend from

- » an unrestricted ability for self-determination together with full capability to decide and consent in the early stage of dementia
- » to a limited ability for self-determination in which the capability to decide and consent is restricted to particular experiential fields of action and where there is still a certain possibility of codetermination in decisions outside direct experience,
- » to a mere possibility of cooperation, restricted to the immediate experiential sphere, in the late stage of the disease.

The question as to whether the characteristic of being “able to act differently”, which is constitutive for self-determination, is also present in the late stage of the disease is decided in the given practical situation. This characteristic is not unattainable or excluded at the outset. In this regard it is important for the various alternatives to be equally accessible and for the person involved to be able to understand them. In the person’s increasingly restricted understanding of the nature and significance of his or her possibilities of acting, this imposes high demands on those who explain the options to the person with dementia. At the beginning of the illness, these may certainly relate to abstract and complex situations, such as the choice of residence, but in the course of the illness they increasingly relate to concrete physical and experiential facts, which can be decided on a needs-oriented basis,

95 Cf. Kitwood 2008; also Woods 2002; Wunder 2008.

96 Cf. Damm 2010.

such as choosing between various activities (going for a walk or staying at home) or particular environmental conditions (opening the window or keeping it closed). A needs-oriented decision on a preference between two or more everyday situations may be strongly marked by the mere attempt to preserve life function, and yet it can express a preference which the person with dementia experiences as something essential to him or her.

The situation is similar with regard to the category of “having reasons” if one concedes that these reasons need not be verbally expressed in every case, but facial expressions indicating happiness or refusal about an action are enough, and that this happiness, which is not further explained, may constitute a reason. Nevertheless, “having reasons” implies a valuation in the sense of a weighing and forming of preferences including reliance on rational considerations, critical observation and ordering one’s own preferences. Such a valuation is scarcely possible in the late stage of dementia. “Having reasons” for a particular manner of acting is then increasingly replaced by “having needs or inclinations”.

Being aware of oneself as originator presupposes an awareness of one’s own self. The perception that it is “I” who started a process and not someone else is expressed when happiness is shown in the situation of acting and again if the action is repeated. In terms of developmental psychology, this is the earliest form of self-determination. The basal perception of one’s own activity may be seen as an essential requirement of the development of self-determination. This characteristic may also still be present in persons with dementia when they cooperate in everyday processes in the third phase of the illness.

In each case, the capability to decide and consent must be assessed with regard to the difference of the various knowable subjects of decision and consent. Whereas, for example, the capability for consenting to a medical research project may no longer be present, the capability for consenting to decisions on everyday matters may very well still be preserved.

The interaction of professional caregivers with a person with dementia is determined by how the person's utterances are understood. There is a fundamental and substantial difference whether an utterance relating to a medical or nursing measure is respected as an exercise of the right of self-determination or merely seen as an indication of the person's current mood, which it may be possible to disregard in therapeutical interaction.

3.3.3 Need for a broad understanding of self-determination

Differences of opinion may arise in relation to the question as to in which stage of the progressive illness it is still possible to speak of self-determination at all. In a narrow understanding of self-determination, the limit will be reached at an early stage of the illness beyond which the utterances of those affected are no longer understood as decisions, but only as indications of their current state and creaturely desires.

Research findings (see section 1.3), practical knowledge and in-depth considerations of self-determination in the case of reduced mental capacity, however, clearly recommend that the above limit should be understood broadly. This means that we may not impose all too strict conditions on people with dementia with regard to the intellectual ability to form their own decisions, nor with regard to the form of their utterances towards others or the assessment of the consequences or to a presentation of reasons. According to the concept of gradation (see section 3.3.2), even where cognitive decline is clearly present, it is still possible, depending on the subject of the decision, to accept and respect the decision as the expression of self-determination. The high status of self-determination continues to have an effect here with the consequence that even reduced self-determination, restricted to matters which are experiential and opinion-oriented, is valued as such.

If the point up to which a person with dementia can still exercise his or her self-determination in the widest sense is crossed, for example because the decisions necessary are abstract and not experiential, then the person is dependent on those caring for and supervising him or her compensating for the loss of ability to decide in the consciousness of their increased responsibility for his or her well-being. The person's indications of feelings and wishes must then be assessed on the basis of experience and expert knowledge and must be taken into account in the further companionship and supervision. In such a case, it remains crucial how those responsible assess his or her intrinsic impulses and possibilities of cooperation when determining the person's well-being. In this case, the self-determination of the person which is no longer possible is replaced by the determination of his or her best interests on the part of the carers and supervisors.

3.4 Knowing the limits for fulfilling wishes

Even where there is no doubt that persons with dementia who need care are capable of self-determination, it does not follow from this that their demands or wishes must always be complied with. The persons responsible for care and supervision may of course not ignore the wishes of the person with dementia with the indiscriminate argument that these are irrelevant or that they themselves know better what is good for the person. But the caregivers may have justified reasons for opposing the wishes of the persons and in certain circumstances not complying with them. And more: it is their duty to oppose the demands directed to them if fulfilling the persons' desires would seriously endanger or harm them. No one may be ethically obliged to fulfil the wishes of another if that other is harmed as a result. If the person acting is responsible for the weal and woe of the other and the other cannot recognize the significance of his or her desires, the person responsible is in fact obliged to refuse to fulfil the wish.

In the weighing of interests which is necessary in such cases of conflict, priority is generally given to the prevention of harm above the realization of self-determination (more details on weighing are given in section 4.4.2). Noteworthy reasons not to agree to a request of the person with dementia may also lie in the person of the caregiver. The caregiver need not undertake unreasonable tasks which would overtax him or her. It is also quite important to establish this because many family members tend to overtax themselves in care and supervision.

In order to assess reasonableness, it is important to consider the relationship between the carers or supervisors and the person with dementia. A person who supervises or cares for a family member by reason of personal attachment will generally feel particularly ethically obliged to fulfil wishes. This is the family member's motivation. But this does not give others, including the person with dementia, a claim for the family member to fulfil every wish. Even spouses who have promised each other love and mutual support in sickness and in health may, in the course of their activity of supervision and caring, refuse services for a person with dementia if they find themselves burdened beyond their own limits or if in order to fulfil the wish they would too much have to put their own interests in the background.

At the same time, until their involvement ends, it will be necessary to require them not to let the person with dementia reach a state of distress, but to obtain help from elsewhere if this happens. They also have an ethical duty to treat the person with dementia in a humane way in the course of the supervision they give. As set out above, the family member may refuse to fulfil the wishes the person expresses, but he or she may not automatically ignore those wishes, as if the person with dementia were someone incapable of self-determination.

However, a person who has become a caregiver by a contractual relationship or as a professional obligation – and in the individual case this may even be a family member – has more extensive duties to fulfil the wishes expressed. But here

too, weighing the claims of the person affected against disadvantages or unreasonableness may result in a justified refusal of the wish expressed. This may be justified, for example, if the request of the person with dementia exceeds what is owed by contract or if it overtaxes the caregiver's ability in the given circumstances. If the person with dementia is at risk of neglect because the caregiver is overtaxed in this way, the persons responsible for the care must obtain relief. This may also mean that they transfer the care to other persons.

But if there is no reason to refuse the wish, then the refusal of the request of the person with dementia cannot be legitimised, and still less can preventing the person from carrying out his or her intentions. In this situation, fulfilling the wish is a precept of professional conduct.

The fact that the request of the person is "unreasonable" is not sufficient for the caregiver to disregard it. The same applies, for example, to demands whose fulfilment would give the person only moderate disadvantages, without creating serious harm. Thus the person with dementia may stay away from a communal event, however much good it would do the person from the therapist's point of view, and similarly may refuse medical treatment which is not essential. And the fact that it is really somewhat too cold to go for a walk in the garden may not in itself mean that this wish is refused.

4 LEGAL PROTECTION OF RESTRICTED SELF-DETERMINATION

4.1 Introduction

Considerations on the legal significance of the self-determination of persons with dementia may relate to experience and principles which have been developed in other areas of life. In many cases, people have to interact with others who can exercise their self-determination only with restrictions or not at all. Parents must care for their children, but also, because the children have no capacity or restricted capacity to contract, represent them legally. Persons of full age who cannot deal with their own affairs because of illness or disability are represented by a legal custodian (*Betreuer*); particular consideration must be given to the desire of the person under custodianship when the custodian is appointed and in the custodian's work.

