



Office of the Public  
Defender of Rights

# Protection of Rights of Elderly People in Institutions, with an Emphasis on People Suffering from Dementia

Marie Lukášová, Adéla Hradilová et al.



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## Foreword

In your hands, you are holding the collection of papers presented at the international conference on the Protection of Rights of Elderly People in Institutions, with an Emphasis on People Suffering from Dementia held on 20 and 21 February 2014 in the Office of the Public Defender of Rights in Brno. The publication also includes papers which accordingly complement the concerned topic. The conference was held as part of the project Together Towards Good Governance (CZ.1.04/5.1.00/81.00007). The project beneficiary and the implementing body is the Office of the Public Defender of Rights.

One of the tasks of the Public Defender of Rights is to perform preventive visits in places where persons are or may be restricted in their freedom. This is a part of the 'national preventive mechanism' agenda, which aims to increase prevention of ill-treatment in the broadest possible meaning of the word. Social care facilities have been visited by the Public Defender of Rights since 2006 and annual reports including the findings and recommendations are continuously published at <http://www.ochrance.cz/ochrana-osob-omezenych-na-svobode/> to make them available to experts as well as the general public.

In 2013 the Defender started a thematically integrated series of visits in social services facilities for the elderly with a special focus on persons suffering from dementia. The Defender carried out 15 visits in social care facilities for the elderly and subsequently also in 7 facilities without registration for provision of social services.

The number of the elderly around the world suffering from dementia is growing fast and, with the rising longevity, this number will continue to grow. In the Czech Republic alone nearly one out of ten persons over 65 years of age suffers from dementia. It is an acute problem of our time which has been compared by some to an incurable epidemic of old age. People suffering from dementia require special care, understanding and substantial assistance from the society. They are among the most vulnerable groups of senior citizens, most in danger of having their human rights violated and their dignity encroached on by others.

The results of the visits by the Defender revealed ill-treatment in almost a half of the registered social services facilities for the elderly. The situation is an order of magnitude worse in the unregistered facilities – accommodation facilities of various types providing care without professional expertise and supervision.

The most frequently reported problem in the facilities is the lack of professionalism in care for seniors with dementia, who require care adjusted to their specific needs. Related to that is the lack of staff in direct care, i.e. nurses and caregivers. The underestimation of the risk of malnutrition in senior citizens and provision of foods which are ill-suited to the needs of seniors with dementia or improperly served are recurring problems. Administration of tranquillisers and sedatives in a manner that is at variance with the law, which sometimes has the character of a measure restricting freedom of movement, is a frequent form of misconduct. In the majority of the visited facilities the clients did not have a fixed bladder voiding regimen (a determination of the form and frequency of assisted toilet use). In some cases the staff were artificially accelerating the onset of full incontinence with the subsequent use of diapers.

Although the Defender's basic stepping stone – the respect for human dignity – is an (evolving) legal concept, the specific features of the Alzheimer's disease and other forms of dementia require that the evaluation of the Defender's findings have a basis in social and healthcare expertise. Issues being now brought into focus concern nutrition, the autonomy of will, prevention of avoidable pain and other forms of bodily and mental suffering. It is perhaps surprising that some of the topics have only been raised in the context of the quality of social services in relation to the Defender's visits. Therefore, the aim of the conference was to provide space for discussion of these topics and give them priority over the sometimes too formalistic perception of quality, considering both social and healthcare issues, and to start a discussion about the conditions in which senior citizens live in facilities where professionals provide them with care.

Anna Šabatová, the Public Defender of Rights, who was just entering the office at the time of the conference, said the following in her opening statement: "Recently, the press brought forward some interesting numbers: in 1930, 45% of the deceased died below the age of 50 and only 10% of people lived to over 80. In the year 2011, almost a half of all people lived to over 80 and only 6% died before reaching the age of 50. The challenge before us is to humanely treat our fellow citizens who have given us a lot in their lives and we now have the opportunity to pay some of it back. I would like to convey a thought which to some of you may be provocative: I believe that meeting these challenges is not a matter of financial resources, but above all a matter of how the society manages these resources and which values it prioritises."

# Basic Introduction to the Issues Concerning Dementia

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## **Keywords**

Dementia, Alzheimer's disease, P-PA-IA strategy, Vážka certificate

## **Abstract**

The paper introduces the issues related to dementia syndrome and care provided to patients suffering from dementia. It also presents the current opinion of the Czech Alzheimer Society. The P-PA-IA strategy is a result of broad discussions within the Society and the informed public. It aims to react to the current state of and situation in healthcare and social services. However, first and foremost it reflects the needs of patients with dementia, differentiated by the stage of its progression.

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## **1. Dementia, Alzheimer's disease**

There are currently 140,000 people with dementia in the Czech Republic (of those, 30% are in the stage of mild dementia, 30% in the stage of severe dementia, and 40% in the stage of moderate dementia). Each of them is cared for and helped by 2 to 3 family caregivers (approximately 350,000 people). This number is further increased by another approx. 160,000 people with mild cognitive impairment, i.e. the state of incipient dementia common predominately among the elderly. Dementia is a syndrome, a set of symptoms. Therefore, it is not a disease but the consequence of a number of different diseases, primarily neurodegenerative and vascular; among such diseases, the most frequent is Alzheimer's disease a neurodegenerative disease of the brain.

Alzheimer's disease usually affects the elderly, but there is no reason to consider it exclusively an old-age disease. Some of its forms affect younger people as well, namely the forms of the disease which have a genetic component. Although Alzheimer's disease manifests most often in an older age, the pathological changes in the brain begin already in the middle age – 10 or even 20 years before the first symptoms become apparent. Besides the impairment of cognitive functions (thinking), dementia includes other sets of problems, especially the lack of personal self-reliance and various other mental problems, including certain behavioural disorders usually resulting from impaired cognitive functions.

The course of dementia is modified by the premorbid personality of the patient, comorbidity and especially the disease causing the dementia. In the most common

cause of dementia, Alzheimer's disease, these are chiefly memory problems, which are often noticed by the patients' families and friends or represent a hindrance in their lives. Aside from memory problems, other symptoms such as disorientation and language impairment – "searching" for words, forgetting terms – gradually appear. Work in a new environment and with different tools and instruments etc. may cause further difficulties. Soon afterwards the impairment of thinking, judgement, planning and organising of certain activities may appear.

The care for patients with dementia depends on the progression of the individual stages of dementia. In the first stage, patients are essentially self-reliant and require only support and advice, as they are confronted with a grave diagnosis. They have to make decisions concerning their future. In the next stage of dementia, disorientation appears and self-reliance becomes limited. As a consequence, the patients require supervision and assistance in many daily activities. With adequate care, however, their quality of life remains good. In Alzheimer's-induced dementia, this stage may last for several years. In the stage of severe dementia and in the terminal stage, the patients require nursing and assistance in almost all of the daily self-maintenance activities. They become fully care-dependent.

People with dementia undergo changes as the syndrome progresses, their self-reliance becomes limited and new complications, such as behavioural changes, appear. Either way, it is important to keep in mind that the patient is still the same adult person with feelings, relationships and needs. Whatever the person's behaviour is, they must be respected as adults at any point of care-giving. Immature treatment, humiliation and encroachment of their dignity must not be tolerated.

Proper communication is always a good starting point and a pre-condition for good relationships and cooperation. In communication with patients with dementia, it is important to accept them, respect them and support their dignity. Empathy and insight into the situation of the patient with dementia is crucial. Many misunderstandings arise in situations which the patients with dementia do not understand. This means that it is necessary to patiently listen and follow their verbal and non-verbal communication and react to them adequately. Aside from the need for adequate communication, the patients have many other needs, including the need for professional health- and social care and assistance appropriate to the stage of their disease.

Dementia represents a serious societal problem in terms of organisation of services and the costs of care. While patients with somatic problems may remain in their home environment for a long time, patients with dementia often require institutional care. Our experience and the results of our research show that a majority of institutionalised people suffer [1] from dementia and that the percentage of people with dementia is continually increasing [2]. Patients with dementia are among the most frail and vulnerable. It is therefore in the interest of the Czech Alzheimer Society to contribute as much as possible to the improvement of the quality of care. The Society accomplishes this through raising awareness among the general public and especially by producing and providing documents which can serve as the basis for improvement of the quality of care for patients with dementia.

## 2. P-PA-IA strategy

Czech Alzheimer Society's P-PA-IA strategy attempts to identify the needs of patients with dementia in the individual stages of the syndrome's progression. The P-PA-IA strategy is a result of broad discussions within the Society and the informed public. It reacts to the current state and situation of healthcare and social services. However, first and foremost it reflects the needs of patients with dementia, differentiated by the stage of its progression. The P-PA-IA strategy was revised last year and published as a part of a professional advice [3]. The principles of the P-PA-IA strategy inform the "Vážka" certification system for facilities providing services to people with dementia [4].

My presentation introduced the P-PA-IA strategy as an essential and "living" document which is being continuously discussed and revised according to the current state of care for patients with dementia and the applicable legislation. The same goes for the certification system which is also being regularly revised. In the following part, I present excerpts from the P-PA-IA strategy which I believe are of crucial importance. The whole text of the P-PA-IA strategy as well as other reference materials for the improvement of the quality of care (Vážka certification) are available at [www.alzheimer.cz](http://www.alzheimer.cz).

"The starting point in providing appropriate support and care for people with dementia in any stage of the syndrome must always be a correct diagnosis, determination of the type and stage of dementia, assessment of the functional status, and a decision concerning the potential treatment.

Modern **pharmacotherapy** makes it possible to slow down the progression of the disease and preserve both self-reliance and a good quality of life for a certain period of time. Correct pharmacotherapy and titration, especially of cognition enhancing medication, can also minimise problematic behaviour. Psychosocial interventions and **non-pharmacological approaches** helping to maintain the quality of life and self-reliance as well as prevention and mitigation of the patient's behavioural disorders are an inseparable part of the comprehensive care for people with dementia. They make it possible to reduce or eliminate the use of tranquillising medication, especially antipsychotics, the side-effects of which may be dangerous for the patients. Ensuring an **adequate supportive and secure environment** is also a part of the non-pharmacological management of the disease.

The majority of care takes place in the family environment, where it is provided by family members who require financial help (currently the allowance for care) as well as other services and **support** to be able to perform this very important role as long as possible. It is important to have sufficient information concerning the disease, services, possibilities of help, the allowance for care and so on.

If home care is not an option, it is necessary to provide for services corresponding to the state and progression of the disease. Dementia-inducing diseases, especially degenerative diseases (e.g. Alzheimer's disease), are terminal, i.e. they shorten and prematurely terminate the patient's life. It is therefore necessary to pay appropriate attention to palliative care which is required for patients in the advanced and particularly in the terminal stages of dementia.

It is important to stress that if care is provided in facilities, it is necessary to adjust the environment to the needs of people with dementia and to have qualified personnel in place who are trained and well-informed about dementia-related issues. The envi-

ronment, equipment and personnel are, to a large extent, complementary – in places where the environment or the equipment is insufficient, the number of personnel must be increased.

Co-operation with the family and the support for family members is important even if the patient with dementia is placed in an adult day care centre or in a residential treatment centre, whether for a short- or long-term. The family members remain important partners in care. Communication with the family is as important as the communication with the patient with dementia. Providing information and care training is a necessary prerequisite for its future continuity and quality. Relatives of the patient with dementia are also affected by the disease, although in a different manner, due to the changes in family roles, competences and the financial costs of the care, as well as a score of other problems. Considerable work load on the caregivers emerges especially in cases of dementia-related behavioural disorders. The relatives of the patient are therefore not only partners in care, but in case of development of behavioural disorders and increasing demands for care they too require support and assistance from a team of professionals or from supportive self-help groups of family caregivers.”

### **3. Description of the individual stages of dementia according to the P-PA-IA strategy**

The acronym P-PA-IA denotes the individual stages in the progression of dementia which are related to specific demands for care and support. “P” denotes the first stage requiring chiefly support, psychological assistance and advice (Czech: podpora, psychologická pomoc a poradenství). “PA” is an acronym for scheduled activities (Czech: programované aktivity) which are needed mainly in the second stage. “IA” denotes individual assistance (Czech: individuální asistence) needed in the third stage, i.e. in the stage of advanced dementia. Provision of the particular types of care depends on the needs of the people with dementia in the different stages of their disease.

#### **3.1 Stage P-PA-IA 1 (early and mild dementia)**

This stage is characterised by the relative self-reliance of the patients, who require some degree of supervision and assistance, but only on an intermittent basis.

Based upon medical examination (medical history, cognitive functions tests, clinical and laboratory examinations and medical imaging of the brain) a diagnosis of dementia and its likely underlying cause is determined. The memory and other cognitive functions are typically affected and non-cognitive symptoms (behavioural changes, depression, etc.) may or may not appear in the individual types of dementia.

Relatively high self-reliance (with some degree of assistance and provision of services) and activity are typical features of this stage of dementia. The patient may for instance live alone for certain parts of the day or week provided that day care or occasional supervision and assistance from family members, neighbours or friends, telephone consultations, various instructions and reminders which the patients understand, etc., are available. The patients usually perceive the changes of their condition and are aware of their difficulties which leads to depression and feelings of anxiety. This stage corresponds approximately to stages 2 to 4 on the Reisberg scale.

### **Needs of patients in the P-PA-IA 1 stage:**

**The need for an early and correct diagnosis, introduction of appropriate pharmacotherapy, if indicated, and acquaintance of the patient with the probable prognosis** for the disease. The physician needs to convey the diagnosis with enough attention and time. The physician must be able to answer questions asked by patients or their accompanying family members, and be able to recommend further steps (follow-up services – a psychologist, social worker, etc.).

**Planning of future treatment and care with the assistance of the physician (previously expressed wishes).** In this stage of the disease a person suffering from dementia can decide about further steps in case the disease progresses. They should be informed enough to be able to express their wishes concerning future treatment and care with which they wish to be provided. It is very important to provide information to the patients and their relevant family members concerning the late stages of dementia. Deciding about nutritional support, treatment of complications, or resuscitation care can be facilitated to a large degree through the institute of previously expressed wishes. Mutual trust and open communication between the examining physician and the patient with dementia and his or her family members is necessary for these wishes to be formulated. Section 36 of Act No. 372/2011 Coll., on healthcare services, prescribes that these wishes must be expressed in writing with the patient's authenticated signature. Previously expressed wishes must also contain a written advice of the patient.

**Legal matters.** In this stage of a dementia-inducing disease, the patient should be sufficiently informed in order to be able to settle important matters and make those decisions which he or she will not be able to make in the later stages of the disease.

**Support, psychological assistance and advice:** Finding out the cause of the existing problems and the diagnosis of dementia brings about the need for support and advice (for instance from the Czech Alzheimer Society) and professional psychological assistance for the patient. The basis of the assistance includes the sharing of problems, support in maintaining of social roles, integration of the person with early dementia into social life, training of cognitive functions and other forms of support for better health (wholesome and tasty foods, exercise).

## **3.2 Stage P-PA-IA 2 (moderately advanced and advanced dementia)**

This stage of dementia corresponds to the possibility of and need for provision of care in adult day care centres and residential care facilities. This stage lasts about 2-10 years in Alzheimer's disease and is accompanied by limited self-reliance, disorientation, the need for assistance in individual daily tasks and the need for permanent supervision. People are capable of performing various tasks, especially those which they have performed routinely for their whole life. In many aspects, the quality of their life remains good or very good, they enjoy particular activities, situations or facts which they perceive and experience and they communicate more or less satisfactorily. These people are happy to participate in a meaningful daily programme and benefit from it. Serious behavioural disorders (restlessness, agitation, resistance to care) or other psychiatric symptoms (e.g. hallucinations) are not usually present (or they are of manageable and transient character). Spontaneous aggressiveness is rarely present in people with dementia. More commonly it represents rather a defensive reaction to specific situations

which with the people perceive as incomprehensible, unpleasant or even threatening. A disapproving or even aggressive reaction may be triggered or magnified by discomfort they feel, for example, as a result of the caregiver's handling, unmanaged pain, etc. This stage corresponds to stages 4 to 5 on the Reisberg scale.

The placement of patients with dementia in a facility must not occur without their consent as indicated by a signature (consent to hospitalisation, signature on a contract for provision of social services). The consent should be reflected also in the person's behaviour and cooperativeness. This is facilitated by careful preparation for the transfer into the facility (planned by an interdisciplinary team including a physician, community nurse, social worker, psychologist and the family), communication skills and an unceasing effort to gain the trust of the person with dementia. The same procedure applies if the person has a legal representative (guardian). The process of dealing with potential clients and the conclusion of a contract for provision of care is regulated by Act No. 108/2006 Coll., on social services. At present, the Act does not take into account situations when a person with dementia refuses to move into residential care or another social service (they may analogously refuse health care at home). These are very difficult situations which need to be dealt with on an individual basis and which require co-operation between the physician, family, social worker and the social service. The so-called behavioural disorders in patients with dementia are often a sign of their disapproval with their stay in the residential care facility or with the way they are treated. They may be prevented through a good quality of the care provided and a person-oriented approach.

If hospitalisation of a person with dementia is absolutely essential (they seriously endanger themselves or people in their vicinity, or their medical condition calls for immediate provision of care) and the patient refuses it during admission or at any later time, the situation needs to be resolved in accordance with the applicable legal regulations (the detention proceedings in healthcare facilities, Sections 38 to 40 of Act No. 372/2011 Coll., on healthcare services, which provide for hospitalisation and provision of health care without the patient's consent, using means of restraint).

People in this stage of dementia benefit from a **regular and structured daily schedule** and from participation in activities according to their individual abilities. This kind of a structured and regular schedule leads to a certain order in care, which is beneficial for them as it brings: interest in purposeful activities, reinforcing of the preserved abilities and self-reliance, quality of life and support for dignity, and maintaining of a normal diurnal cycle where the day is filled with activities while the night is spent resting. A regular and predictable structure of the day, maintaining of a natural daily rhythm and the corresponding offer of activities for a person with dementia are useful also for the caregiving family members, who are thus able to provide care in a home environment for as long as possible.

In institutions, permanent care for patients with dementia includes activity programmes, which allow involving several people at once. Daily activities are the basis of a regular daily structure which aims at creating conditions for undisturbed nightly rest for all the residents.

Although the activities and the structure of the day in residential care facilities will be touched upon later, it is necessary to stress that care should be oriented towards the individual patients with dementia and meeting *their* needs, not towards the per-

formance of the ward (i.e. maximising the offer of various activities). The individual activities and the structure of each day should be understood as means of improving the quality of the patients' life, not as the goal of the care.

**Scheduled activities** are activities which fill the person's day with individual tasks with the aim of maintaining the person's self-reliance. These include especially self-maintenance activities (morning and evening toilet use, regular meals) and other activities which improve the quality of the person's life and fill the day. Also included are non-pharmacological approaches and psychosocial interventions which, based on scientific evidence, can reasonably be expected to have a positive effect on maintaining self-reliance, physical condition and on prevention of behavioural disorders (e.g. kinesiotherapy, walks, cognitive rehabilitation, sensory stimulation, reminiscences and others).

Meals and dining at the table are important milestones during the day, a pleasant experience and an opportunity to engage in community activities and social interaction. The preparation and serving of meals must be treated as a serious matter. Food should be individualised according to the preferences and abilities of the clients, thus supporting their self-reliance and dignity, for example through the manner of serving the food. Aside from providing for sufficient nutrition, food has a number of other personal, social and cultural meanings. This should be reflected in the attention given to food & eating with respect to care of people with dementia. The above-mentioned activities may also take place in day care centres which people with dementia attend on daily basis, accompanied on the way by their relatives or professional caregivers.

In care facilities, it is necessary to create a suitable care environment (similar to home environment) and ensure technical equipment and aids as well as adequate staffing (for more details see the Recommendations of the Czech Alzheimer Society and Vážka® Certification Resources).

### **3.3 Stage P-PA-IA 3 (severe dementia, dementia complicated by behavioural disorders or somatic problems and the terminal stage) with the need for provision of health (health-social) care, long-term care and palliative care.**

This category includes patients advanced and severe stages of dementia and forms of dementia aggravated by behavioural disorders (stages 6 and 7 on the Reisberg scale).

People in this stage of dementia benefit from **individualised assistance and activities specific to their needs**. Their condition has deteriorated so much that they are unable to take part in the scheduled activities regimen, or such participation is no longer beneficial to them as it becomes too taxing and leads to discomfort. The dementia-causing disease has advanced so far that these people benefit rather from a tactful individualised care and assistance in those self-maintenance activities which they can still perform. A significant reduction in verbal communication occurs at this stage of dementia, presenting challenges to the ability of the staff to maintain communication with persons with dementia, communicate with them non-verbally and be able to understand them. Furthermore, the ability to competently analyse the causes of problem behaviour, which may be caused by a somatic disorder (pain, discomfort, dehydration, constipation, urinary retention, etc.), is crucial. Mobility becomes impaired and, therefore, the patient needs a tactful and qualified rehabilitation, or alternatively

appropriate positioning in order to prevent painful contractures. Basal stimulation can also be useful. Due to frequent swallowing disorders, caregivers' attention is needed to ensure proper ingestion of food, nutrition and hydration. Overuse of PEG (stomach tube feeding), permanent catheterisation and other "medical procedures" which may in effect result in patient discomfort should be avoided.

Nevertheless, taking part in daily activities, or at least being present at them, may be useful even for people in this stage of the disease, but only if they consent to and benefit from this.

It is clear from the above description of the problems related to this stage of dementia that facility care cannot be provided without a permanent (24-hour) presence (or availability at night) of qualified medical staff – independent nurses trained in handling dementia patients. A physician should also be available at all times.

Even in this stage of dementia, the stay in a facility providing care for the patients must be exclusively voluntary. These persons can express their consent through their behaviour, by showing signs of satisfaction, which can be documented in the records. In case of hospitalisation that is not approved of by the person with dementia (expressed through his or her behaviour) or the stage of dementia is too advanced to determine consent with the stay in the healthcare facility from the patient's behaviour, and where the stay is necessary considering the medical condition of the person (they endanger themselves or people in their vicinity), detention proceedings are initiated through a notification given without delay to the court. The procedure is the same as in P-PA-IA 2 (see the relevant part, Sections 38 to 40 of Act No. 372/2011 Coll., on healthcare services)."

## 4. Conclusion

In 2006 the Czech Alzheimer Society formulated its Strategy P-PA-IA, Care for and Support of Persons Suffering from Dementia Syndrome, according to the specific needs of patients in different stages of dementia. This strategy is based on a broad discussion of experts and professionals and informal caregivers in the Czech Alzheimer Society and other institutions and organisations that were dealing with the issue of quality of care for patients with dementia at that time. Later, the P-PA-IA strategy was discussed also on the international level with representatives of Alzheimer Europe and within the framework of the ELTECA (Exchange of Experience in Long-term Care) working group. The Office of the Public Defender of Rights working group was among our important partners in this country. The P-PA-IA strategy has served as the basis for indicators of quality of care for persons with dementia, which today form a comprehensive system, and a reference point for the system of quality certification of wards and facilities providing care to people with dementia according to the principles and opinions of the Czech Alzheimer Society (the "Vážka®" certificate). The strategy was revised again in 2013, following yet another broad discussion within the Czech Alzheimer Society and with the professional public. For many years this document has remained the basis of advocacy and improvement of the quality of care in the Czech Republic. I chose to present this strategy, because it represents a truly "living" document comprising not only the current trends in providing care, but it also takes into account the up-to-date

legislative and economic realities in the Czech Republic, similarly to the “Vážka” certification of quality.

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# Management of Behaviour Disorders Connected with Dementia

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## Keywords

Dementia, behavioural disorders, prevention, relationship care

## Abstract

The author presents and defines the term “relationship care” as a way towards good individual service without behavioural disorders. With respect to managing behavioural disorders, the author stresses the need for looking for causes and prevention based on the knowledge of the client’s normality and its reinforcement.

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## 1. Behavioural disorders and their management

*Relationship care* is the answer to behavioural disorders in clients. It stems from the knowledge of the recipient of the care. In order to obtain this knowledge, it is necessary to follow and map the rituals, needs and interests of the person; to work with the person’s life story (history, biography). This results in correct mapping of the range of the necessary support (do not overcare, do not neglect) and the arrangement of the service – commission with the clients or their family. It is then evaluated whether the expectations of the commissioned service are met.

### 1.1 Looking for causes

How can we find possible solutions to behavioural disorders of a person with dementia? We need to be creative, look for all the **whys** which have led to the problematic situation. We should start from the “normality” of the client. We should not expect his or her adaptability.

We should avoid conflicts in all circumstances. We should strive to maintain calm and equanimity. Fretting will only make the situation worse. We respond calmly to accusations. We should avoid getting angry.

We should never forget that the cause of this behaviour is the disease and that it is not the fault of the patient! The accusing person usually feels fear. The person does not know what is happening to him or her. Action, fight and self-preservation come to the fore; it is better to attack than to be attacked. The client may be trying to limit his or her personal space or deal with phobias he or she can no longer name.

## 1.2 Prevention

The attacker's behaviour should be observed and documented, including any attack against the staff, any form of situation management or conflict resolution with the family or other colleagues or a physician.

Attempts should be made to calm the client down verbally and isolate him or her; then notify the nurse and call the emergency medical services. All attacks by a client should be reported to the nurse, whereas the key worker (co-ordinator) informs the family. If the client's aggressiveness proves to be unmanageable in a social services facility and it cannot be mitigated by medication or any other approach, the client needs to be transferred to another facility based on a decision of a physician. It is important to defend oneself without harming the client; the staff can be trained in useful defensive grips.

Each successful problem management is an achievement while each failure is an invitation to a change in the procedure. We should appreciate and reward ourselves.

## 2. Principles of dealing with clients suffering from dementia

We act in a way enabling the client, to the greatest possible extent, to:

- Be perceived as an adult, not a child, during all handling by the staff.
- Be taken seriously when expressing his or her feelings.
- Not to be treated with psychotropic substances if possible.
- Live in a secure, comprehensible and predictable environment.
- Enjoy everyday activities which give life a meaning. Have an opportunity for regular outings. Feel personal contact including embraces, caresses and holding of hands. Be useful in work and entertainment as long as possible.
- Experience more normality, i.e. that which is natural to the client.
- Feel their dignity being respected.
- Be restrained-protected to a bearable degree.
- Have staff always present.

## 3. Conclusion

Evaluation of the residential service through inspections is perceived by the providers as burdening and stressful. Massive paperwork will not lead to greater satisfaction with the commissioned service.

What can be done? Look for solutions in experience, finances and changes in the system of provision of care. Let's look together for possible solutions for reduction of the administrative burden in our country. Training and education of staff in direct care is a serious challenge for the Czech education system, having been left without comprehensive solutions in the previous two decades.

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# Non-regular Use of Medication with Tranquilizing Effect in the Practice of Social Service Facilities for Seniors

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## Keywords

Medication, the elderly, restlessness, aggression, restrictions

## Abstract

Many clients in social facilities for the elderly who suffer from dementia have been prescribed medication for cases of restlessness or aggression; it is therefore not a regularly administered medication. Although the purpose of the administration is often to restrict the client's movement, such administration of the tranquillising medication (sedatives) is not considered a measure restricting the freedom of movement by the facility. The Public Defender of Rights is critical of prescriptions indicating only "in case of restlessness" or "as needed". In such cases the medication is de facto prescribed by the nurse in the facility, not a physician. A suspicion may also easily arise that medication is used unlawfully as a measure restricting the freedom of movement.

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## 1. Regular visits in social care facilities for the elderly

As part of her function as the national preventive mechanism in the Czech Republic, the Public Defender of Rights carries out "preventive visits", a form of inspection in facilities where persons are or may be restricted in their freedom.<sup>1</sup> The reason for the restriction may be either a decision of a public authority or dependence of the person on the care provided.