By social consensus and in legislation, practices and basic rules have been developed for the interaction with such persons who need help; these rules claim to be more or less valid for all areas of application, which may well be very different. Those who have to make decisions for others – either alone or together with them – on the organization of their lives should

- >> listen to them in order to hear their wishes with regard to the decision to be made,
- >> to the best of their ability endeavour to understand them, and if necessary to learn how to do this,
- >> encourage the ability of those affected to have self-determination and to express their desires, for example by personal attention and by creating an atmosphere of encounter which supports them,
- >> as far as possible seek to have conversations with them and to discuss the questions relating to the decision with them,

- >> if at all possible, involve them in the decision and support them in cooperation,
- >> take account of their wishes in decisions and measures unless there are important reasons (the threat of substantial danger) against this,
- >> accord a high value to their self-determination when weighing it against one's own or other conflicting interests,
- >> perceive them in every respect in their specific individuality, instead of making wholesale judgements and thus ignoring the variety of life situations,
- >> help them to develop, express and realize their wishes.

From these duties there follow specific and varying legal obligations for those who are in a binding relationship with rights and duties to the persons they supervise or care for. This applies, for example, for parents towards their children, for court-appointed custodians, for persons holding a power of attorney or for professional caregivers who work under a contractual agreement. Voluntary carers also in some cases render their services under a legal agreement. However, there are no obligations in a legal sense for family members who work for a person in need of care purely on the basis of personal attachment.

The application of these principles, but also their varying emphasis, can be seen in considering the individual groups of persons concerned.

4.2 Growing self-determination in children

As children grow older, they gradually acquire an independence which is not merely legally guaranteed but can also be perceived by them with their own capabilities. As long as and as far as they are not able to act independently, others must care for them. Whether, and if so to what extent, such care is

necessary is something which those who have custody for them must constantly review. At present, children are more strongly seen as having their own rights and independent means of shaping their lives than was formerly the case. It is generally deprecated today to describe them primarily in terms of deficits and to subject their upbringing and education totally to the will of their parents and teachers.

Following other statements on the rights and the position of children⁹⁷, the United Nations in 1988 produced a Convention on the Rights of the Child, which Germany ratified in 1992. It requires the contracting states to guarantee and respect the child's rights to freedom of conscience, freedom of speech and for its opinion to be taken into account in its own affairs, and even to information, freedom of association and freedom of assembly. The wording of the Convention leaves a wide latitude for interpretation. It creates an obligation for states, but in the predominant view no rights for the individual. Its importance lies in the appeal for the independence and decisions by free will of children to be allowed to take effect more strongly.

There is increasing social consensus that children develop their own view of life and the world and that this must be recognized. In this view, it is necessary to take children's utterances seriously and to learn to understand them. In education the child is an actor, that is, a subject, not an object. Accordingly, parent-and-child law requires of the parents that they should discuss the affairs of the child with it and take account of its will. It is a general principle that parents' powers decrease as the child becomes older, but this is also clearly shown by age limits after which the child acquires particular rights of its own.

Particular importance attaches to the right of children to consent to medical intervention or refuse it themselves. Such a

97 Article 25 (2) of the Universal Declaration of Human Rights (1948) and Declaration of the Rights of the Child of the General Assembly (1959).

declaration is effective if the child is capable of consent. It must understand the nature and the implications of the intervention and the importance of the consent. This power is not tied to fixed age limits or to capacity to contract; the legal opinions on this are not completely uniform. It is generally assumed that children aged from 14 to 16 are capable of consent. The right to refuse medical intervention is accorded the child at an earlier age.

Such decisions by the child are legally relevant but they must be reviewed by those with custody. For if the child risks substantial disadvantages if its will is carried out, its right of self-determination must be weighed against the risk of the harm feared, and if necessary there must be a decision against the child's wishes.

4.3 Representing the interests of those who are temporarily incapable of deciding

Where the interests of another person are or have to be represented, for example in the case of agency of necessity (*Geschäftsführung ohne Auftrag*) and in particular when an operation is carried out on someone incapable of consenting, one should be guided by a declaration of will made at an earlier time, or alternatively by a presumed will, and by the interest of the person concerned. The presumed will must be determined from earlier statements by the person involved. Where there are no such statements, the person's family members or persons to whom he or she relates must be questioned in order to determine what the person would presumably want in such a situation.

The will of the person concerned expressed at an earlier date may in an emergency be in conflict with his or her interest, for example as the treating doctor sees it. Then, in the case of medical treatment, the currently discernible interests of the person involved, who is temporarily unable to make a

declaration, take priority over the person's earlier will in so far as the declaration of will refusing treatment is not unquestionably applicable to the concrete situation.

In general, in such cases it is only for a short time impossible for the person concerned to exercise his or her self-determination. This makes it necessary in addition to review whether it is really necessary to act in this period of time. If it is necessary to act immediately, then it is necessary to act according to one's best judgment in the best interests of the person, taking account of the person's will expressed at an earlier time or alternatively of the person's presumed will.

4.4 Care relationships and restrictions of liberty

4.4.1 Principles

The actual possibility of determining one's own personal circumstances and one's own actions oneself may be completely or partially lost by a person as a result of illness or disability. In this way the person comes into danger of suffering harm, without and also against his or her own will, because the person is not in the position to avert the harm and to safeguard his or her other interests. If the person concerned has not made other provisions for this case, a custodian must be appointed to act for the person. In this process, the dispositions of the person made for this case must be taken into account. With an order of custodianship the person can ensure that as a rule only the person he or she names can be appointed custodian.

If the person has made a lasting power of attorney entrusting another with all necessary powers to represent him or her, there is no need for a court-appointed custodian if the person authorized assumes the task intended. The mere power of attorney does not create an obligation to do this. But if the person authorized uses the power of attorney, this is done as a

favour to the grantor of the power of attorney, but at the same time the person authorized enters a legal relationship with the grantor. This relationship is governed by the legal provision on mandate (*Auftrag*) (Sections 662 ff. of the *Bürgerliches Gesetzbuch* [Civil Code]) with the necessary modifications. This also means that the person authorized must take account of the will of the grantor in his or her activities by following the directions given under the mandate. However, the person authorized may at any time disengage himself or herself from these duties.

Comprehensive rules for a custodianship relationship have been laid down in statutes and court decisions. They apply equally to professional and voluntary custodians.

4.4.2 Custodianship – conflicts and weighing of interests

Where a custodian or authorized person acts for another under a legal custodianship or a power of attorney, the custodian must allow the person to have control over his or her own life if he or she is capable of this. The person's affairs must be discussed with the person and his or her wishes taken into account. This can result in conflicts between the will and the best interests of the persons under custodianship. The best interests of the person under custodianship here include the possibility "within his capabilities, to shape his life according to his own wishes and ideas" (Section 1901 (2) sentence 2 of the Civil Code)⁹⁸. In contrast to this subjective understanding of best interests, it may be necessary, in order to safeguard the person's objective best interests, and above all to avert harm, to refuse a request of the person. It is always necessary here to consider

98 Translator's note: Translated by the Langenscheidt Translation Service. Online: http://www.gesetze-im-internet.de/englisch_bgb/englisch_bgb.html [2013-11-05].

whether priority should be given to the person's wish or to his or her objective best interests.

Thus, for example, according to the case law of the *Bundesgerichtshof* (BGH – Federal Court of Justice), care homes, to protect their patients and to protect themselves against liability, may not take any wholesale paternalistically motivated protective measures (measures depriving the persons of freedom, such as immobilization).⁹⁹ As a result, when the representatives of those concerned or the health insurance funds with liability claims against homes seek reimbursement for the costs resulting from accidents to patients, they cannot rely on a standard approach based solely on the patient's safety. In the law relating to homes and liability, there is no general priority given to safety above self-determination. "The legal duties of care, on the one hand to respect human dignity and the right of freedom of an old and sick person and on the other hand to protect his life or physical integrity, may not be decided in a standard manner, but only on the basis of a careful weighing of all the circumstances of the individual case".¹⁰⁰ A similar weighing is necessary where the freedom of the mentally ill is restricted under committal law. Where the risk is relatively small, the drastic freedom-restricting measure may not be used; within certain limits, a mentally ill person is granted "freedom to be ill", the Federal Court of Justice has held.¹⁰¹

On the other hand, the person under custodianship may not be granted the freedom to decide against every measure ensuring his or her own preservation. For example, if no other income is available for living expenses, the custodian must apply for state welfare assistance, even against the wish of the person under custodianship. In the same sense, declarations

99 Cf. BGH, NJW (*Neue Juristische Wochenschrift*) 2005, 2613 ff. and 1937 ff. – on health insurance funds claiming reimbursement for treatment costs following falls of confused patients.

100 BGH, NJW 2005, 1937 (1938).

101 Cf. Federal Court of Justice, decision of 1 February 2006 (ref. XII ZB 236/05); a similar conclusion is reached by the Federal Constitutional Court, BVerfGE (*Entscheidungen des Bundesverfassungsgerichts*) 58, 208 (224).

of intention in business dealings may be refused recognition if the person affected would cause himself or herself serious harm through them. “To prevent a substantial danger for the person or the property of the person under custodianship” (Section 1903 of the Civil Code)¹⁰², for example, is a sufficient reason to permit such declarations of intention to apply only subject to reservation. The guardianship court (*Betreuungsgericht*) may require the consent of the custodian before they become effective.