In 2013 the Defender initiated a long-term project of visits in residential facilities providing care to senior citizens, especially those suffering from dementia. Last year, a total of 14 social services facilities, i.e. retirement homes and special regime homes, were visited.

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<sup>1</sup> This is the realisation of the international legal obligation of the Czech Republic which arose from the ratification of the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Communication of the Ministry of Foreign Affairs No. 78/2006 Coll. of International Agreements).

## 1.1 Risks associated with improper administration of tranquillising medication

During visits in these facilities, the Defender always focused on the manner of use of medication, especially sedatives. There is a number of reasons for this.

Improperly administered sedatives may represent a serious risk for the health or even the life of the patient. They may represent an encroachment of the fundamental rights and freedoms of the client, either as a restriction of personal freedom, violation of human dignity or the right not to be subjected to ill-treatment. Improper administration of sedatives may also represent a measure restricting the freedom of movement and it is therefore necessary to monitor compliance with Section 89 of Act No. 108/2006 Coll., on social services, as amended (hereinafter also the “Social Services Act”).

## 1.2 Ethical aspects of the administration of sedatives to persons with dementia

Administration of sedatives to persons with dementia is closely related to certain ethical questions, which arise even in cases where medication is correctly administered.

Administration of sedatives without an informed consent of the person with dementia infringe on the patient’s autonomy of will. Some authors compare the use of sedatives to a ‘chemical straitjacket’. Sedation prevents persons with dementia from expressing their wishes and the caregivers can then decide for them. Such a situation is more convenient for the latter, but it is ethically unacceptable [3]. Administration of sedatives sometimes negatively affects the ability of the person to communicate with others, which can have a negative impact on their ability to maintain personal relationships. An extreme case, the concealment of sedatives in food or drink (covert medication), represents a fraud or a betrayal of trust. Some sedatives also have serious side effects [1].

Therefore, due attention should be paid to use of medication.

## 2. Distinguishing measures which restrict the freedom of movement

Administration of sedatives to the client on an irregular basis falls into one of two possible cases: it is either a measure restricting the freedom of movement according to the Social Services Act or it involves irregular administration of medication based on prior exact orders of the physician for a particular situation (see below). These two situations need to be carefully distinguished.

It is self-explanatory that administration of medication amounts to a measure restricting the freedom of movement if the purpose of the administration of the drug is to restrict the client’s movement (walking, getting up from bed or chair, touching objects or persons, etc.). If the drug is administered due to the client’s aggressive<sup>2</sup> behaviour,

<sup>2</sup> Volicer uses the term resistiveness to describe aggressive behaviour of persons with dementia. This means that clients may respond aggressively to certain situations due to a lack of comprehension and understanding. For example, the patient does not understand why a certain act has to be performed within the provision of care. However, he believes that it is wrong to label such behaviour as aggressiveness, because it is actually the caregiver who is seen as the aggressor by the client [12].

it always constitutes a measure restricting the freedom of movement too, because the purpose is to sedate and restrict the client. It is inconsequential whether a physician prescribed the drug “in case of aggression” or other ad hoc situations. Regardless of this, the administration of the drug will be considered a measure restricting the freedom of movement and the requirements stipulated in the Social Services Act will have to be met [10].

## 2.1 What can be used as means of restricting the freedom of movement

The use of restrictive measures in medical facilities is regulated in Act No. 372/2011 Coll., on healthcare services and the conditions for their provision (the Healthcare Services Act), as amended (hereinafter the “Healthcare Services Act”). However, social services facilities are subject to a somewhat different legal provision contained in Section 89 of the Social Services Act.

The difference lies chiefly in the kinds of measures that can be used with respect to the client (patient). In social services facilities these include only grips,<sup>3</sup> placement of the person in a safety room<sup>4</sup> and the administration of sedatives.

Restricting the client’s movement by other means is not allowed in social services facilities. However, locking the unit or building where persons with dementia are kept does not constitute a restrictive measure. This applies only if persons with a good awareness or clients not suffering from dementia can freely enter and leave the facility. Permanent presence of staff in the enclosed environment and on-request stays outside the facility as a part of the client’s daily programme are also required [7].

## 2.2 Statutory conditions for the use of medication as a measure restricting the freedom of movement

### 2.2.1 Prevention duty

The provider of social services must, first and foremost, avoid situations in which the use of measures restricting the freedom of movement would be necessary. This is stipulated in Section 89 (4) of the Social Services Act. In order for this duty to be effectively fulfilled, the provider must look for causes of the problem behaviour (pain, discomfort, side effects of medication, bad caregiver-patient relationship, depression, other disease, etc.) and try to prevent them [6], for example through the use of non-pharmacological methods, psychosocial interventions and suitable changes to the environment [8].

### 2.2.2 Direct threat to life and health

In Section 89 (1), the Social Services Act stipulates that *“in the provision of social services, measures restricting the freedom of movement of persons who are being provided with these services cannot be used, except in situations of direct threat to their health and lives or the health and lives of other natural persons.”*

<sup>3</sup> It is irrelevant whether the client is gripped by a person trained to this end or not. If clients are prevented from moving by members of the staff who are holding them, this is considered a measure restricting the freedom of movement.

<sup>4</sup> The prerequisite for the use of this measure is that the facility in question has such a room. Locking clients in their rooms does not fall under this category.

Direct threat to life and health is a relatively high threshold. This is because the use of restrictive measure inflicts serious consequences on the client (see part 1.1). Restrictive measures should therefore not be used routinely but only in very serious circumstances when the life or health is put in danger. In other words they should only be used when absolutely necessary.<sup>5</sup>

Other rules follow from this statutory condition. Firstly, preventive use of measures restricting the freedom of movement, i.e. their use in situations where life or health is not being put in danger, is not acceptable. Secondly, mere “restlessness”, no matter what is considered as such, is not a reason to use measures restricting the freedom of movement.<sup>6</sup>

### **2.2.3 Use for the necessary period of time only**

The above-mentioned Section 89 (1) also stipulates that measures restricting the freedom of movement can only be used for the necessary period of time required for the elimination of the danger to the health and life of the client or the life of other persons. This precondition is not relevant solely to the use of physical grips and placement in safety rooms. Medication must also be administered only for the necessary period of time and in the lowest possible doses [9].

### **2.2.4 Ineffective use of other measures**

The ineffective use of other (non-pharmacological) measures to prevent the person’s behaviour endangering his or her health and life or the health and life of other natural persons constitutes another statutory condition for the use of measures restricting the freedom of movement. The law stipulates in Section 89 (2) that the provider is obliged to first attempt to calm the client verbally and by other means, e.g. diversion of attention, distraction, or active listening.

## **22.5 Provision of information to clients**

The provider of a social service (or its employees) must appropriately inform the client that he may be subjected to a measure restricting the freedom of movement before its actual use.

### **2.2.6 Presence of a physician**

Under the Act, administration of medicinal products is allowed only on the basis of physician’s orders and in his or her presence. Therefore, a nurse may not administer drugs based solely on prior orders of a physician or a telephone consultation with the physician.

In case of extraordinary circumstances requiring immediate solution, the law allows paramedical professionals in healthcare facilities to indicate measures restricting the freedom of movement under the condition that a physician must be informed without delay and confirm the justification of the use of such measures (Section 39 (3) (d) of

<sup>5</sup> With respect to the necessity to use restrictive measures in connection with the right not to be subjected to ill-treatment, see for example judgement of the European Court of Human Rights of 24 September 1992 in case *Herczegfalvy v Austria*, Application No. 10533/83, para 82.

<sup>6</sup> With respect to the unacceptability of use of restrictive measures due to mere restlessness, see judgement of the European Court of Human Rights of 18 October 2012 in case *Bureš v the Czech Republic*, Application No. 37679/08, paras 95–96.

the Healthcare Services Act). Analogous procedure is not permissible in social services facilities where the Act stipulates that administration of sedatives must always be indicated by a physician who is physically present in the facility.

It is a common objection that it is impossible to provide for a non-stop presence of a physician in these types of facilities, i.e. that this condition cannot be met. However, situations where a client with dementia needs to be restrained and sedated should arise rarely; by no means should this be a normal occurrence. Facilities should first and foremost look for the causes of the problem behaviour and attempt to remedy them (see part 2.2.1.) in co-operating with the client's examining physician. If a behavioural disorder occurs, it should first be treated using non-pharmacological means (see part 2.2.4.); only then can a deliberate use of medication be pursued.

### **2.2.7 Duty to inform the legal guardian**

Should a measure restricting the freedom of movement be used against a client with diminished legal capacity, the provider of social services is obliged to inform the person's legal guardian without undue delay (Section 89 (5)).

### **2.2.8 Keeping records**

Finally, the Act stipulates that the provider of social services is obliged to keep records of instances of uses of measures restricting the freedom of movement and to provide access to these records to the person subject to the measures or to other persons listed in the Act (guardian, close person, founder of the facility, physician, members of the inspection team, the Public Defender of Rights, etc.).<sup>7</sup>

## **2.3 Non-observance of statutory conditions**

Failure to observe the statutory conditions concerning the use of measures restricting the freedom of movement is an administrative offence investigated by the Inspectorate of Social Services. A fine up to CZK 20,000 may be imposed in case of breach of the duty to inform the client's legal guardian of the use of restrictive measures or in case of failure to keep records. A fine up to CZK 250,000 may be imposed for use of measures restricting the freedom of movement at variance with the principles set out in Section 89 (1) to (3)<sup>8</sup>.

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<sup>7</sup> Pursuant to Section 89 (6), documentation should be kept in the following scope:

- a) name(s), surname and date of birth of the given person;
- b) date, time of commencement and place of use of a measure restricting the freedom of movement of persons and type of the measure;
- c) reason for the use of the measure restricting the freedom of movement of persons;
- d) name(s) and surname of the person who used the measure restricting the freedom of movement of persons;
- e) administration of medication as a measure restricting the freedom of movement of the given person;
- f) date and time of end of use of the measure restricting the freedom of movement of persons;
- g) description of the situation immediately preceding the use of the measure restricting the freedom of movement of persons, description of the situation of use of the measure, its assessment and description of the situation immediately following the use of the measure;
- h) record of fulfilment of the obligation provided for in paragraph 5;
- i) description of any injuries caused to persons during the use of the measure restricting the freedom of movement of persons;
- j) description of the manner of informing the given person under paragraph 2.

<sup>8</sup> Restriction of movement of clients in situations other than direct threat to life and health, use of restrictive measures for longer than necessary, failure to try other measures, administration of medication without a physician being present.

## 2.4 The Defender's findings from the visits in facilities

While visiting social services facilities for persons with dementia, the Public Defender of Rights has criticised, in relation to the use of sedatives as measures restricting the freedom of movement, for example blank forms for the use of restrictive measures which were pre-signed and pre-stamped by a physician. This created room for evasion of the law and arbitrary use of sedatives by the paramedical staff.

The Defender has also criticised insufficient documentation related to the use of measures restricting the freedom of movement. Risks were not systematically evaluated in the clients' individual plans and no records were kept on particular forms of behaviour, which could then serve as a resource to the physician. This is connected with the problem of failure to search for the causes of problem behaviour, or negligence in the prevention of use of measures restricting the freedom of movement (see part 2.2.1).

Administration of sedatives by the staff in order to restrict the client's freedom of movement without the presence of a physician was also often criticised. The Public Defender of Rights has also encountered instances of administration of medication by the facility's paramedical staff.

## 3. Irregular use of sedatives on the basis of prior orders of a physician

Irregular administration of sedatives does not necessarily constitute a measure restricting the freedom of movement. In many cases the clients do not need to take the given medication regularly. Nevertheless, cases of restlessness may occur which do not represent a danger to health or life and thus do not give a valid reason to restrict the client's freedom of movement.

Situations may arise where clients need to be relieved of a certain unpleasant condition (restlessness, insomnia, anxiety, etc.) that seriously reduces the quality of their life. A physician who is acquainted with the medical condition of the client may foresee the occurrence of such conditions and prescribe appropriate medication in advance. Therefore, if medication is administered under such circumstances it does not constitute a measure restricting the freedom of movement and the medication in question may be administered by a nurse without the presence of the physician. However, it is absolutely necessary that the physician exactly specify in the prescription those situations occurring as a manifestation of the client's condition for which the given medication is prescribed [11].

Nevertheless, the causes of the restlessness (agitation) and ways of eliminating them should be sought primarily. Holmerová et al. believes that the available non-pharmacological solutions should be considered first in all cases, while the elementary steps in this process always include: 1. identification of the problem behaviour, 2. determination of the cause, and 3. taking measures in care, communication, approach, or environment which will mitigate or eliminate the problem behaviour [4].

### 3.1 Criticism and recommendations of the Defender

The two situations, i.e. the use of drugs as measure restricting the freedom of movement and the administration of drug based on prior prescription by a physician, must

be carefully distinguished. As Holmerová et al. notes, any sedative can be used (and misused) as a restrictive measure [5]. During visits in social facilities for elderly people, the Public Defender of Rights encountered several cases of suspicion that medication, albeit prescribed by a physician in advance, had been used as a measure restricting the freedom of movement at variance with statutory conditions.

### 3.1.1 Vague prescriptions

The Public Defender of Rights found problems with vague prescriptions of sedatives for *ad hoc* situations in 13 out of 14 social services facilities for the elderly visited in 2013. Vague prescriptions do not clearly state when the medication should be administered by the nurse. Prescriptions containing formulations such as “as needed” or “in case of restlessness” are a typical example of this problem. The following physicians’ orders can be shown as examples:

- “Mild restlessness – Tiapridal 1 amp IM, severe restlessness – Tiapridal 1 tab.”
- “Mild restlessness – Prothazin 1 tab, severe restlessness – Tisercin 1 amp IM.”
- “In case of restlessness Tiapridal 1 x 30 ml, 5-5-0 as needed.”
- “Tisercin 1-2-2 in case of restlessness.”
- “Apaurin 1 amp IM in case of restlessness, dosage as needed.”
- “In case of restlessness and insomnia, administer Tisercin 1 tab p.o. (or 1 amp IM), Diazepam rectal tube 10 mg.”