The number of orders of such reservations of consent under Section 1903 of the Civil Code has steadily risen in Germany, in 2009 by 6.21 per cent (from 13,306 to 14,132 cases) and in 2010 by 5.15 per cent (to 14,860 cases). The number of statutory custodianships has risen by only 1.43 per cent and 1.75 per cent respectively in the same periods of time. In addition, considerable regional variations can be seen. The proportion of reservations of consent in 2010 was between 3.37 per cent in Saarland and 9.48 per cent in Brandenburg.¹⁰³

A conflict which is particularly difficult to solve may arise from complying with a lasting power of attorney granted by the person under custodianship. If it has been validly created (Section 1901a of the Civil Code), the decision made in it as to the permissibility of therapeutic treatment takes precedence over other concerns if the person later becomes unable to consent. Then, measures by the custodian do not depend on the best interests, as the custodian sees them, but on the expressed will of the person under custodianship and the appropriateness of the person’s lasting power of attorney in the present life and treatment situation.

There may be a conflict between the lasting power of attorney and later utterances of the person concerned. Where the person under custodianship is capable of making a decision, the lasting power of attorney does not apply. There is no

102 Translator’s note: Translated by the Langenscheidt Translation Service.

103 For these and the following figures: Deinert 2011.

valid waiver of the right of self-determination exercised in this decision. If the patient who is capable of making a decision makes statements, these are therefore valid even if the lasting power of attorney provides for such utterances to be irrelevant. If, in contrast, it can reliably be determined that the patient is permanently no longer capable of making a decision, then the lasting power of attorney applies.

However, the custodian must always review whether its terms apply to the present life and treatment situation (Section 1901a (1) of the Civil Code). The behaviour of a patient who is no longer able to decide is relevant in this context. Life-affirming behaviour contradicting the tendency of the lasting power of attorney must be taken into account when the custodian decides whether the lasting power of attorney applies to the present situation. Application in the present situation is an essential requirement if the lasting power of attorney is to be given priority over later statements by the patient. In addition, *inter alia* it is important to consider whether the patient when he or she wrote the lasting power of attorney was at all able to anticipate his or her feelings as a person with dementia and the situation for a decision to be made which would then arise.

If there are doubts as to the patient's ability to decide, that is, if it is impossible to reliably determine whether the patient is still capable of making a decision by free will which is sufficient to revoke the lasting power of attorney, the question arises as to what requirements of the ability to decide must be satisfied for the revocation or annulment of a lasting power of attorney.¹⁰⁴ These must be taken into account legally not only if it can be assumed that self-determination is fully present. Even imperfect self-determination and remnants of self-determination are deserving of legal protection and need legal protection. The legal assessment must always proceed from the consideration of the individual case. An excessive increase

104 On this and on the following, in detail, cf. Damm 2010.

of demands of self-determination may not be made, and nor may a restrictive, wholesale orientation towards particular care groups and categories of illness. If it cannot be established that the patient is incapable of making a decision, then because the omission of life-preserving measures is irreversible, priority should always be accorded to life-affirming statements over a lasting power of attorney to a different effect.

4.4.3 Requirements of the Convention on the Rights of Persons with Disabilities

In conformity with widespread opinions among experts, the United Nations Convention on the Rights of Persons with Disabilities of 2006 – which entered into force and was ratified by Germany in 2008 – calls for the self-determination of those affected to be comprehensively respected. Their aims and wishes, it states, should be taken into account in order to guarantee that they can lead as independent lives as possible, and in particular they should be enabled to take part in social, cultural and political life.

These aims are also followed by the Ninth Book of the German Social Code, which gives persons with disability a number of specifically named rights and grants them support in realizing these. It provides that the highest possible degree of independent living, which includes taking part in social life, should be aimed for. In order to sufficiently safeguard the wishes of persons with disability, it is necessary to assist mutual understanding.

The Convention on the Rights of Persons with Disabilities is also of substantial importance for the practice of custodianship. Thus, the custodian must in principle regard a decision made by the person under custodianship as binding, if not without exception. In every case, the custodian must support the person under custodianship in exercising his or her legal capacity and capacity to act (Article 12 (3)). This includes

help for the person to develop and express his or her will. Only through such assistance does the custodian take into account the degree to which even persons whose self-determination is limited are deserving of protection.

With regard to measures depriving persons with a disability of freedom¹⁰⁵ the Convention on the Rights of Persons with Disabilities (Article 14) calls for these measures to be carried out in accordance with law and statute and if they are ordered that they should be subject to the same procedural rules as apply for other members of society. It provides that they cannot be justified by a disability as such. This conforms with German custodianship law (Section 1906 (1) of the Civil Code) in this respect, which permits the restriction of the right of self-determination by measures depriving persons of their freedom only to avert serious dangers to the life and limb of the persons under custodianship and makes the measures dependent on the consent of the guardianship court.

Opinions differ as to whether legislative measures are necessary in custodianship law as a consequence of the obligations taken on by the Federal Republic of Germany in ratifying the Convention (Article 4).¹⁰⁶ In this connection it is emphasized that German law has since 1992 respected the principle of help instead of patronization. But it is contested whether, in view of greatly increased numbers of statutory custodianships¹⁰⁷ and in particular judicially ordered

¹⁰⁵ This includes placement in the case of self-endangerment (Section 1906 (1) sentence 1 of the Civil Code), placement for the purpose of therapeutic treatment (Section 1906 (1) sentence 2 of the Civil Code) and measures by which mechanical devices (bars) or medicinal products restrict freedom.

¹⁰⁶ Thus it is pointed out that the application of the provisions of Sections 1896 ff. of the Civil Code presupposes that there is a disability or mental illness. This is said to contradict the strict interpretation of the United Nations Convention, because this would mean giving a special position to persons with a disability or with a mental illness (Klaus Lachwitz, personal communication, 25 June 2010).

¹⁰⁷ Whereas the number is stated as approximately 400,000 at the date when the new custodianship law came into force in 1992, the number of statutory custodianships in 1995 was already 624,695 and in 2010, it was 1,314,051 (cf. Deinert 2011, 14).

measures restricting freedom¹⁰⁸ custodianship law is in practice sufficiently marked by the stronger emphasis required by the Convention on the legal capacity and capacity to act of the person with a disability, beside which the effects of others should have only a supportive but not a substituting function (Article 12). Where a person with disability can without the risk of serious disadvantages decide on the organization of his or her life and act accordingly, custodians may not deprive the person of this possibility by their own decisions. Instead, they must support the person in exercising his or her self-determination. Judicial decisions and practice may not overlook this duty and the legal limits of the power of action of the custodians.

4.5 Summary

For all the diversity of the life situations and groups of persons affected considered here, the conflicts which arise in each case between personal decisions and the decisions of others, and the courses of action developed to date point in a clearly recognizable direction: Where a person does not have or no longer has the mental ability to safeguard his or her best interests against

¹⁰⁸ The number of court approvals of measures removing freedom under custodianship law rose by approximately 70 per cent (from 31,000 to 55,000) from 1992 to 2010. In the case of restrictions of freedom in the form of mechanical devices and medicinal products for immobilization under Section 1906 (4) of the Civil Code in care homes and institutions, the number has even increased nine times (from 10,000 to 98,000). This may result from stricter compliance with the duty of judicial approval, but it may also show a genuine expansion. The striking regional differences in placement proceedings (per 1,000 inhabitants) may indicate this. The average of those in placements per 10,000 inhabitants in 2010 was between 1.66 per cent (previous year: 1.59 per cent) in Thuringia and 13.42 per cent (previous year: 13.59 per cent) in Bavaria. The average number of measures similar to placement per 10,000 inhabitants in 2010 varied between 1.15 per cent (previous year: 0.96 per cent) in Berlin and 19.67 per cent (previous year: 20.59 per cent) in Bavaria (cf. Deinert 2011, 15). With regard to the placements under the statutes of the *Länder* on protection and help for mentally ill people (*Psychisch-Kranken-Gesetze*), the regional differences are considerable (cf. Deinert 2010, 26).

serious harm, others must decide and act for the person in his or her interests. But the person's own will, even if the person can only imperfectly form and express it, has paramount importance when weighed against the person's own interests as others see them. In recent decades, legislature, case law and practice have given stronger emphasis to taking into account a will even if it is imperfect. Remaining shortcomings, for example in the practice of care, show the need for further development in this direction.