Restlessness is an extraordinarily vague term which manifests differently with respect to the medical condition of individual clients. If medication is prescribed “in case of restlessness”, it is not clear when exactly it should be administered. In effect, the medication is prescribed by the attending nurse instead of the physician. This poses a problem since she is not authorized to do so.<sup>9</sup> Facility staff are also much more involved in the care of the clients and thus their decisions may be unduly influenced by their own needs instead of the needs and interests of the clients [2]. By issuing vague orders, the physician is unacceptably and unreasonably delegating responsibility for decisions and their possible consequences for the medical condition of the client to the attending nurse. Unclear prescriptions such as these also create considerable room for misuse by the facility staff. A suspicion may easily arise that an administration medication, albeit prescribed by a physician in advance, constituted a measure restricting the freedom of movement at variance with the Social Services Act.

Clearly, the physician bears the greatest share of responsibility for issuing poor sedatives prescriptions. However, in the end the drug is administered to the client by the social services facility staff. The Public Defender of Rights recommends to the facilities to insist on exact and precise orders, i.e. that the physician state the specific situations for which the irregularly used medication is prescribed. In other words, the prescription should contain a clear definition of the client’s “restlessness”. If the facility performs its duty under Section 88 (1) (f) of the Social Services Act, i.e. it keeps records on the course of provision of care, it should be easy to ascertain from the client’s documentation the

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<sup>9</sup> It follows from Section 4 (3)(a) of Decree 55/2011 Coll., on activities of healthcare workers and other professionals, as amended, that a general registered nurse may only administer medicinal products based on a physician’s prescription.

manner in which restlessness manifests in his or her case. The physician's prescription should then correspond to this description.

### **3.1.2 Incomplete or ambiguous prescriptions**

With respect to prescriptions of tranquilliser drugs and sedatives administered *ad hoc*, the Public Defender of Rights has further encountered missing indication of the medication potency, form, dosage and the possibility of repeated administration after a certain time period. The Defender has further criticised prescriptions containing considerable ambiguity as to which medication should be administered by the nurse ("*Tisercin in case of restlessness, Prothazin in case of restlessness and insomnia, Tiapridal in case of insomnia*").

In this case too, the primary responsibility is also borne by the physician. However, the Public Defender of Rights recommends that the facilities insist that the physician indicates precisely which medication has been prescribed (potency, form), the dosage of the medication and how often can the medication be administered in a given time period.

### **3.1.3 Failure to keep records on ad hoc administration of sedatives**

If the facilities want to avoid suspicion that a sedative might have been used as a measure restricting the freedom of movement, it is necessary to pay attention to records of administration of tranquillising medication and sedatives. The Defender primarily recommends precisely documenting the condition of the client which led to the administration of the medication, recording who and when administered a dose of the medication, and what potency and effect the medication had.

## **4. Related concerns**

The manipulation with sedatives is connected with a number of issues which can potentially present a danger to the client.

### **4.1 Hazardous storage of drugs**

The Public Defender of Rights is concerned about unsafe storage of drugs (not limited to sedatives). In some cases medication was not safely locked away and could be accessed by all, including paramedical, staff.

### **4.2 Storage of medication unassigned to a particular client**

In some facilities, the Defender has found packages of sedatives not assigned to a particular client; these were usually left over from clients who had moved out or died. If those drugs were not secured and the remaining amount of medication in the package was not recorded, a serious suspicion arose that they could have been misused to unmonitored sedation of clients.

### **4.3 Administration of drugs without a physician's prescription**

In exceptional cases, drugs were administered to the client without a physician's prescription, or administered by a member of staff who was not authorised (unregistered nurse or a social services worker).

## **5. Conclusion**

The administration of sedatives to a person with dementia carries a number of adverse consequences. Regardless of whether we speak of measures restricting the freedom of movement or not, it is always necessary to focus on the prevention of problem behaviour, look for its causes and eliminate them. When a behavioural disorder occurs, it is necessary to first attempt a solution by non-pharmacological means (excluding other kinds of restrictive measures, of course). The administration of a sedative should in no way be an automatic reaction of the staff to a specific behaviour of a client with dementia.

Some have suggested that sedatives should be removed from the list of measures restricting the freedom of movement in social services. They reason that the provisions on restrictive measures in the Social Services Act are not reflective of or suitable in the practical realities in social services facilities, and that a permanent presence of a physician is not feasible due to high workload, and so on. However, such excuses and complaints about the system are usually motivated by the desire to make one's own work easier, not by the interests of clients with dementia.

Even if such legislative changes were implemented, it would not allow physicians to arbitrarily dispose of sedatives. If the client's freedom of movement is restricted by sedatives preventively, excessively or routinely in situations where it is avoidable or for the purpose of making the staff's work easier, it will constitute a breach of law. The difference will lie only in the fact that this will not be an administrative offence under the Social Services Act; rather, an action for the protection of personal rights or criminal prosecution will have to be considered.

Hopefully, the discussion among professionals in the Czech Republic will gradually move away from the issue of physician's presence at the administration of sedative towards the ethical aspects of use of restrictive measures on people suffering from dementia.

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# Issues of Nutrition Related to Alzheimer's Disease and the Relation between Nutrition and Cognitive Functions in Persons Suffering from Dementia (Research Results)

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## **Keywords**

Alzheimer's disease; malnutrition, sipping; Mini Nutritional Assessment (MNA); Mini Mental State Examination (MMSE), nutritional support

## **Abstract**

Although opinions with regard to the metabolic changes involved in the loss of weight in patients with Alzheimer's disease still vary, the energy intake necessary for maintaining body mass is clearly higher than in general population. Recent Czech research showed that a timely initiation of nutritional support before the patient becomes malnourished can prevent secondary complications of Alzheimer's disease, slow down its progression and improve its course. It has also been proven that nutritional support does not affect the survival of the patients – it concerns the quality of the patients' life, but does not prolong life in the terminal stage.

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## **1. Alzheimer's disease and malnutrition**

### **1.1 Introduction**

Dementia results from a progressively deteriorating chronic disease of the brain the characteristic feature of which is an overall deterioration of higher cortical functions, i.e. memory, cognitive functions, sensor and motor functions, and the ability to engage in social contacts. The control of emotional reactions is also impaired and social behaviour and motivations deteriorate. However, consciousness remains completely unaffected by these changes.

#### **This syndrome appears in:**

- 5% of the population over 65 years of age (13% of the Czech population = 1.3 million people)
- 20% of the population over 80 years of age

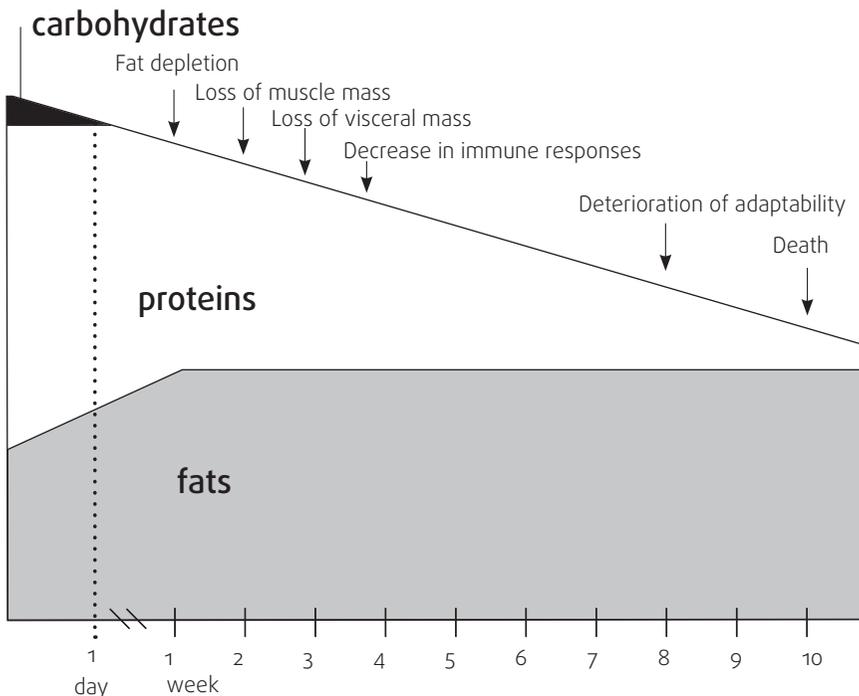
Alzheimer's disease is one of the most widespread forms of dementia, making up 50–80% of dementia cases, and it is progressive and irreversible. Ischemic vascular diseases of the brain account for the remaining 15–30% of dementia cases.

Alzheimer's disease appears most often after 65 years of age, affecting persons in higher and old age.

**Progressive development of malnutrition** is a major problem with this disease. It manifests in a gradual decrease of body mass, the shrinking of adipose tissue and especially in the loss of muscle mass. The sooner the onset of the disease, the more malign the progression and the faster the development of malnutrition. Malnutrition then further complicates rehabilitation, increases the risk of infectious complications and bedsores, and slows down healing. This gradually diminishes the quality of life and substantially reduces the patient's chance of survival. If the weight loss exceeds 5% a year the probability of fatal ending is high [15] and, conversely, weight gain reduces the mortality risk [3].

Experience with hospitalised patients with Alzheimer's disease in the Intensive Care Unit at the Department of Psychiatry of the University Hospital Brno (ICU DP UHB) and also the outpatients monitored by the Consulting Centre for Metabolic Disorders and Nutrition shows that progressive development of malnutrition manifests through **a substantial decrease of body mass, approx. 10 kg/year**, with shrinking of adipose tissue and significant loss of muscle mass.

Figure No. 1: The course of uncomplicated starvation



## 1.2 The causes of decrease of body mass in Alzheimer's disease

The development of malnutrition in Alzheimer's disease may have several causes:

- reduced food intake resulting from the decrease in cognitive functions with subsequent decrease in appetite or negative motivation for food intake [2];
- gradual decrease in physical activities with subsequent skeletal muscle atrophy;
- rise in basal metabolism [1, 9, 16];
- unclear metabolic changes, partially similar to cancerous cachexia;
- affection of metabolism of certain micronutrients [10, 11].

Progressing dementia virtually excludes the ability of the patients to provide themselves with adequate nutrition for a long term. Other factors may also be involved in the nutritional deficit of seniors with dementia: loneliness, depression, inability to obtain food, inability to feed themselves, but also swallowing disorders, teeth defects or the loss of smell and taste [12].

Incorrect diet also has a substantial role in the development of malnutrition. Patients with Alzheimer's disease usually have relatively good appetite; some even have a considerable appetite. However, progressive loss of body mass occurs in many patients even though their per-oral intake remains satisfactory [3].

Spidler et al. demonstrated in 17 patients with Alzheimer's disease a higher energy requirement to maintain body mass (minimum of 35 kcal/kg/day) in contrast with 23 control subjects [13]. Our experience gained chiefly in the ICU at the Department of Psychiatry clearly shows that the energy requirement may be even higher. Some patients required up to 50-80 kcal/kg per day while even with an energy intake this high we only managed to prevent further decrease in body mass.

Although the opinions with regard to the metabolic changes involved in the loss of weight in patients with Alzheimer's disease still vary, both literature and our clinical experience indicate that the energy intake necessary for maintaining body mass is clearly higher than in general population. One of the possibilities is to supply a balanced diet between the main meals accentuating proteins and all necessary micronutrients.

## 1.3 Reaction to the need of increased energy intake

The overall amount of energy, carbohydrates, fats and proteins necessary to maintain nutritional condition can be increased by including small meals (snacks) in between the main meals. These additions should include chiefly foods rich in calories (rations rich in fats and drinks rich in carbohydrates). The additions should have a distinct flavour (changes of taste in patients with Alzheimer's disease) and good appearance of both the food and the table-ware to ensure that the additions look attractive to the patients (patients often preferred pastel-coloured plates to standard white plates). The additions should be available to the patients so that they can take them as needed. In domestic as well as hospital conditions, the patients should always be prompted to take the additional foods when they are in contact with relatives (during visiting hours and the like).

In the ICU DP UHP it has proven useful to administer complete preparations containing all the nutritional components in a balanced ratio (Fresubin, Renutryl, Resource, etc.). With administration of the first package at around 9 a.m., the second one at around 2 p.m. and the last one before bedtime, it is possible to increase the daily energy intake by as much as 50%.

Nutrition may also be supplemented by additive modules (protein – usually casein, carbohydrates – maltodextrin) added to meals.

Food modules may also be supplemented by food and vitamin supplements, vitamin C in a dose of 1000 mg per day and vitamin E in a dose of 500 to 1250 mg per day. A sufficient supply of group B vitamins and the folic acid is also advisable.

If oral intake is not possible or sufficient, the patients may be fed using a thin probe inserted into the stomach or the small intestine. Feeding through probe can be administered during night time so that during the day the patient can be fed per orally in a normal way. In extreme cases and in conditions when nutrition needs to be provided after deprivation (e.g. following an acute disease), it is possible to switch to a continuous enteral feeding through a probe. Direct puncture gastrostomy or jejunostomy is used in serious cases [5].

The aim of the realimentation and nutrition in Alzheimer's disease is to slow down the mental deterioration and thus maintain a good quality of life for as long as possible, not to prolong the life of the patient with Alzheimer's disease in its terminal stage.

Evaluation of the nutritional condition in gerontological patients is a necessary condition for initiating a proper nutritional support in the indicated cases.

## 2. Results of the Czech research

### 2.1 Summary

I will be dealing with a study performed on 165 patients in 7 facilities in the Czech Republic, which included 100 patients with Alzheimer's dementia and 65 patients with vascular dementia. [8]

We observed that in patients with Alzheimer's disease the spontaneous energy intake (in kilojoules) and fats intake (in grams) did not significantly differ from the intake in patients with a vascular disease of the brain. In the first year of study, i.e. in the period without nutritional intervention, the energy intake in individuals suffering from Alzheimer's disease was comparable to the energy intake in individuals with vascular dementia. Despite this fact the nutritional condition of the patients with Alzheimer's disease was significantly worse than in patients with vascular dementia. This finding corresponds with the findings of authors who observed greater energy requirement for maintaining body mass in patients with Alzheimer's disease in contrast with the healthy population [13, 16].

Therefore, in the second phase of our study we studied the influence of the administration of nutritional supplements on the course of the disease. Our results show what nutritional support administered by sipping outside main meals had no negative impact on the spontaneous food intake. On the contrary, we have found that individuals receiving nutritional supplements by sipping not only did not reduce their spontaneous intake, but increased it by a small, yet statistically significant margin. This corresponds

to studies and meta-analyses which demonstrated that nutritional supplements lead to an improvement of the overall energy intake in the elderly [11].

Surprisingly, not even the increase of energy intake by sipping influenced the mortality in patients with Alzheimer’s disease. This apparent paradox can perhaps be explained by the fact that mortality is mostly influenced by the complicating diseases rather than the course of the Alzheimer’s disease itself.

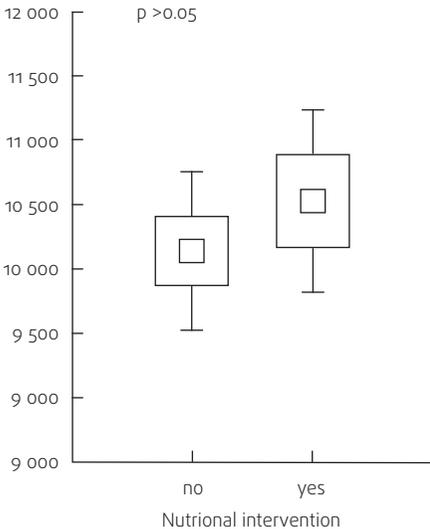
An important finding is that nutritional support in the form of nutritional supplements had slowed down the gradual deterioration of mental functions in patients suffering from Alzheimer’s disease.

Although the opinion with regard to the metabolic changes involved in the loss of weight in patients with Alzheimer’s disease differs in literature and our personal experience, the energy intake necessary for maintaining body mass is clearly higher than in general population.

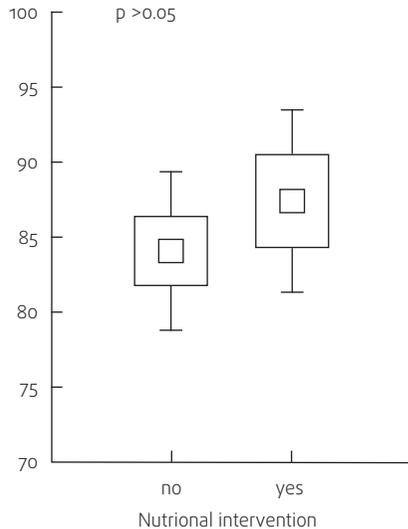
## 2.2 The influence of nutritional intervention on the spontaneous intake of food

Nutritional intervention in patients with Alzheimer’s disease does not lead to a reduction in spontaneous food intake. On the contrary, we have demonstrated that individuals receiving sipping have slightly, but statistically significantly increased their spontaneous intake of nutrition (see Graph No. 1).

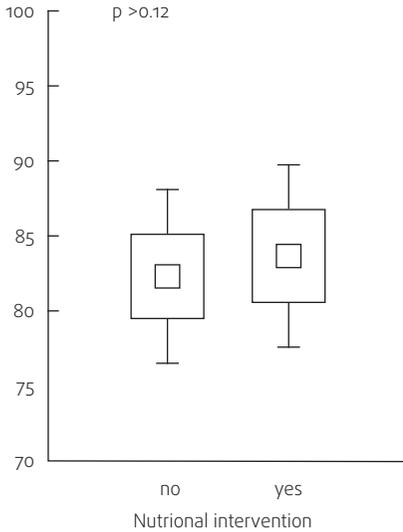
**Energy intake (kJ)**



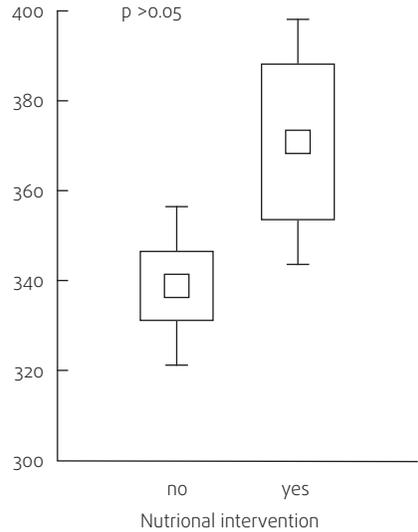
**Proteins (g)**



### Fats (g)



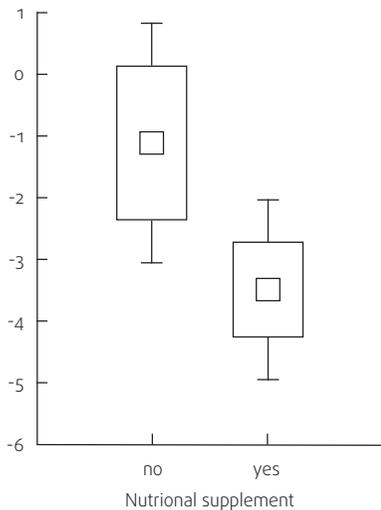
### Carbohydrates (g)



Graph No. 1: Spontaneous intake of energy, carbohydrates, fats and proteins in patients with Alzheimer's disease in dependence on nutritional intervention ( $p < 0.05$ ).

## 2.3 The influence of spontaneous food intake

Very importantly, individuals with nutritional support by sipping showed a slowdown in deterioration of mental functions as evaluated using Mini Mental State Examination (MMSE; see Graph No. 2). This finding is significant because our results indicate that nutritional support may be one of the methods to prolong the period of good quality of life and to slow down deterioration of mental functions in patients with Alzheimer's disease.



Graph No. 2: Change of MMSE in patients with Alzheimer's disease receiving nutritional support and in those without nutritional support ( $p < 0.05$ ).

## 2.4 Conclusions

- Most significantly, we have found that **nutritional intervention** by sipping (600 kcal per day) led to **a significant slowdown in deterioration of mental functions in Alzheimer's disease**. An intervention study of this type and scope has not yet been mentioned in literature which makes our findings unique in this regard.
- Nutritional support also led **to a stabilisation in the body mass and prevented its further decrease**. **Administration of nutritional support did not increase the body mass, but prevented the development of malnutrition with all its adverse effects**. **This means that a timely initiation of nutritional support before the patient becomes malnourished can prevent secondary complications of Alzheimer's disease, slow down its progression and improve its course**.
- The results of our study show that nutritional support can slow down the progression of dementia in Alzheimer's disease while not affecting the survival of the patients. The significance of these results lies especially in the fact that nutritional support could improve the quality of life of patients with Alzheimer's disease without prolonging their lives in the terminal stage.

Nutritional support can thus justifiably be considered as an integral part of care for patients with Alzheimer's disease.

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# Providing Meals to Persons with Dementia in Social Services Facilities

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## Keywords

Individualised needs, basic services, nutritional screening, nutrition therapist, malnutrition

## Abstract

The Public Defender of Rights carries out preventive visits to social services facilities with the aim of improving protection against ill-treatment. One of the basic services in residential social service is the provision of meals. Provision of meals which are not suitable to the needs of patients with dementia or provided improperly can represent a violation of human dignity. In extreme cases it can negatively affect the patients' medical condition. The Defender's visits have focused also on the attention given to the risk of malnutrition. The social and aesthetic dimension of dining and catering to persons with dementia is also in the centre of attention.

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## 1. The Public Defender of Rights and the protection of persons restricted in their freedom

On the basis of Section 1 (3) and (4) of Act No. 349/1999 Coll., on the Public Defender of Rights, as amended, the Defender carries out preventive visits to places where persons restricted in their freedom are or may be present due to their dependence on the care provided, especially social services facilities, with the aim of **strengthening the protection of these persons from ill-treatment**. Therefore, the visits should primarily be pre-emptive. Ill-treatment is defined as treatment which does not respect **human dignity** or represents an interference with the fundamental rights. Following each visit to a facility the Defender prepares a report of the findings. It may contain recommendations or suggestions for remedies. The Defender will request that the facility provide a statement on the report and recommendations. The Defender may also request the founder of the facility or the competent authorities issue a statement. If the Defender finds their statement satisfactory, the Defender will inform the facility or its founder or the competent authorities to this effect. Otherwise, the Defender may exercise her powers to impose sanctions by notifying the Government or informing the public. This power was exercised against a provider of social services or other similar facility for example in 2012, in case of two facilities. [1]

In 2013 the Defender visited a total of 14 social facilities for the elderly whose clients included persons suffering from dementia. The visits and the following recommendations focused on persons suffering from dementia, the protection of their rights and adjusting the service to their specific needs. All recommendations sent by the Defender to the individual facilities concerning catering to persons with dementia are based on the below-specified legal regulation and reflect the general principles of providing meals to persons with dementia.

## 2. Legal rules on catering in social services, specific features of people with dementia

The provision of meals in retirement homes<sup>10</sup> and in special regime homes<sup>11</sup> represents one of the basic services. Catering is understood as the provision of daily food appropriate to age, the principles of proper nourishment and specific dietary needs, comprising at least 3 main meals a day.<sup>12</sup> Catering must be based on **individualised personal needs** of the residents. Catering is a part of the social service and must therefore be provided in the interest of the residents and in proper quality by means consistently respecting human rights, which are the basis of provision of social services.<sup>13</sup> In catering, social services facilities must **take into account the specific circumstances of persons with dementia**. For example the fact that dementia is an energy-intensive disease and persons with dementia thus require an increased intake of energy and nutrients. Persons with dementia also do not feel thirst and must be provided with regular drinks. Swallowing disorders may likewise be present. [2]

Specialised literature also mentions the following principles of nutritional care for persons with dementia: “Timely recognition of the decrease in the patient’s appetite; regular monitoring of the patient’s weight and muscle strength; keeping regularity and order in food intake, dividing into main and side meals; maintaining the standard and style of dining; respecting the patient’s tastes where possible (beware of fatty and sweat meals); maintaining a balanced composition of diet; providing sufficient and continuous hydration; being objectively aware of the real food consumptions; motivating and involving the patient in the preparation and serving of meals.” [3]

## 3. Catering as a basic service

The maximum payment for daily meals in retirement homes<sup>14</sup> and special regime homes<sup>15</sup> is CZK 170. This maximum payment must cover the provision of daily food appropriate to

<sup>10</sup> Section 49 (2)(b) of Act No. 108/2006 Coll., on social services, as amended

<sup>11</sup> Section 50 (2)(b) of Act No. 108/2006 Coll., on social services, as amended

<sup>12</sup> Sections 15 (1)(b) and 16 (1)(b) of Decree No. 505/2006 Coll., implementing certain provisions of the Social Services Act

<sup>13</sup> Section 2 (2) of Act No. 108/2006 Coll., on social services, as amended

<sup>14</sup> Section 15 (2)(b) of Decree No. 505/2006 Coll., implementing certain provisions of the Social Services Act

<sup>15</sup> Section 16 (2)(b) of Decree No. 505/2006 Coll., implementing certain provisions of the Social Services Act

age, the principles of proper nourishment and specific dietary needs. Catering as a basic service following from law cannot be treated and reported as an optional service. "A provider of a social service charging its basic service as an optional service acts erroneously." [4] In other words, the maximum payment must cover the provision of meals appropriate to the nutritional and energy needs of the clients, their eating habits including individual customisation and nutritional supplements where standard meals are insufficient or where the client is unable to consume the necessary amount of food in a normal way. Optional services cannot be used to narrow down the scope of provided basic services which should include the provision of meals. Charging for snacks after dinner, diabetic nutritious snacks and for catering as an optional service is at variance with law. **The Defender recommends providing such an amount of food as part of the basic service (with the maximum payment of CZK 170 per day) that fully meets nutritional and energy needs of the clients and reflects their medical condition.**

## 4. Malnutrition

The Defender has pointed out to the facilities their failure to identify the nutritional condition of the clients and to pay attention to the risk of malnutrition. [5] Nutritional screening is necessary to identify client with a nutritional risk. [6] Mini Nutritional Assessment question-form can be a useful tool in this regard. Unfortunately, although screening is easy to do, many facilities are yet to implement it. In one visited facility the staff did not measure the height since the clients "do not grow any more", and Body Mass Index as an indicator of malnutrition was not used at all. In many facilities the staff did not know that clients who are unable to step on the scales can be 'weighed' by taking a measurement of the circumference of their arms. **The Defender recommends consistently monitoring the clients' weight and systematically evaluating the eventual weight losses.** Clients incapable of stepping on the scales should be weighed and checked for weight loss using alternative methods.

Often the Defender had to conclude that the monitoring of daily food and drinks intake was unsystematic and not objective. Data entries such as "ate very little" have no objective value and cannot be used in determination of the nutritional condition of the client. Records need to be kept in an objective manner, using for example forms for monitoring of the daily intake of food and drinks, in which the rations can be marked as 1/4, 1/2 or completely eaten. **The Defender recommends to set criteria for determining which clients' food intake should pre-emptively be monitored and recorded using objective methods. The records must be regularly evaluated by a nutritional therapist or a physician who determines the subsequent steps.**

Unsuitable administration of nutridrinks can be singled out as an example of **intuitive but unprofessional** solution of food intake deficits. In one facility some of the clients were provided with a nutridrink instead of a standard evening meal with the argument that they were in risk of malnutrition and the nutridrink completely supplants a regular dinner.

It was found that in many clients the regular intake of drinks is not monitored, not even in those in an advanced stage of dementia. This was happening even though clients in this stage of dementia are unable to provide regular drinks for themselves.