Carers and supervisors may not automatically ignore the will of the person affected with reference to their responsibility and their professional knowledge. If the person involved cannot express his or her will clearly, assistance should be given in stating the will and in certain circumstances also in forming the will. Careful weighing of the measures necessary in a person's best interests against the resulting violation of the person's self-determination will then sometimes result in the need to satisfy the person's will despite accepting risks and even limited harm.

The application of these principles is independent of how far those who interact with people with limited capability of deciding can be made liable for complying with them. In this connection there are differences depending on whether a binding relationship with rights and duties exists or services are rendered only on the basis of personal attachment. In no case should the decisions made personally by the person under care be completely ignored. There are no simple solutions which apply in every individual case. There may be no avoidance of the difficulties which are presented to responsible supervisors and companions by the growing emphasis on self-determination.

5 AREAS FOR ACTION AND STEPS OF IMPLEMENTATION TO IMPROVE THE SITUATION OF PERSONS WITH DEMENTIA

5.1 National Dementia Plan

In view of the increasing number of persons with dementia and the widespread difficulty in finding good-quality counselling, care and supervision accessible to all, despite the existence of excellent projects and approaches in a number of regions, there is a need both for regional action plans and for a National Dementia Action Plan such as the one which the federal government has already begun to tackle.¹⁰⁹

On the model of the national dementia action plans, for example in France, Norway and Scotland, the aim is to create a framework for the coordinated action of all actors, which includes the legal and administrative fields of action set out below and results in the nationwide improvement of medical, nursing and social care of persons with dementia. A National Dementia Action Plan should also contain measures to create awareness which counter the exclusion and stigmatization of those concerned. Measures to improve the situation of persons with dementia need such high-visibility campaigns to create awareness, designed for long-term effect, in order to create a climate of acceptance and appreciation in society for those concerned, their family members and the caregivers. In particular the family members who act as carers deserve to be highly

¹⁰⁹ In 2011, the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth commissioned a pilot study for a National Dementia Action Plan from the *Institut für Sozialforschung und Sozialwirtschaft* (Institute for Social Research and Social Economy). In this connection, the German Alzheimer Society, in a letter of 21 October 2011 to the Federal Chancellor Angela Merkel, proposed a national dementia strategy which provides for coordinated action by all actors in order to substantially improve the situation of persons with dementia and their families.

regarded and receive public recognition for the work they perform every day. The central idea of a national action plan is to be that people with dementia are part of an inclusive society in which every individual has a right to a life in dignity to the end with affection and recognition of what self-determination is still possible in the given situation.

5.2 Entitlement to care in the conditions of dementia

The aim of care which preserves self-determination is given in Section 2 (1) of Book XI of the Social Code. This states: “The benefits of long-term care insurance are intended to help the persons in need of care, despite their need of help, to lead as independent and self-determined a life as possible, which conforms to human dignity.” This objective needs to be defined more precisely to explicitly include persons with self-determination potential which is restricted by dementia and difficult to discern, and must comprise both measures which preserve self-determination and measures of support. In a further step, this objective should also be extended to other care benefits, for example after a stay in hospital. It should also be reviewed whether the systematic divisions between inpatient care in hospital and outpatient care at home can be made more flexible, in order that the caregivers familiar to a patient with dementia from home may continue to give care when the person is an inpatient in hospital.

5.3 Better consideration of the needs of persons with dementia in care

In connection with the care reform, the new definition of the term “need for care” (*Pflegebedürftigkeit*), there should be sufficient consideration of the needs of people with dementia,

which result from their specific life situation and the possibilities of self-determination which they have in their specific case.

Benefits of long-term care insurance are subject to the need for care. At present, despite the statements in Section 2 (1) of Book XI of the Social Code and in Section 14 of Book XI of the Social Code, this is essentially defined in terms of performance and on a somatic basis. A person in need for care is one who by reason of a physical, mental or emotional illness or disability is expected to need a considerable or high degree of help for the usual and regularly repeated tasks of everyday life – this means personal hygiene, feeding, mobility and domestic assistance¹¹⁰ – for an estimated period of at least six months.¹¹¹ But a person who, by reason of a physical, mental or emotional illness or disability, needs not only these forms of help, but also communicative or psychosocial support, falls outside the entitlement to care benefits as far as this need is concerned. A person who only needs this help, as is often the case in the early stage of dementia, is normally completely outside the entitlement to care benefits.¹¹²

In the final report of the *Beirat zur Überprüfung des Pflegebedürftigkeitsbegriffs* (Advisory Board to Review the Definition of the Need for Long-Term Care), on the other hand, participation in life in society is emphasized.¹¹³ It calls for a turning away from an image of persons with need for care which is focused on their deficits and inability and towards a view

110 There is an exhaustive list of the usual and regularly repeated tasks in Section 14 (4) of Book XI of the Social Code: “in the area of personal hygiene washing, showering, taking a bath, dental care, combing, shaving, defecation, urination; in the area of feeding, cutting food into bite-sized pieces or feeding; in the area of mobility, independently getting up and going to bed, dressing and undressing, walking, standing, climbing stairs or leaving and returning to the home; in the area of domestic assistance shopping, cooking, cleaning the home, washing dishes, changing and washing laundry and clothes and heating.”

111 In certain circumstances, statutory health insurance may accept liability for a temporary need for care of less than six months. But in this area too, the need for care is not defined in a fundamentally different way.

112 Only those who are classified in Care Class 0 in such a case may receive low-threshold additional benefits as reimbursement benefits.

113 Cf. *Bundesministerium für Gesundheit* 2009.

proceeding from their current degree of independence. Care is to be integrated and context-related and should consider the current life situation of persons with need for care, and thus also to safeguard the self-determination of those concerned which is still possible in the individual case. Previous unequal treatment of people with physical disabilities on the one hand and people with cognitive or mental disabilities on the other hand are to be ended. According to the findings of the board, the need for care of the two latter groups has not yet been sufficiently taken into account, and therefore these groups, which explicitly include persons with dementia, are disadvantaged. The board recommends that in future the need for care should no longer be classified in care levels based on deficits, but in degrees of need for care, within which the support benefits are oriented towards the degree of independence or the risk of loss of independence; this complies with the concerns of persons with dementia.¹¹⁴

In order to adequately safeguard the possibilities of self-determination of persons with dementia, the German Ethics Council, supplementing the recommendations of the Advisory Board to Review the Definition of the Need for Long-Term Care, is of the opinion that the following requirements should be made of a new definition of need for care and the necessary quality assurance; furthermore, they apply to the majority of persons in need of care in old age:

- » Care should take into account the special features with regard to communication, in order to recognize what potential for self-determination is still present (this includes, for example, interpreting messages which are hard to

¹¹⁴ The call for the current three care levels to be replaced and expanded by five need-for-care levels, in order to include a broader spectrum of benefits, in particular psychosocial benefits, has been under discussion for a long time in various bodies and within the health care sciences (cf. *inter alia* Bundesministerium für Gesundheit 2009; Wingefeld/Büscher/Schaeffer 2007).

understand, respecting non-verbal communication, taking account of individual biographical and group-specific imprinting/traumatization).

- » Care should secure activities outside the home, such as participation in social and cultural activities, in order to avoid isolation and social exclusion.
- » Care should take into account the fact that persons with dementia often need help not only with individual tasks, but by reason of their cognitive losses in every aspect of their housekeeping and life; above all for many persons with dementia who have little need for care with personal hygiene, such assistance, which is often not directed to regular tasks, is necessary to maintain their independent and self-determined lives.
- » Care should at the same time always respect the fact that persons with dementia, like other people who are dependent on care, wish to determine or at least co-determine the way in which care is provided, and if they are given enough time they can do so.
- » Care also includes the respect, treatment or reduction of the effects of the special health problems of persons with dementia, such as for example particular experience of pain and urges, anxiety in connection with the course of the illness, behavioural problems, changed behaviour with regard to self-protection and insufficient ability to cope with the disease.¹¹⁵

A particular challenge is presented by the growing number of people with dementia who live alone and are single, who, like others with dementia, also wish to live as long as possible in their own homes. The revised definition of need for care and the associated further development of care benefits has a particular importance, together with assisted living at home (cf. section 5.4) and the use of everyday companions (cf. section 5.6).

115 Cf. also Wingenfeld/Seidl 2008.

The Care Reorientation Act presented by the federal government in March 2012 provides that the benefits of long-term care insurance are to be more flexibly structured and possibilities of choice between periods of time and benefit packages must be granted. This is an important first step which strengthens the possibility of self-determination of persons with dementia.

5.4 Relief, support and financial recognition of family-member carers

Relatives who care for their family member who has dementia often report extraordinary physical and emotional burdens. Many of them must certainly work beyond the limits of their ability. It is undisputed that they are extremely important for individual supervision, preservation of self-determination and for the relation to stay in his or her domestic surroundings. It is therefore in many respects an important concern to give them support and relief.