Records such as “sufficiently hydrated” or conversely, “drinks too little” can be found. Such records only reflect subjective perceptions. In reality, the clients may be dehydrated, which is often the case. This is demonstrated when clients have to be moved to a hospital bed due to dehydration. **The Defender recommends systematic monitoring of the intake of drinks.**

## 5. Nutritional therapist

Catering is not understood as a part of the complex professional care and some facilities do not have a dietary system created. This is happening despite of the presence of clients with a dietary regime prescribed by a physician. The Defender advises that plans of meals and food prescriptions for the individual diets, including a calculation of biological and energy values of the diets, can only be drawn up by a nutritional therapist.<sup>16</sup> Therapeutic nutrition is an integral part of nursing care and the risks of low-quality and unprofessionally provided nutrition are comparable with the risks of incorrect treatment in this target group. **The Defender recommends that a nutritional therapist be a part of a multidisciplinary team taking care of persons with dementia.**<sup>17</sup> It further recommends that the facilities create a dietary system suitable for their client target groups, which should include the characteristics of a particular diet, i.e. its composition: energy, the amount of proteins, fats and carbohydrates and the energy content of nutrients. Menus should be drawn up based on the dietary system and the specified nutritional values should be met.

The Defender asked a nutritional therapist to evaluate the menus in one of the visited facilities. The facility uses a system of seven weekly menus which are continuously repeated. The nutritional therapist found profound shortcomings in the menus. They contained a great amount of meals to which many individuals are intolerant (legumes, sweet foods, offal, etc.) while **the choice of another meal was absent**. The share of vegetables and fruit and milk products was completely inadequate. By contrast, it contained too many sweet foods (nine times sweet food for dinner, e.g. sweet pasta with cinnamon), sweets for afternoon snacks were also common as well as sweets for dinner (for example sweet pastry with poppy seed and cottage cheese, sweet poppy seed pasta, Christmas bread, rice and semolina porridge, etc.). The meat content was insufficient in contrast with the excessive share of smoked meats and sausages. Variety was lacking – for example goulash soup was served for lunch and potato goulash

<sup>16</sup> Under Section 15 (3) of Act No. 96/2004 Coll., on paramedical professions, as amended, an activity within the framework of preventive care in the field of clinical nutrition and specific nursing focused on meeting nutritional needs is considered as exercise of the profession of a nutrition therapist. Furthermore, nutrition therapists collaborate with the physicians to provide diagnostic and therapeutic care in the field of clinical nutrition. Under Section 14 of Decree No. 55/2011 Coll., on activities of healthcare workers and other professionals, nutrition therapists provide specific nursing within the provision for nutritional needs of patients in the area of preventive and therapeutic nutrition. Furthermore, nutrition therapists draw up and assess nutrition history, propose changes to the prescribed diet, manner of intake of food or administration of dietary supplements, perform examination to determine the nutrition condition of patients and organise the preparation of meals in conformity with their knowledge on healthy and therapeutic nutrition.

<sup>17</sup> Section 36 of Act No. 108/2006 Coll., on social services, as amended, in conjunction with Section 14 of Decree No. 55/2011 Coll., on activities of healthcare workers and other professionals.

for dinner in the same day. As a whole the menus were evaluated as unsatisfactory, insufficiently varied and unsuitably drawn up. **The Defender recommends including the possibility of choice from two or more dishes, to make individualised adjustments in the menu according to the clients' tastes and to prepare menus according to the principles of proper nourishment and specific dietary needs.**

## 6. Preparation and serving of meals

For some clients meals are mechanically treated, for example cut into smaller pieces, minced or blended. Blending meals should be the last resort, mincing should be preferred. Transition to mechanically treated meals represents a major change in the lives of the clients since they perceive the gradual loss of their abilities and self-reliance and lose sense of the fullness of the meals, the enjoyment of consuming them. **The Defender recommends to record the decision to start with mechanical treatment of meals in the clients' documentation (in the nutritional plan) in order to make clear who made the decision, when and for what reasons.** In some cases the individual parts of the blended meal were mixed together which is not aesthetically pleasing; it can even look disgusting and cannot bring any enjoyment to the client. **The Defender recommends treating the individual parts of meal separately and never mixing them together.**

Some clients need help in serving of meals or they need to be fed. Often the staff were feeding the clients while standing, which prevented eye contact. Sometimes the staff did not prepare the clients for food and they started feeding them without talking to them and telling them that it is meal time, what meal is being served, etc. **The Defender recommends serving meals in a way that the caregiver stays at the same level as the client and prepares him or her properly for the meal (provides information on the meal, etc.).**

The Defender warned against unsuitable or unsuitably prepared meals whose consistence and texture did not allow the clients to chew the food. He had also warned against the failure to cut the meal into smaller pieces or mince it even though it was clear that the clients could not consume the served untreated meal independently. The practice of **adding crushed drug pills into the blended meals** was denounced as unacceptable by the Defender. The crushed pill may change the taste of the food which can lead the client to start refusing food completely. Furthermore, this does not allow determining the amount of the drug the client has taken.

It is necessary to take into account that persons with dementia require more time to consume their meals and need to be guided and encouraged. They can also have trouble with movement co-ordination or swallowing. Meal time with the clients can often be very demanding in terms of the caregivers' time. Feeding a single person with dementia may take as much as 40 minutes. [7] **The Defender recommends adjusting the duration of feeding to the needs of the clients.**

In one of the visited facilities the clients were admonished for taking food off the plates and inserting it into their mouths. It should be noted here that the current trends in care for persons with dementia stress the benefits of the "finger foods", including meat, vegetables, fruits and side-dishes. [8]

Operational matters related to the preparation and serving of meals must be adjusted to the clients' needs, not vice versa. The case described below could thus be called an example of cynicism in dining. A female client who normally eats together with others sat and waited for her diet meal (she could not eat semolina porridge due to allergies) for 30 minutes while the other clients dined. In the end the client was moved to her room with the explanation that the kitchen staff was "too busy" and that she would receive her dinner later in her room.

## 7. Environment, equipment and tableware

One of the visited facilities was divided into two wards, each corresponding with one floor of the building. However, there was only one dining room which was barely sufficient for clients residing in that particular floor. All the clients from the other floor had to eat meals in their rooms. **The Defender recommends that there be enough of sufficient dining space in which all the clients can be served meals.**

In a different facility there is a single-room canteen for 190 clients which is not compartmentalised in any way. Three TV sets were on during lunch- and dinnertime. The sound intensity was very high. However, dining should provide room for casual communication, the staff should talk with the clients, ask about the food and encourage them. The facility should reconsider whether the clients can benefit from the noise from TV sets or it is there just for the staff. **The Defender also warns that large and unsuitably compartmentalised spaces and noise are completely undesirable for persons with dementia, especially during meal time.**

Serving meals in the clients' rooms is considered completely unacceptable by the Defender, especially if the rooms are improperly equipped. In some cases a TV stand served as a table, or a chair was used instead of a mobile table, which were not even used in the facility. In such cases one cannot speak of a dining culture; it is a parody of dining. The Defender has also drawn attention to the fact that keeping mobile toilet chairs in the room while the clients are dining is not appropriate. **For a person with dementia, dining should represent an important event and the environment should make this possible and support it.**

In some facilities a major part of the clients were fed in bed, not even being taken out to a table. It was impossible to determine who made the decision and for what reason and the staff was unable to provide any explanation beyond "it's the client's wish" or "we just do it that way". The Defender disagrees with such practice. Only a profoundly bad medical condition of the client justifies his or her spending the whole day in bed and experiencing there even such important activities as dining. The Defender criticised the inappropriate practice of feeding in bed, where the clients were not vertical, eating while lying down. [9] **Meals should only be served in bed on a decision by nursing team and the physician or physiotherapist.**

Concerning the matter of communal dining, this should primarily be decided by the client and, in case the client can no longer decide, and effort should be made to make dining in a common dining room possible. **Eating meals in their rooms increases their sense of isolation in patients which already is fairly high due to their dementia.**

The Defender sees as unsuitable the sweeping approach of providing clients with dementia only with spoons instead of a full set of cutlery. Furthermore, the use of baby bottles is not acceptable. The use of plastic yoghurt cups instead of proper glasses or cups was among other excesses criticised by the Defender. **Clients with dementia must be provided with proper tableware**, e.g. cups with two handles or tulip-shaped cups or cups with a spout, or alternately the cups should be fitted with a mouthpiece, the plates with an elevated rim, etc.

## 8. Examples of best practice

The Defender informs the facilities of examples of best practice observed during visits in other facilities. **Permanent availability of food** is one of them. Another is example is **reheating of food** if it becomes cold due to the client's slow pace of eating Including **pictures of meals in the menu has also been praised by the Defender**. In one visited facility, one serving of a dish was always displayed in order for the clients to see what the dish should look like and to compare it with what they were actually served. A serving of a minced meal is also displayed with each of its components minced separately to avoid producing a homogeneous substance which would lack the appearance of food.

## 9. Conclusion

The above-mentioned findings and recommendations do not apply to all facilities. They also do not represent the entirety of findings and recommendations concerning the provision of meals. The need to overcome stereotypes in accentuating and relying on the autonomy of will of the client is the common denominator in care of persons with dementia in social services facilities. At some stage in the progression of the disease, a multidisciplinary team has to take responsibility for the client and make decisions and plans in conjunction with them, taking into account **the principle of protection of human dignity** of every single client. Provision of meals which are not suitable to the needs of patients with dementia or which are provided improperly can represent (or does represent) a violation of their dignity. In extreme cases it can also negatively affect **the patients' medical condition**.

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# How to Eat Well in Long-term Care Facility, Autonomy in Activities of Everyday Life

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## **Keywords**

Autonomy, dementia, long-term care, food

## **Abstract**

Deterioration of cognitive capacity and the ability to make rational decision and a decrease in self-reliance do not make a person less human. The abstract ideal of autonomy which is often connected with the ability to make rational and (relatively) independent decisions takes on a specific shape in the elementary everyday activities. The autonomy of any person is always renegotiated in a web of relationships. Food and the related activities provide, aside from nutrition, an opportunity to support identity, dignity and self-reliance of every person as well as room for building and strengthening relationships. If catering is understood as an integral part of care, it can become one of the most meaningful activities of the day.

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With the development of dementia, self-reliance becomes gradually limited, beginning with the 'instrumental activities' of the day. With respect to activities related to food, this includes for example the ability to prepare a meal. In a later stage, some of the basic self-maintenance activities become limited. People with dementia may experience trouble with independent consumption of prepared and served meals or drinks placed on a table in front of them. In advanced stages of dementia, further complications related to changes in co-ordination and regulation appear, which leads both to worse preparation and processing of a morsel in the mouth and its proper swallowing [2].

The ability to eat independently in a way the patients were used to becomes limited in the stage of advanced dementia. A person with dementia can manage food on his or her own only to a certain point, gradually with the support and help of caregivers is needed – a reminder of how to manipulate the objects on the table, the food on the plate, and so on. The ability to feed oneself is an important part of a person's self-reliance, the feeling of being in control. The ability to eat independently in any dignified and feasible manner (for example by eating finger foods) should thus be prioritised over the feeding of patients by the staff.

The degree of autonomy is renegotiated to some extent in concrete situations based on existing strategies that help in maintaining positions and promoting will, but

the results are never certain. Decision-making and activities carried out by a person are a part of a wide web of relationships, absolutely concrete interactions in a certain environment and time [1,3,4]. They are a product of this web. In the everyday routine a person does not think of autonomy as an ideal. If they can manage, they do it alone, and if they cannot, they think of what will happen and whether somebody will help. These are the situations which are worth of observing, studying and contemplating if we are interested in who exercises their will, how they do it and to what extent, and to what ends as well as what strategies they use and what forms does autonomy have in long-term care. The focal point is the basic daily activities. This is why it makes sense to concern oneself with food, activity and related issues.

Food, its preparation, sharing and eating bring much more into our lives than the necessary nourishment of the body. Food plays a key part in shaping of our individual cultural and social roles. It is a means of creating and strengthening of relationships. Food eaten in the company of a dear person has the power to heal. People in a residential care facility or in a different facility type that provides long-term care do have the right to live a normal personal and social life to the greatest extent possible. This includes preparation of meals, dining, free access to food and sharing of food with relatives [5].

In supporting autonomy, it is very important that the staff in long-term care facilities know well the clients' habits, the role which they played in relation to food (e.g. whether they used to serve or used to be served, cooked or just tasted), and to get acquainted with the manner they enjoyed everyday and holiday meals, how they used to eat, where, what do they like best, what they do not eat at all, and so on. In each stage of provision of service (the entry examination, reception and stay in the facility) there is a necessity to add and update the information. Aside from tastes and habits, the clients' abilities also change. It is not possible to fully utilise the potential of a person with dementia and to fully support their self-reliance and dignity without a perfect knowledge of their degree of self-reliance. Information on eating and dining is an important part of life stories which the staff gradually create.

In 2012, the Czech Alzheimer Society has invited four special regime and retirement homes to participate in the implementation of the 'Bon Appetit – The Joy of Dining in Long-Term Care' programme. Ergotherapist Jitka Zgola and a specialist in gastronomy Gilbert Bourdillon were the initiators of the programme. The staff in the these facilities and later in ten others formed interdisciplinary teams, evaluated the situation and focused on the development of the aspects important for eating and dining with respect to the needs of persons with dementia.

The food itself is a subject of special attention within the programme. It is important to make sure that the food is attractive, tasteful, nutritious, of a suitable consistence and available when needed in a form which the clients can manage to eat on their own. This obviously means that we need to know each client very well. Not only the nutritional therapist but also the other members of staff need to add information on people for whom they cook and to whom they serve meals. This could pose a serious challenge if there are between eighty and one hundred residents in the facility. A nutritional therapist in one of the facilities follows the motto "We do not cook anonymously" and carefully records the clients' tastes and preferences.

The following is an **example of notes** taken by a nutritional therapist for the purpose of individualised adjustments to the menu:

**Mr. G.:** replace by normal butter, do not serve spreads (except crackling spread), exclude spinach, sardines and canned tuna, exclude grated Eidam cheese – could be served in slices, exclude processed cheese, exclude sausages for breakfast, exclude mashed potatoes – replace by boiled potatoes

**Mr. N.:** milk for dinner instead of buttermilk (do not serve hot), serve whole chicken – no mincing, exclude oatmeal porridge – replace by semolina porridge, soups for breakfast – broths with soft pasta and egg, adjust the menu according to the client’s condition

**Mrs. L.:** exclude stewed cabbage, cabbage salads and other dishes with cabbage can be served, do not serve wafers and biscuits, exclude pickled herring, fish spread sardines and tuna, serve diet yeast dumplings instead of standard, exclude gooseberry compote, exclude baked potato dishes (farmer’s potatoes, potatoes with cheese, gratin) – replace by e.g. potatoes + egg omelette, stewed carrot etc., exclude cheese croissant, exclude yoghurt – replace by fruit, from chicken serve only the legs

Adjustment to the environment in which people eat is also important for the improvement of the quality of serving of meals and the enjoyment of food. Despite the initial belief that the dining rooms were nice, the furniture and tableware completely adequate and that all those eating in their rooms wish so and everything should stay as it was, many things have usually changed after a couple of weeks since the start of the programme. The caregivers began to see people and things differently and tried new things. They began to notice the difficulty some may encounter while eating from a plate using cutlery or how difficult it is to bring the spoon to the mouth when a person sits too far from the table or is slipping down from the (wheel)chair. Interior changes and modifications of tableware and cutlery and a reduction of noise in dining rooms was followed by new perceptions concerning the manners and atmosphere. Each stage of a daily meal – preparation, consumption and completion – need to be given the necessary amount of time and attention. Accompanying the client on the way to the dining room, finding a proper position, the initial contact with the other people at the table, a few words about the dish that is being served, and also removal of the dishes after the meal followed by a friendly get-together and chat after the lunch, these are all important details which contribute to a good experience from food.

The individual “details”, little things and easily overlooked moments to which a healthy person does not assign too much importance often represent a major obstacle to an elderly, sick person. We try to look for the details and to find situations that are difficult for the clients. These are later worked with (caregiver ideas, team brainstorming). We think about ways to making difficult situations easier for the elderly and how to adjust them to their abilities and capabilities (we ask, observe and offer). We are not afraid of the new, we try different alternatives and share those which have proven good.

(From the presentation of the program coordinator at the Bon Appetit – Enjoyment of Food conference)

Thanks to the attention to detail and willingness of many caregivers in direct care to look at things differently and thanks to the support from the management willing to change work schedules and procedures of units or the whole facility, the food has become a more enjoyable experience in many cases. Intervention in the system of care was necessary in some cases to “make more time for food”. It is useless to argue with the caregivers about the issues of dignity, individualisation, creating of a good atmosphere and to help them develop skills connected with eating assistance when they are in a hurry to carry dishes back into the kitchen and to eat their own lunch before other tasks need to be carried out.

The programme to improve the provision of meals in long-term care facilities is not possible without a concrete idea of how the provision of meals should look like, how it should be carried out. In many places the food improvement teams which included head workers in facility units and wards agreed on clear rules concerning the manners, preparations and the way of serving the meals. The teams were successful only in the facilities where they managed to introduce regular training, monitoring of changes being implemented and invented a simple and effective way of providing feedback between the caregivers in wards and between units. The inter-professional cooperation aspect is very important in the programme. It is necessary for the cooks to know for WHOM they are preparing meals. They do not cook only for the caregivers who take the meals over in the kitchen and carry them to the ward. They need to know their clients and the difficulties they struggle with due to the disease. This will help them better understand the “requirements and suggestions coming ‘from above’ (the ward)”. The connectedness of health and social care does not need to be mentioned. Health care is not involved only in serious cases, such as pain or depression. Even a suitable position or an advice how to correctly serve meals or whether it is possible to serve finger foods instead of “mixed food” can bring more enjoyment from food to the clients and the caregivers alike. Shared brainstorming, agreement and looking for ways towards better interconnectedness and mutual support in the area of food can have a wider impact to the life of the organisation.

“I see the Bon Appetit programme as another important piece in the puzzle of improvement of the quality of care [...] in our facility. Although we were sceptical at first, we are grateful [...] that the programme was implemented. I personally was surprised by the overlap between the Bon Appetit programme and the issues of food in general and the other areas of care. We expected to change and improve the quality and standard of dining, but we have also improved it in ways we had not predicted. Bon Appetit has interconnected and, I must say, professionally and personally joined together the individual units like no programme before. I believe the key to success was the good choice of programme co-ordinators and the inter-professional working group of employees who understood its importance and convinced not only the other employees, but also me as the director who had originally resisted change, not seeing their far reaching consequences. In fact, Bon Appetit has changed us all a bit.”

If we ignore the potential of dining, the appetite gradually fades, the atmosphere in the dining room grows worse and the opportunities for social interaction are reduced. The clients do not receive proper nutrition, their self-reliance, dignity and the enjoyment of food disappears not only because of the disease, but also due to the approach to and organisation of the provision of meals in the facility. Not much is needed to change that.

Food and related issues must be given an appropriate significance and must be firmly anchored in the network of care.

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# Food as an important part of complex care for persons with dementia

## Case Study of Implementation of the Bon Appetit Programme

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### Keywords

Catering, care, dementia, inter-professional cooperation

### Abstract

Case study of implementation of the Bon Appetit programme.

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I am sitting on my favourite sofa, this time sharing it with Jitka, the initiator of the Bon Appetit programme. She came for a visit after six months and this time we set out for the facility to talk with people about specific situations. We are sitting near a table at the right side of a dining room. Mr Kudrna, a tall and very lean man, is sitting on a chair at the table, a plate of blended food in front of him. A bowl of blended tomato salad is a part of the meal on a big plate which includes the parts of the main dish. Mr Kudrna is being assisted by Tereza. She's kindly and nicely feeding him with a spoon. Perhaps she does not notice that what we see from afar. Mr Kudrna is leaning slightly, pushing aside or grabbing – it is hard to say – Tereza's hand. Both of us interpret the scene as a sign that Mr Kudrna does not enjoy the food very much. Jitka leans towards me: "I wonder why he got blended food. I don't want to interfere," she says, looking at Tereza, "I know nothing about the man, it's annoying." I feel the same. To always watch somebody, to observe, what they do, what they say. Perhaps we've already grown accustomed to each other here, so I reply: "Ask her, Tereza will manage." Jitka leans to Tereza and asks, smiling: "Why are you serving blended food, does the man have any trouble swallowing?" While Mr Kudrna is processing the morsel, Tereza replies: "I don't know, Mr Kudrna has only been here for a couple of days, he's just arrived from the hospital." Jitka observes Mr Kudrna and surveys pieces of fried cauliflower at the plates of other diners: "Ask for the cauliflower." In a few minutes a plate with fried cauliflower appears in front of Mr Kudrna. The smell! The rim of the plate with food is too high. Mr Kudrna hesitates for a while, he cannot see well what is on the plate and he cannot easily reach it with his hand. But then it turns out that the obstacles were not so serious. He picks up the first piece and puts it in his mouth. The pleasure, the joy. He licks his fingers and picks up another. He eats happily. The whole table is visible from the sofa. Aside from Tereza, there are two more caregivers and one more employee helping with the serving

of meals. They observe what is happening and when Mr Kudrna begins to enjoy his meal, they all brighten up. I make notes, recording words and facial expressions. We will definitely get back to this during the afternoon briefing with the staff.

In my mind I make sense of what is happening here and how care is being provided here. The local team has formulated an ideal towards which they proceed: "catering that is appropriate to the needs of the clients while preserving their dignity and individuality as well as taking into account the changing needs of the individual clients." They have agreed on principles and rules of proper serving of meals: "When serving a meal, the caregiver sits at a right angle to the client. She or he will tell him what is being served..." In so far as we have seen, Tereza knows the rules and tries to use them for the benefit of Mr Kudrna. The whole team in the retirement home tries to ensure that people eat what they like, in the best possible treatment and in an appropriate way. "Caregivers in wards and in dining rooms should know..." We have now seen that this did not really work with Mr Kudrna during the lunch. Maybe there is somebody else in the home whose lunch was not perfect, although the system might work well for dozens of others. Perhaps it is worth considering if more people could be provided with finger foods. There were eight people at the table with Mr Kudrna. Five of them ate the cauliflower with their hands. What will this experience mean for Mr Kudrna, Tereza and the other caregivers? Will it influence the way they provide care? That will depend on many other people, circumstances, resources and other things.

During the afternoon briefing we share the experience with the other caregivers. In the beginning, we review what goes on in the facility, what the past months have brought and we agree that some things have turned out well. Today, for example. "Tereza, could we share what happened today at lunch? Yes? Thank you, so could you begin?" Tereza knew that Mr Kudrna was supposed to get special food. She knew that he was right-handed so she sat at his right-hand side. She knew that he could not feed himself with the spoon alone but she tried to have him guide her hand with his own. She tried to make his experience from food as enjoyable as possible. She looked at him and talked to him. I add a quote from my notes: "Mr Kudrna, do you want the salad?" She could not guess the answer from the reaction and so she continued: "I'll give you a sample." She proceeded as best she could. We continue recounting with Jitka, sharing what we have seen and experienced. We ask questions and together we try to answer them: Why is Mr Kudrna getting blended meals? What are the health reasons for that? How long has he lived in the retirement home and what do we know about his character, about his history? How do we determine his needs and abilities, participates in that, how does the adaptation developing ... Nurses, caregivers, the nutritional therapist, social worker, manager, all have something to say to that. The active role of Mr Kudrna during our meeting with the employees was only mediated – he conveyed non-verbally to Tereza that rather than pureed food he would eat the fried cauliflower with his own hand. Mr Kudrna will not draw up his own care plan, he will probably not even say what he needs and what he wishes. To have a good quality of life despite all his limitations, he will need the whole team – and also his family if they are willing and have something to contribute. It would perhaps be better for him to get stronger and gain weight now after the stay in the hospital. Maybe. He wants to eat, that much he has clearly conveyed to us. It went very well today with the cauliflower. Tomorrow there will be chicken, so we may need a different approach. The discussion is drawing to a close.

I recall the reactions I sometimes hear in similar situations: “Well, then we would have to think about every single patient and prepare the food differently for everyone. We simply don’t have the time, there is too few of us.” I hesitate, deciding whether it is the right time to share this experience. In the end, I decide to banish the thought, the memory of what happened today at lunch prevails. What’s unforgettable about this story is not only the fact that Mr Kudrna left the table today full and satisfied, but also the joy which he brought to the caregivers present. With this we dissolve the meeting.

We have encountered two things today which we found very important. First, the willingness to recognize that things are not going as we would have hoped and planned and prescribed, but they happen “*ad hoc*” in the intricate web of relationships making up care. Second, we have encountered joy from joy – a clearly recognizable pleasure felt by the caregivers because Mr Kudrna felt good, he ate well and with his own hand and he will probably get stronger after the stay in the hospital. The members of the Bon Appetit team devote a lot of effort to planning, training, inventing new procedures and monitoring and inspection of compliance with them. The following was recorded in the minutes from one of the first Bon Appetit team meetings: “It is always necessary to remind the employees that for every rule there is an exception if it brings benefit to the client (of course only in accordance with the applicable legislation). The employees should know the reason why they are performing a task or activity differently than they are used to.” The rules say what we should do and what we must not do. The caregivers we have met today were performing their tasks – caring – according to these rules. Whether their actions are guided, aside from rules which direct their immediate conduct, also by the interest in a good and dignified life of the residents in the retirement home, we cannot say for sure. In this particular case, however, there is no reason not to trust in their good intentions.

Let’s move back to the dining room during lunch. Mr Kudrna is eating his cauliflower, many of us are watching what is happening. Tereza is focusing on Mr Kudrna. The plate with the cauliflower is put on the table linen. The table linen is slipping on the surface of the table and Mr Kudrna’s trembling hands have trouble picking up the individual pieces. Tereza removes the table linen and snaps the plate to the table with a suction gripper. “This will be better for you.”

Tereza may relay her experience to others and perhaps the topic for the next days will be finger foods, or maybe this was an exception and the next day Mr Kudrna will again eat pureed meal for lunch and the meals will be prepared as before. We do not know.

It is difficult to describe and delimit what constitutes good care. General definitions given by law, the methodology and rules cannot uniquely and concretely cover every possible situation. Not even the Bon Appetit programme is an exhaustive prescription for an enjoyment of food. A meaningful relationship, tasteful and well-prepared food, good position and adequate aids come before everything else, but there is so much more that all of us who together contribute to care must decide, do, change and try, often in difficult and ambiguous situations when we are not sure if we are doing the right thing. Good or bad, appropriate or not appropriate, this varies and changes in care. This presents a great moral and practical challenge to the caregiving professionals as well as the people who receive their care. Every meal – one of the most basic and most important activities we perform in life – has a form of experiment in which the interest in the best possible life of the other person has an important (if not the most important) role.

*The case study was a part of the afterword to the Czech edition of the book by Jitka Zgola and Gilbert Bordillon Bon Appetit! The Joy of Dining in Long-Term Care. The book was published in 2013 by the Czech Alzheimer Society.*

# Frail and Misunderstood

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## Keywords

Geriatric frailty, health in an old age, de-medicalisation, dignitogenesis, longevity, negative competence conflict

## Abstract

The paper deals with the lack of understanding for frail geriatric patients and clients and the dangers they face in health and social services. It draws attention to the change in the nature of health problems in the old age, the risks of neglect of the necessary care due to ignorance, discriminatory banishing from the competence of the healthcare system, including disproportionate changes in the staff qualification structure, and to the existence of serious negative competence conflicts. It mentions the issue of the 'banal evil' in relation to blurred responsibility, maladjustment of the system and over-estimation of the externalisation of control, and calls for systematic protection of human rights in connection with the implementation of long-term care in the CR with the need for dignitogenesis.