Many measures are already offered by charities and support groups. These include information events and training courses, such as the programme “Hilfe beim Helfen” (Help with Helping) of the German Alzheimer Society, discussion groups for family members, day care, aids in the household and short-term care if the family-member carer is ill or overburdened, or supervised holiday in order to enable family-member carers to have a rest. Measures of the legislature, such as the *Pflegezeitgesetz* (Long-Term Care Leave Act)¹¹⁶ and the increase of the

¹¹⁶ Long-term care leave under the Long-Term Care Leave Act is intended to enable employees to be released from work for a limited period of time without continued payment of salary or to work part-time in order to supervise and care for family members in need of care without this endangering their employment relationships. During the long-term care leave, the employees have special protection against dismissal.

amount of care allowance¹¹⁷ or the Bavarian model “Betreutes Wohnen zu Hause” (Supervised Living at Home) have brought relief, even if they do not appear sufficient.¹¹⁸ The same also applies to the new *Familienpflegezeitgesetz* (Family Long-Term Care Leave Act)¹¹⁹, which entered into force in 2012, since it excludes from the legislation persons concerned who have not yet been allocated to a care level but who nevertheless need supervision, as is the case for many persons with dementia.

117 For example, the monthly care allowance for family-member carers in Care Level I, from 1 January 2012, is 235 euros (from 2013 305 euros), in Care Level II 440 euros (from 2013 525 euros) and in Care Level III 700 euros (no increase in 2013) if they dispense with professional assistance. If professional help is used, the care allowance is reduced by the proportion of benefit care service received to the maximum possible benefit. To make it clearer, here is an example: if, for example, at present in Care Level II a service is used and charged at 449 euros, this is 45 per cent of the possible maximum benefit (1,100 euros). The potential financial allowance of 440 euros is reduced by 45 per cent and the care allowance is only 242 euros. From 2013, it is intended that there shall also be a care allowance in Care Level 0 in the amount of 120 euros per month or non-cash care benefits of up to 225 euros per month.

118 For example, family-member carers criticize the dependence of the amount of care allowance on the use of professional care, which results in it quickly being reduced to zero even if only minimum claims on care services are made. In addition, the Long-Term Care Leave Act and the new Family Long-Term Care Leave Act apply only to family-member carers who are employees, not to the unemployed or old-age pensioners.

119 The Family Long-Term Care Leave Act, which entered into force on 1 January 2012, is intended to reconcile family and occupation better. It provides that employees may reduce their working hours for a period of two years to a minimum of fifteen hours per week in order to care for a family member. In return for this, there is to be a state-assisted wage adjustment. But since the gross wage is reduced only half as much as the working hours, if the employee's working hours are reduced by 50 per cent, the employee will receive 75 per cent of his or her wages. The employer can finance this overpayment which it makes in the period of care leave by an interest-free loan. The *Bundesamt für Familie und zivilgesellschaftliche Aufgaben* (Federal Office of Family Affairs and Civil Society Functions) is responsible for the loan. After the end of the care leave, the employee must work in such a way that the wage adjustment is paid back. The employee must therefore work more than he or she receives wages until the adjustment is compensated for. However, there is no binding legal right to this; instead, the care leave must be contractually agreed with the employer. A further requirement is that the person in need of care must be receiving benefits under long-term care insurance in at least Care Level I. Consequently persons with dementia who do not yet fall into a care level, but nevertheless often have a greater need for supervision, are excluded from the new provisions.

If one proceeds on the assumption that in future more and more family-member carers will wish to maintain their own prospects in life and also continue their occupation or at least preserve their financial independence, the following measures appear particularly important:

- » relief of the family-member carers by the development of a network of day-care possibilities and other individually appropriate measures, for example domestic help,
- » expansion of professional and voluntary assistance near the person's home in the form of information and dialogue for family-member carers, in particular including encouragement to have regard to themselves and improvement of self-directedness, in order to recognize excessive burdens and demands at an early date and to reduce them,
- » appropriate financial compensation for the supervision provided by the family members instead of the current provisions of care allowance or of the Long-Term Care Leave Act, which many of those concerned regard as insufficient,
- » improved crediting of long-term care leave to the pension rights of the employed, by equal treatment of parental leave and long-term care leave¹²⁰,
- » improved access to health cures and rehabilitation measures for family-member carers,
- » organized acknowledgement of long-term care leave in connection with training and in job applications,
- » measures to legalize the currently illegal use of foreign carers in private households; an example might be the Austrian solution, where a minimum wage is paid and free board and accommodation given, and the carer is registered with

¹²⁰ For example, one year of care for a person in need of care in Level I, consisting of fourteen hours' care per week, increases the monthly pension by 7.42 euros (west Germany) or by 5.77 euros (east Germany), in Care Level II and 28 hours' care per week by 22.26 euros (west Germany) or 17.31 euros (east Germany). One year of parental leave increases the pension claim by 27.47 euros (west Germany) or 24.37 euros (east Germany).

the long-term care insurance fund, which then bears the costs of social insurance and itself then only guarantees the medical treatment.¹²¹

5.5 Improvement of the health care of persons with dementia

The self-determination of persons with dementia requires access without barriers to health care. Barriers in this case refers less to physical barriers than to organizational, communicative and professional barriers.¹²² The medical diagnosis and therapy of persons with dementia requires not only particular care, but also expertise, time and empathy on the part of those giving the treatment, so that they do not speak over the heads of the persons concerned and only with the persons accompanying them. In the advanced stage, the family members have an important function as interpreters of the utterances of the person with dementia. Illnesses that are not recognized or are inadequately treated are a great danger for persons with dementia and result in substantial consequential problems. The specific occupational training and consultation of general practitioners and of medical specialists should be promoted. It is also recommended that there should be regional lists and recommendations of particular practitioners; this is already being done by some support groups for the outpatient area. In the inpatient area, it is necessary to develop dementia-oriented wards or partial wards where the equipment, the daily routine and the additional services and personnel structures are oriented towards the needs of persons with dementia.¹²³

121 In the draft bill of the health working group of the CDU/CSU parliamentary group on the key points of a long-term care reform, Austria's system is considered under the topic of carers from Eastern Europe (cf. *CDU/CSU-Fraktion im Deutschen Bundestag* 2011).

122 Cf. *inter alia* Sachse 2009.

123 From October 2005 to April 2006, the *Institut für Pflegewissenschaft* (Institute of Nursing Science) of Bielefeld University carried out a survey of the

The formation of regional networks to improve local and regional communication is recommended, in order to improve the cooperation and accessibility of the suppliers. Such networks should be encouraged and financially supported by the local and regional authorities. On the national federal level, the developments in the area of the health care of persons with dementia should be included in supervisory accompanying research and reports in connection with the implementation of the United Nations Convention on the Rights of Persons with Disabilities, since these are measures towards an inclusive health care system.

5.6 Financial assistance for domestic and residential communities for persons with dementia with outpatient care

Persons with dementia wish to live close to their present home and are usually able to do so, even if their own homes are no longer suitable for this or their families are overburdened by permanent care. Possibilities which have been shown to be beneficial and which preserve the self-determination still present in the individual case include self-organized domestic and residential communities with outpatient care and also residential care communities.¹²⁴ The financial conditions of such communal forms of residence and care for persons with dementia, however, are inadequate. On the one hand, the non-cash benefits in Care Levels I and II are inferior for the insured to the

care situation of older persons with dementia in hospital. The main part of the survey consisted of guideline-based interviews of representatives of the nursing staff, the doctors and the departments of social work and transfer into care (managing discharge from inpatient care and transfer between hospital and domestic sphere). In addition, patient data available in the hospitals were analysed.

¹²⁴ The provisions of regulatory law which were long disputed for the forms of communal residence and care, are now in most *Länder* contained in *Land* statutes which replace the previous federal Care Home Act (cf. Kremer-Preiß/Stolarz 2006).

non-cash benefits of the same levels for inpatient long-term care insurance; on the other hand the creation of such forms of residence and care is adversely affected by up-front costs which are not refinanced and high costs of rental property for initiators and investors. A fundamental demand made in this context is the call for sufficient financial safeguarding. This includes not only providing suitable residential space with rent levels acceptable to the social welfare funding agency, but also providing sufficient financial start-up support for initiators, in order to compensate for the up-front expenses for structural alterations to the homes and the creation and ongoing support of the organizing committee which is necessary for residential communities with outpatient care and which consists of family members or of statutory custodians. But since in the foreseeable future a large proportion of care for persons with dementia will take place in care homes, it should also be ensured, at the stage of building permission for care homes, that account is taken of quality requirements to implement care and supervision concepts which reinforce a care and supervision encouraging self-determination and the involvement of the residents in society.

Regrettably, for local social welfare funding agencies in many places it is more affordable to care for persons with dementia in a home than in a residential community with outpatient care. When the persons are in a home, the agency must only bear their own contribution, which is laid down as a fixed amount of the care charges, if they satisfy the means test. But in the case of a residential community with outpatient care, if the person satisfies the means test, the agency must bear the costs of the actual care exceeding the refinancing of the long-term care insurance fund. These may be higher than the personal contribution of the person in a care home, since rent for the premises which are needed for such a residential community may be high. But the heterogeneity of the members of such a residential community, which means a larger proportion of members at lower care levels with the same high need

of permanent care, may drive up the actual care costs for the individual member. Against this background there is the danger that local authorities, for financial reasons, do not develop measures to replace care homes such as residential care communities. As a result, the principle of “outpatient before inpatient”, as specified as an objective of Section 3 of Book XI of the Social Code, often fails to be realized in practice.¹²⁵ But the only way to ensure that the number of care home places does not need to be further increased is if there is a rapid increase of residential possibilities with outpatient care close to the occupants’ homes.¹²⁶

In detail, the following changes are called for:

- » bringing the non-cash benefits provided by care insurance for outpatient residential care in line with the inpatient non-cash benefits provided by care insurance,
- » targeted promotion of residential premises for communal residential care arrangements for persons with dementia with the goal of achieving rental costs which are accepted by the social welfare funding agency,
- » provision of adequate subsidies for adaptation and conversion in order to make homes suitable for the purposes of a residential care community and to fund up-front costs of initiators,
- » review as to how far, in addition to support for care, other benefits of Book XII of the Social Code, such as integration assistance (*Eingliederungshilfe*), may be provided to enable persons with dementia to participate in society in the sense of companionship outside their homes.

125 “Long-term care insurance should provide benefits primarily to support domestic care and the readiness of the family members to give care, in order that those in need of care can stay in their domestic surroundings as long as possible. Benefits of day-patient care and short-term care take priority over inpatient care” (Section 3 of Book XI of the Social Code).

126 Thus the number of care homes for the care of old people rose from 1999 to 2003 from 8,859 to 9,743, and the number of places in care homes from 645,456 to 713,195 (cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2006, 36).

In March 2012, the federal government presented the Care Re-orientation Act; this provides for measures to promote outpatient residential communities, such as granting an earmarked lump sum to employ a coordination worker and provide start-up funds in the amount of 2,500 euros per person. These are important steps to encourage such forms of living.

5.7 Inclusion of methods encouraging self-determination in geriatric nursing training and for health workers and nurses

Training courses for health care and nursing and for geriatric nursing, and training courses for nursing auxiliaries, care home assistants, health care and care assistants or everyday companions for the elderly should have more modules on dementia, on the specific needs of persons with dementia and on the everyday activities which preserve the independence and self-determination of persons with dementia. In all caring professions, there is also a need for new competencies to involve and recognize family-member carers and to coordinate the supplementary use of volunteers. Such competencies should be part of the training courses in order that the cooperation of all involved in the care and companionship of persons with dementia is reinforced. The health-care professions must overall be made more attractive in order to avoid the aggravation of the long-term care crisis. In addition to generally increasing the value of the image of the profession, standardizing the requirements for entry, making the possibilities of work and promotion more flexible and giving a salary that takes account of the emotional and physical strain, this includes improving the transfer between theory and practice and using a person-centred approach which respects the self-determination of persons who need care.¹²⁷

¹²⁷ Cf. *inter alia* Lauber 2001, 8.

5.8 Promotion of research

In view of the anticipated increasing number of persons with dementia in society and against the background of the ethical precept that the possibilities of self-determination of the persons affected should be preserved as long as possible, the call for appropriate promotion and coordination of research is well-founded. This applies both to the medical and nursing field and to the psychosocial field and the interfaces between medicine, nursing, psychology and existing care. A step in this direction has been made with the coordination of research by the *Deutsches Zentrum für Neurodegenerative Erkrankungen* (German Centre for Neurodegenerative Diseases) in Bonn, particularly since the research centre represents both medical and also non-medical dementia research. In addition to this, decentralized research activities should be promoted and greater weight be given to care and nursing research.

The promotion of research in the area of dementia, for example in cell biology, neurological imaging and molecular medicine, should be oriented towards clinical practice in the sense of translational research. Important research topics in the areas of health care sciences and psychology include the preservation and improvement of possibilities of self-determination of persons with dementia and possibilities of recognizing and interpreting the expressions of wishes and needs of persons with dementia, even in an advanced stage of illness. It is necessary to evaluate new forms of accommodation, such as residential care communities, and programmes to avoid constraint and violence in care. In the area of therapies without medication, rehabilitation and prevention there is also as yet too little knowledge on the effectiveness of measures.

There is also need for research with regard to the evaluation of the clinical use of early diagnosis procedures, and here in particular of tests (for example of biomarkers) which make it possible to detect a possible illness in very early stages, at a time when the patients do not yet display any clinical symptoms. At

present, very little is known of the psychosocial consequences of such tests in persons who are (largely) asymptomatic.

5.9 Improving statutory custodianship and ensuring alternatives

The number of statutory custodianships has grown enormously since custodianship law was introduced in the year 1992, although as yet the demographic factor has not yet had a decisive effect on the distribution of the age groups. Thus in 2005, 22 per cent of the persons under statutory custodianship were in the group of 18- to 39-year-olds, 35 per cent in the group of 40- to 64-year-olds and 43 per cent in the group of over 65-year-olds. But in 2050, it is expected not only that the number of persons under statutory custodianship will increase to over two million, but also that the group of 18- to 39-year-olds will decrease from 22 per cent to 11 per cent, the 40- to 64-year-olds from 35 to 22 per cent, the 65- to 74-year-olds from 11 to 9 per cent and the group of the over 75-year-olds will increase from 32 to 58 per cent; the group of the over 85-year-olds will increase most strongly.¹²⁸

According to the statistics of recent years, the number of older people is increasing most rapidly among the custodianships ordered every year; approximately 44 per cent of the new appointments of statutory custodians for the group of 65-year-olds and older relate to persons with dementia. In relation to all statutory custodianships, dementia, at 34 per cent, is the most frequent diagnosis for persons under statutory custodianship, followed by 13 per cent for persons with mental illness and 10 per cent for people with mental disability.¹²⁹

In recent years, the proportion of what are known as voluntary custodianships (usually by family members) to

128 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2005, 40.

129 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2005, 78.

professional custodianships has shifted slightly towards professional custodianships.¹³⁰ This is also attributed to the fact that many first appointments for old people are made in consequence of a dementia and in these cases family members are less often available than was formerly the case, or they feel overburdened and the guidance and incentives are insufficient for voluntary custodians.¹³¹

Against this background it is becoming important for the possibilities of custodianship law to be exploited in full with the goal of preserving the right of self-determination of the person with dementia. On the one hand, this relates to complying with the principle of necessity under Section 1896 (2) sentence 1 of the Civil Code, which provides that a custodian may be appointed only when and only for the groups of tasks in which the custodianship is really necessary. On the other hand, the exercise of custodianship should as a rule, for example when it is extended, be reviewed to determine whether it is in the best interests of the person under custodianship. Under Section 1901 (2) of the Civil Code, the best interests of persons subject to custodianship include the possibility to shape their lives within their capabilities, according to their own wishes and ideas. Undisputedly, the best interests of the person under custodianship also include the individual right of self-determination.¹³² In addition, care should be taken that the order of reservation of consent (Section 1903 of the Civil Code) and the approval of placement in accommodation and measures depriving the person of liberty (Section 1906 (1) and (4) of the Civil Code) are made only to the extent absolutely

130 Thus in 1999 70.33 per cent of statutory custodians were voluntary custodians, in 2009 64.9 per cent and in 2010 63.7 per cent, while the proportion of professional custodians constantly increased in the same period: in 1999 29.67 per cent, in 2009 35.1 per cent and in 2010 36.28 per cent (cf. Deinert 2011, 13). In the area of persons with dementia under professional custodianship, the proportion of voluntary custodianships in 2005 was 67 per cent (cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2005, 27).

131 Cf. *Bundesministerium für Familie, Senioren, Frauen und Jugend* 2005, 40 f.

132 Cf. Hoffmann 2001.

necessary.¹³³ Similarly, measures of information, guidance and support for family members or friends of the persons with dementia should be encouraged to undertake voluntary custodianships, because as a rule the family members know more about and are better able to recognize the person's wishes and interests, which are individual and influenced by his or her personal life, and the potential for self-determination which is still present.

If one considers the number of persons with dementia, then a statutory custodianship is not always the appropriate and necessary response to their increasing limitations.¹³⁴ Greater weight should be given to arrangements under private law. For this, there must be more measures of education and support, such as the appointment in the regions of special advisers on matters such as lasting powers of attorney and custodianship (*Vorsorgelotsen*, literally guides on precautionary measures) or the social advisory services of the judicial authorities.

5.10 Giving weight to the expression of the will to live by persons with dementia

In lasting powers of attorney in which particular forms of medical treatment are to be excluded it is a fundamental requirement that when such an instrument is applied in practice, appropriate weight is given to the expressions of the will to live made by persons with dementia.

- >> As long as the person is still fully capable of making decisions, a lasting power of attorney may not be used.
- >> If there is no capability of making a decision whatsoever, current utterances by the patient which are directed to the

¹³³ On the increasing number of reservations of consent ordered see section 4.4.2; on the increasing numbers of liberty-depriving measures ordered see footnote 108.

¹³⁴ Cf. Förstl/Bickel/Kurz 1999.

continued preservation of life and to medical and nursing activities which serve this purpose should be given weight in the examination as to whether the lasting power of attorney is applicable to the present life and treatment situation.

- » In so far as there are doubts as to the extent to which the person concerned is still capable of making decisions, there must be a particularly careful examination as to whether he or she is capable of evaluating the meaning and scope of the decision to be made. If it is not absolutely certain that the person is incapable of making a decision, then his or her own will as far as it can be formed must be respected. All forms of expression of will must be taken seriously here, including non-verbal ones. If the will is then discernibly directed to preservation of life and to medical treatment promoting this, then it must always be given priority over a lasting power of attorney to a different effect, because the results of omitting treatment are irreversible.

5.11 Applying the United Nations Convention on the Rights of Persons with Disabilities to Persons with Dementia too

Recognizing the rights of persons with dementia and ensuring their social inclusion should be oriented towards the principles of the United Nations Convention on the Rights of Persons with Disabilities. A particular argument in favour of this is the fact that the United Nations Convention proceeds from a comprehensive concept of disability for which it is relevant *what* assistance a person needs, and no longer *why* this is the case.

The Convention also offers in its fundamental principles set out in Article 3 a suitable framework to respect and strengthen the rights of self-determination of persons with dementia in all areas. Mention should here be made above all of the principles of respect for inherent dignity and individual autonomy,

non-discrimination, an unreserved inclusion in society and an effective participation in society. The fundamental principle of the Convention of not creating special rights for persons with disability but instead explicitly setting out their self-evident rights, because it is difficult for those concerned to have access to these rights, applies to persons with dementia and is suitable for the recognition of their rights.

In this respect, Articles 12, 14 and 19 of the United Nations Convention are particularly relevant for reviewing and improving the situation of persons with dementia. In Article 12 of the Convention, persons with a disability, and therefore also persons with dementia, are in principle recognized as persons before the law with equal rights and with full legal capacity and capacity to act. Measures which relate to the exercise of legal capacity and capacity to act or make it possible for others to exercise these should be individually appropriate and not out of proportion. In a corresponding way, legal practice and court decisions with regard to persons with dementia should be reviewed and if necessary improved.¹³⁵

Article 14 of the Convention states that if persons with a disability are deprived of their liberty, they should be subject to the same rules of procedure and have the same right to treatment by state bodies as all other members of society. The enormously increased numbers of measures restricting liberty, in particular mechanical measures and sedating medicinal products, should be reduced by educating carers, case reviews, individual planning of measures and a strict duty of documentation. Relevant in this connection, for example, are the experience and recommendations of the project ReduFix to reduce physical restraint supported from 2004 to 2006 by

¹³⁵ Here, consideration should in particular be given to the serious examination of the wishes of persons with dementia with regard to the choice of their statutory custodian, but also the choice of their place of residence or the nature of their assistance. But consideration should also be given to the regular appointment of guardians *ad litem* in order to assist persons with dementia in representing themselves before state instances and institutions.

the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth.¹³⁶

In Article 19, under the heading “Living independently and being included in the community”, there is a call for a free choice of place of residence, living arrangements, support benefits and unrestricted access to community support services and community services and facilities for the general population. Applying this Article to people with dementia would in particular prevent care home residence against the will of those affected, including where this is done for reasons of cost. But it would also comprise the very important right to assistance with personal hygiene by someone of the same sex as the person concerned. In addition, an application of this Article would result in the development of local government dementia-oriented options which could greatly improve the lives of those concerned and their family and communal life in general. Implementing these ideas in practice calls for substantial but rewarding efforts.

5.12 Additional financial resources are needed for people with dementia

In order to genuinely improve the situation of persons with dementia and their family members and to satisfy the ethical requirement of maintaining an independent life and preserving self-determination as long as possible, greater funds are needed than at present. The measures recommended by the

¹³⁶ Physical restraints include abdominal belts, for example in bed or on a chair, but also bedrails, fixed flat tables and closed doors, and psychotropic drugs for sedation. The aim of the ReduFix project was to prevent or reduce measures which restricted the freedom of care home residents with dementia by targeted interventions without this resulting in negative consequences for those affected. The results show that it is possible to reduce physical restraints without negative consequences for the person involved by initiating a process of reflection among the carers and showing practical alternatives to immobilizations and other methods of restriction of liberty (cf. Hoffmann/Klie 2004).

German Ethics Council increase the financial requirements in the area of caring for and ensuring participation for those with dementia. An essential aspect legitimizing this increase is that dementia is a problem which is increasingly affecting the whole of society and that social solidarity also includes the recognition of old age in the form weakened by dementia.

6 RECOMMENDATIONS

The German Ethics Council sees that in many families and many homes the principles of an interaction with people with dementia which is attentive and which supports self-determination as long as possible are implemented with great commitment. For their commitment, voluntary and occupational carers deserve great recognition and support such as are aspired to in these recommendations to improve the situation of persons with dementia.

1. The German Ethics Council reinforces the intention of the federal government to develop a National Dementia Action Plan in order to coordinate the efforts of all actors for nationwide improvement of the medical, nursing and social care of persons with dementia. The fields of statutory and administrative activity listed below should also form part of the Action Plan and form a campaign with sustained effect to provide education about this illness and the needs of those concerned and of their family members. This is intended to strengthen the social inclusion of persons with dementia and to recognize their right to self-determination.
2. The general objective of nursing care, to enable the patients to lead a life which is as independent and self-determined as possible (Section 2 (1) of Book XI of the Social Code), should be defined in detail in such a way that the possibilities of self-determination of persons with dementia which are still present in the individual case are explicitly included. It should be reviewed whether the persons who are known to the patient as carers at home can also care for the patient in hospital.
3. A revised definition of the need for care (*Pflegebedürftigkeit*) should take sufficient account of the possibilities of self-determination of persons with dementia and the resulting duties of care. The care of persons with dementia

should also cover the particular need in the area of activities outside the home and of an independent lifestyle and communicative and psychosocial needs.

4. The work of family-member carers needs effective support and financial recognition. For this purpose, a variety of supportive measures should be rapidly expanded, such as day care, supervised holidays, short-term care, but also possibilities of further training and discussion for family members near their homes, and in particular also measures to improve self-directedness and attentive observance of their own limits. The financial compensation for the care services provided by the family members should be made within an appropriate range and be separated from the care allowance. The crediting of long-term care leave to pension rights should be made by equating parental leave and long-term care leave.
5. Politics should support initiatives to improve the health care of persons with dementia. Measures of the further occupational training of those who give medical treatment in the field of dementia care and the formation of regional networks to improve local and regional communication should be promoted by public health administration funds.
6. Residential communities of persons with dementia relying on outpatient care should be given more financial support. This includes in particular residential care communities near their homes which create a framework enabling self-determination and in which professional carers and family members work together.
7. Training courses for health care and nursing care, geriatric nursing and nursing or geriatric care assistance should include modules on dementia as an illness, on the special needs of persons with dementia and on ways of interaction which preserve self-determination.
8. The promotion of research in the area of dementia with regard to basic research in the sense of translational research should be oriented towards clinical practice. In addition,

it should include clinical and medical, psychosocial and health-care science aspects, ethical and legal accompanying research and health services research.

9. In order to preserve and protect the possibilities of self-determination of persons with dementia, the principles of the United Nations Convention on the Rights of Persons with Disabilities, which also include persons with dementia, should be consistently applied.
10. In order to reduce the need for statutory custodianships, the use of lasting powers of attorney under private law should be promoted by education and support.
11. Statutory custodianships should also regularly, for example upon renewal, be reviewed to confirm that they take sufficient account of the decisions and wishes of those under custodianship.
12. The readiness of family members to assume voluntary custodianships should be reinforced by practical support during the custodianship and by social appreciation.
13. The *Länder* of the Federal Republic of Germany should at least every two years prepare a joint report on the number of placements and restrictions of liberty under Section 1906 of the Civil Code and under the statutes of the *Länder* on protection and help for mentally ill people (*Psychisch-Kranken-Gesetze*) and the reservations of consent (Section 1903 of the Civil Code). The report should be the basis for an evaluation of practice, since the measures set out above must remain restricted to cases of absolute necessity.
14. In the review of the current application of a lasting power of attorney, expressions of the will to live made by persons incapable of deciding should be included.
15. In cases where it cannot be established with certainty that the patient is incapable of making a decision, priority should always be accorded to life-affirming statements as against a lasting power of attorney to a different effect, because the omission of life-preserving measures is irreversible.

16. In total, more financial resources should be made available than at present for the accompaniment and care of persons with dementia and their families.

DISSENTING POSITION STATEMENT

The tragedy of dementia must not be passed over in silence

The present Opinion of the German Ethics Council has the objective of comprehensive social education on the illness dementia. It is intended to make accessible to a broader public the knowledge gathered in research and nursing care, and it advocates more understanding both for persons with dementia and in particular also for those who have to interact with them. If the call to respect the self-determination of those with dementia and to give them more individual attention is in the foreground here, this has my full support.

The ethical concept of self-determination has long since also had a constitutional significance which is closely connected to the political freedom of the individual and to personal dignity, which must be respected in all circumstances. If it is imperative to preserve this self-determination, then it follows from this that it must be promoted to the best of the promoter's ability as soon as there is the risk that a person will lose his or her ability to assert this self-determination adequately in person. Consequently, the social promotion of self-determination, as paradoxical as it may appear at first glance, is a public requirement. To this extent I am in agreement with the political and social intentions of the Opinion.

Nevertheless, I abstained in the final vote, and this primarily for two reasons:

Firstly: No Ethics Council is needed to direct public attention to legal and social obligations. This is why we have parliaments, courts, parties, churches and associations, and it is certainly better if the instances and organizations speak openly in favour of their own views instead of giving themselves the semblance of thoughtfulness under the title of a philosophical discipline.

An Ethics Council must attract attention to ethical problems in order to make a well-thought out assessment and

derive from this recommendations for individual and social action. It goes without saying that legal, medical, social and theological competence are necessary for this; but if ethical pretensions are claimed, the fundamental philosophical argument is absolutely essential. The present Opinion, however, specifically avoids the central ethical problem of dementia. It is true that after long discussions it was in fact mentioned. But the declaration as a whole relentlessly discounts it.

The fundamental ethical question associated with the development of dementia is plain to see as soon as not merely the legal concept of the person is taken as a basis, but instead it is recognized that humans choose their own life goals in free self-knowledge and world knowledge, and then pursue them in self-aware decision. As long as a person has his or her own will and follows it in accordance with his or her insight and own reasons, the person determines himself or herself. The contemporaries must accept this, even if they do not agree with it, as long as there is no breach of law or public policy.

But the ethical problem of dementia lies in the fact that a person with dementia can no longer be accorded this self-determination. It is frequently the case that a person with dementia no longer thinks he or she is capable of self-determination. But even if the person would like to continue to lead his or her own life in the familiar way, others cannot permit this. This is the end of what the arduous upbringing to autonomy and maturity was directed to. The person is no longer the person he or she was meant to be and personally intended to be. Nor is he or she the person as whom others have learnt to esteem and love him or her. And what under the conditions of individual freedom must be seen as the foundation of a system based on knowledge, insight and mutual agreement in this individual case no longer exists.

For in our claim to insight and the ability to learn, to our own efforts and good resolutions, we count on qualities in ourselves and others which are no longer available to the person with dementia. Education or rebuke, praise or blame no longer

have consequences in a person with dementia for which he or she can be held accountable; we can scarcely hope that the person can improve by his or her own efforts. It is therefore consistent to proceed on the basis that persons with dementia have restricted culpability.

If in particular in the first phase of the illness there may still be moments of customary independence, yet the individual self-determination of a person's own life, based on self-observation, self-reflection and personal responsibility, cannot be expected, especially not in the important situation where existential acts are called for. It would normally be most natural to tell the person to "pull yourself together", but this no longer has any effect. In consequence, other people must assume responsibility for what until the beginning of the illness was each person's personal responsibility.

This is the ethically decisive point. In this, a tragedy in the person's life takes place. It consists in the fact that what is lost is precisely what makes a person a responsible being. This loss, in which the self-determined life of the person with dementia breaks off, is a biographical catastrophe which cannot be whitewashed either by dementia research or by the promises of optimized care.

It should be noted: I regard the suggestions that research should be increased and care improved as of the greatest priority. I am well aware that a person who is ill can have many pleasures and can experience deep happiness. I rate it highly that there are care homes where the occupants can play, dance, sing and laugh. And I am familiar with the pictures of the persons with dementia taken to Thailand who are patiently fed by friendly helpers in a subtropical idyll. But even if one considers it possible to remedy the growing crisis in long-term care, to increase the individualization of care and at the same time to reduce the heavy physical and emotional burden on the family members: dementia results in a dramatic change in the life of a person, because it removes living persons from the existence in which they acquired their personal self-awareness and their

social recognition. And it holds the risk of irrevocably alienating them from those close to them.

The ethical foundation of an individual life is thus destroyed and the invalid becomes a case for social care. It is true that the case obliges his or her fellow human beings to concern themselves as best possible with fulfilling the person's wishes. Nor can it be denied that in interaction with the person with dementia one may obtain new insights into his or her individual biography, into his or her family and occupational environment or into human existence itself. For this reason, literature dealing with the topic of dementia is of great value, and the astonishing personal testimonies of those concerned deserve general interest.

But those who do not explicitly state that this is the irreversible end of what defines a person in interaction with people like him or her trivialize dementia and are in danger of trivializing the basis of their own existence, which comprises not only a legal foundation but specifically also an ethical foundation.

Secondly: The second objection, which may be dealt with more briefly, is connected with the danger of placing little value on personal self-determination, which after all cannot exist without the claim to reason and self-awareness: if one realistically assesses what a loss dementia constitutes, one may not close one's eyes to those who in the awareness of the value of their personal presence not only do not desire their lives to end in this way, but would like to avoid it by their own self-determined act.

I am anything but an advocate of suicide. It is my view that social responsibility, which is our foundation, contains the obligation not to escape from this responsibility in any circumstances. But if pain or abandonment is so great and future prospects of life are so poor that a person is prepared to overcome his or her own will to live, all counter-arguments lose their power. Then one can place one's hope only on personal assistance and taking new hope. It therefore depends in every

individual case on giving the person courage again and giving him or her new hope through love and support. At the same time there is the wish to end one's life in the face of imminent dementia. And since this wish exists, the Ethics Council should also have addressed this ethical problem which asserts itself.

If the wish to die in a self-determined way before one becomes dependent on care and unable to make one's own decisions is seriously expressed, if, in expectation of the foreseeable circumstances of a person's life and death, the wish becomes a thoroughly considered demand expressly set in writing, it must be permitted to be conscientiously examined and to be decided in accord with the expressed wish. But those who are not of this opinion must state their opposition openly, in view of the longstanding crisis in nursing care and the foreseeable deterioration in its provision. The ethos of our culture, based on freedom, self-determination and human dignity, is undermined if the wish that is natural in view of the decline heralded by the illness, if the demand expressed explicitly by self-aware persons in public and private, and the act carried out by more than a small number are passed over in silence.

It is unacceptable that self-determination should be declared the sustained goal *in* dementia but self-determination *before* dementia is not mentioned at all. Those who assume that there is a personal continuity between the person who is well and the person who is sick must also take account in their assessment of the person who is sick what that person laid down while he or she was well with regard to the state in which he or she is found in dementia.

Those who disregard the will expressed earlier undermine the personal unity of the person which is the basis of the reference to self-determination in all phases of life. As long as the autonomic vital signs of an incurably ill person weigh more than the decision expressly formed in full consciousness by a person exercising self-determination in this decision, it is of no value whatsoever to esteem the remaining elements of the expression of personal wishes and opinions of a person with

dementia so highly as is done in the present Opinion of the German Ethics Council.

Self-determination means that everyone can decide on his or her life. Logically and de facto, this includes the decision on how one's life is to end. And it excludes the possibility of obliging another person against his or her conviction to help the dying person in his or her self-chosen suicide. This is the ethical dilemma, the dilemma of the person with dementia and of those close to him or her. What follows from this for society should at least have been considered where dementia is discussed under the heading of self-determination.

Volker Gerhardt

Weyma Lübbe concurs in this dissenting opinion (Axel W. Bauer concurs only in Part 1 of the dissenting opinion).

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