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## 1. Institutional "elder abuse"

Unnecessary suffering or even a threat to life can occur in health and social services for different reasons and on many levels. From a gerontological point of view it includes the structure of causes of institutionalised "elder abuse", a violent and inappropriate treatment of the elderly. It may include the following:

- Violence, criminal acts of asocial individuals which are often picked up by the media as part of run-of-the-mill news, even though they cannot be systemically generalised.
- Individual professional errors – violation of professional *lege artis* procedures, non-observance of standards, errors in diagnosis, treatment or care, negligence.
- Lack of interest in the patients/clients and their problems, unwillingness, discourtesy and simple rudeness of the staff contribute to a cold, unfriendly atmosphere, often in connection with the burnout syndrome.
- Inappropriate treatment conditioned by systemic or institutional circumstances and conventions, e.g. the financing, the amount of payments for health care, the blurring of responsibility, the number of staff and their structure of qualification, the number

of caregivers in shifts, etc. It may also include discrimination, e.g. the ageism and contempt for the supposedly “useless” people, sometimes stemming from the general public mindset and disdain.

- Ignorance, lack of understanding of particular issues when the individual caregivers “don’t know what they don’t know”.

## 2. Conceptual approaches to old age

Senior citizens are subjected to two kinds of systemic conceptual (ideational) failures. First is the underestimation of the onset and the needs of a longaeval society, the need to overcome stereotyping and the approaches to the provision of health and social services created in the circumstances of a society with short lifespans and functionally ineffective lives in the old age [1]. Examples of issues that are underestimated:

- The potential for a successful ageing and an active old age – the continuous improvement of the health and functional condition of the newly aged generations to which a shift should correspond from the fixation with “care” that conserves incapability towards “support” in the form of supportive interventions aiming to restore the previous functional condition: self-reliance and autonomy.
- The issues of the changed nature of health in the old age including the meaningfulness of support for the relative health of chronically ill people, their fitness, resilience and adaptability.
- Competent provision of healthcare services to clients in long term care and in social services facilities including the respect for their human rights including the right to health care.
- The issues of geriatric frailty and its clinical consequences, the loosening of geriatric disability and the health problems arising from the index diseases.

The second area of systemic conceptual failures is related to reductionist contempt for frail, often multimorbid people whose self-reliance is under threat or completely lost. These people are often perceived as little more than biological systems which need to be cared for in the most austere manner possible. The consequences include:

- The challenging of the general applicability of the Maslow hierarchy of needs in its higher levels. [5]
- Priority assigned only to meeting biological needs.
- Contempt for the autonomy and will of these people and to the very meaning of life with serious functional deficits (Viktor Emil Frankl). [2]

- The underestimation of the risk of inducing dependency and the loss of self-reliance, the preference for institutional care over community care.
- The overestimation of the need for austerity and the economisation of care.

The effort to overcome these negative reductionist opinions can be based on several widely accepted humanist concepts which need to be implemented in specific gerontological applications. These include especially:

- The concept of health (WHO), according to which health is more than just the absence of illness (Aaron Antonovsky); pathology is thus more than just the presence of index diseases – it may also be the condition of the organism.
- The concept of the bio-psycho-socio-spiritual unity of a person who cannot be reduced to a biological system.
- The concept of successful ageing and a healthy old age (WHO), according to which disability often becomes disconnected from illnesses; however, it remains a preventable and intervenable medical condition.
- The hierarchy of human needs (Abraham Maslow), which includes not only biological but also higher psychosocial needs and the highest spiritual-existential needs for self-actualisation. [5]
- The formulation of a universal, highest human need to be positively accepted as a unique human being with unforfeitable dignity understood in the continuity of their personal development and life story.
- The ontogenetic task for the old age, which is to preserve personal integrity against hopelessness, despair and the fear of death (Erik Erikson).
- The principles of societal support of disadvantaged elderly people (UN, 1991), which includes not only their basic (biological) needs being met, but also dignity, autonomy, self-actualisation (meaningfulness) and social participation.
- The concept of geriatric frailty as a specific conception of health and illness on a low level of health potential understood as the inter-connectedness of fitness, resilience and adaptability. On lower levels the occurrence of “banal” bio-psycho-socio-spiritual stressors with the potential to decompensate the organism and its dynamic balance.
- The concept of intervening in all factors of functional health – biological and nonbiological (Mary Tinetti), if discriminatory exclusion of “atypical” geriatric patients from healthcare competences is to be prevented. [6]

### 3. The concept of long-term care

In order to save money and increase the purposefulness of expenses, the Czech healthcare system has long rejected medicalisation of the “natural” old age including healthcare competences in dealing with health problems of geriatric patients with no connection to the index diseases. Such patients are often labelled as “social cases” or “casus sociales”, which are only unjustifiably blocking hospital beds (so-called “bed blockers”). This happens not only to people in need of social help (i.e. asylum), but also to people with endangered or lost self-reliance whose health-social problems were not even described, evaluated or understood e.g. as part of the comprehensive geriatric assessment (CGA) or geriatric evaluation and management (GEM). Sometimes people with a mere risk of lengthy and more complicated stay in the hospital are *a priori* labelled as such – patients who are “too old”, unkept, unfit (frail), not liked and unwanted (called disparagingly GOMERs – Get Out of My Emergency Room – in Samuel Shem’s novel *The House of God*).

In the 1980s the international community has formulated a concept for a reform of support for people, especially senior citizens, or frail geriatric patients with a long-endangered or lost self-reliance. Unlike the current care focused on institutional care connected with a series of very serious psychological, ethical and economic problems, these concepts called for:

- de-institutionalisation – a focus on community services and support allowing ageing and dying in familiar and natural domestic environment and the domestic community (ageing in place, dying in place); in case of the necessary institution, these should be opened as a part of the natural community space;
- de-sectorialisation – breaking of departmental and professional barriers while increasing the flexibility of the system and patient/client comfort, since their needs are usually multidisciplinary and health-social in nature;
- de-professionalisation – the admittance of laypeople, especially family caregivers but also friends, neighbours and volunteers as members of the team, who are often capable, after training and under supervision, of carrying out a number of tasks, especially in care-giving and rehabilitation, much faster, more flexibly and conveniently for the client than professionals;
- humanistic de-medicalisation – making services more civil and putting first the quality of life, the purposefulness of care, the basic human right for care, the “hunt” for diseases, hospital regimen and the lifelong role of the patient.

From these priorities of humanisation and economic sustainability of high-quality care evolved the concept of long-term care (LTC, with an important financial backing from OECD) as a health-social pin and the third pillar supplementing health care and social help. [1,3]

These purposeful and positive measures can, however, be seriously, even “gravely” deformed in a discriminatory way by the efforts to reduce costs for long-term care and its pushing out of healthcare competences and away from payments from public

resources including the general health insurance in the interest of stabilisation of public budgets and their mandatory expenses. The risks include, for example:

- de-institutionalisation without community preparation (“expulsion from institutions”);
- de-professionalisation of care in terms of making it more primitive, reducing the qualification structure, unauthorized delegation of competences to unqualified staff;
- Economic-reductionist de-medicalisation – excessive reduction of expenses, unauthorised termination of care, excessive and unethical pseudopalliation of care (palliation of “useless people”), reduction of contact with the physicians and caregivers, discrimination and worse access to health care especially in institutions.

The argument is based on a myth of healthy chronically ill patients whose primary condition is medically untreatable (e.g. post-cerebrovascular accident condition), but who are not in any way protected against comorbidity in an unstable state (a very common condition in the old age) or an occurrence of acute diseases and complications (post-CVA paralysis is no way protecting against acute heart infarction, gallstone colic or a decompensation of arterial hypertension). Still, there is an apparent willingness to create in essence “no-doctor high-capacity ghettos” in long-term institutional care facilities which cannot realistically be covered by local general practitioners.

## 4. Negative competences conflict

A very dangerous phenomenon is present in the form of serious and frequent negative conflicts of competences, a no-man’s land not assigned to anybody in terms of competences and responsibilities (a deficit of de-sectorialisation). Many frail people thus become unwanted, with no recourse or support due to the simultaneity of:

- discriminatory de-medicalisation – they are too “social” for healthcare services (casus sociales, hospital “bed blockers”);
- de-socialisation – they are too sick for social services, especially for residential care facilities (social care institutions). They are rejected, face inaccessibility or serious complications to accessibility, massive reductions in the quality of health care, especially that provided by a physician;
- de-municipalisation – in the absence of the right of residence, the municipalities lack the competence, money and interest to deal with the situation.

Furthermore, there is an ageist social contempt for people excluded in this manner (i.e. socially excluded, “unwanted”) who remain at the fringes of society, as well as a form of de-personalisation – a de facto denial of human uniqueness and autonomy, with a uniform application of institutional care with only formal pseudo-individualisation. It

constitutes an unacceptable assent to the argument of “overageness” and “uselessness” of a large group of people, a confirmation that they have become a “social burden”.

Overall, the situation can be characterised as follows:

- There is a large group of predominantly old people with limited or lost self-reliance with a combination of health-social needs.
- They are frail, face specific risks and have special needs as well as atypical health problems.
- They are often misunderstood by professionals and thus harmed by geriatric hospitalism – by needless complications resulting from stays in hospitals without a safe regimen which could prevent predictable complications including the induction of self-reliance loss (overstay in low-cost interventions, excessive restriction of movement, malnutrition, “*non lege artis*” procedures in prevention and management of deliria, etc.).
- This is tolerated due to the disdain for the quality and value of their lives – they are people “left behind to be neglected”.
- Hospitals are plagued by insufficient nutrition, unauthorized restrictions, needless loss of self-reliance and excessive induction of the need for aftercare.
- There is a tendency to place these citizens, often prematurely and in non-stable condition, in facilities providing wrongly perceived after- or long-term care with a limited availability of physicians and nurses.
- There is also a tendency to excessively connect these facilities with palliative care.
- This poses a real risk of unavailability of health care for a large group of patients/clients.
- Non-professional caregivers are under threat of delegation (imposition of) excessive competences, which carries not only additional stress but also the legal risks stemming from making unauthorised decisions.
- Even in this after- and long-term care facilities and hospitals too much focus is given to biomedicine, the provision of biological needs and paternalism.
- The staff accept the status quo, their excessive competences and harmful practices, and they identify more with the system rather than with the interests of the clients.
- There is a growing sectorialisation of care – teamwork, co-ordination and personal responsibility are declining.

- Conditions are not being created for the development of community care/support (described by Milan Cháb as a “network of services for people in danger of institutionalisation”) leading to a prevention of institutionalisation.
- Quality standards are often degenerating into formal adherence to rules (“copy-paste”) and bureaucratic busywork diverting attention from the work with clients and also reducing personal accountability.
- The limiting of the number of autopsies starting with the year 2014 will also reduce the likelihood of detection of professional errors in hospitals, let alone in the after- and long-term care facilities and it will contribute to discriminatory de-medicalisation and reduction of care.
- The societal failures are much more serious than the individual failures of caregivers.

In general, the geriatric patient/client is currently:

- stereotyped,
- misunderstood,
- underestimated,
- endangered,
- written off,
- driven out of health care,
- connected with de-medicalised “long-term care” which is often identified with the institutions and palliative care.

The risks brought by new competences to unclearly defined long-term care and its paramedical staff are considerable:

- problematic (non)acceptance of primary responsibility – performing fictitious indications by fictitious physicians;
- simplification of health problems and interventions into nursing, or even basal treatment;
- simplification of dying as nursing, even though home care of a dying person is not a comprehensive palliative care, not a home hospice!
- preservation of unacceptable practices.

## 5. Current threats in the health and social areas

The preservation of dangerous practices in health care includes for example:

- enduring absence of comprehensive geriatric diagnostics, CGA, GEM;
- a renaissance of restrictive measures accompanied by the desensitisation of the public, speculations of an informed consent given prior the admission into care, use also in home care;

- deterioration of nutrition during stay in institutional care;
- needless and unauthorised insertion of urinary catheters in cases of incontinence;
- Massive pharmacological sedation in cases of deliria, behavioural disorders and harmless restive behaviour induced by dementia instead of changes in regimen;
- withdrawal from care accompanied by a reduction of pharmacotherapy instead of providing a comprehensive palliative care with mobilisation of the residual life;
- restriction of human rights by a decision of head physicians and the attending nurses.

The preservation of dangerous practices in social and long-term care includes for example the following:

- the physician is not a member of the team;
- the lack of comprehensive documentation and the lack of hierarchical organisation of the existing documentation;
- the absence of clear-cut personal responsibility for the client;
- the absence of procedure determining who makes decision in case of change of the medical condition and who reviews it.

On a societal level, the following contributes to this situation:

- hyper-economisation of society;
- the change of the social paradigm accompanied by the fall of *a priori* values (religion, higher moral principles) – “God is dead, Hippocrates is dead”;
- a symbolic shift from “combating death” towards “sustainable healthcare”;
- neomalthusian fears of human “overpopulation”, the ageing of humanity, demographic alarmism, gerontophobia, ageism;
- eugenic consciousness among physicians (Otakar Motejl);
- anti-Hippocratic collaboration of the caregivers (from the physicians to the nurses) with the system;
- the failure of the academia and medical schools which contribute to the fragmentation of medicine, geriatric illiteracy and single-minded focus on research accompanied by the exploitation of patients instead of a holistic understanding and support. [4]

The blurring of personal responsibility, relativisation of traditional values, hyper-economisation of social life, a growing influence of isolated orders by authorities and a bureaucratic externalisation of control through excessive standardisation furthermore contribute to the spread of the “banal evil” (Phillip Zimbardo) in the society as well as among the caregivers [7,8].

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# The Role of the General Practitioner in Care for the Institutionalised Elderly, Treatment of Pain

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## Keywords

General practitioner, facilities for the elderly, total pain, restlessness

## Abstract

This paper is concerned with specific characteristics of a general practitioner's care for the elderly, especially those living in an institution. The author presents the complicated nature of her patients' ailments, the possibilities of and demands for communication with the staff and the patients' families. Specifically, she contemplates the ways of addressing pain and acute restlessness.

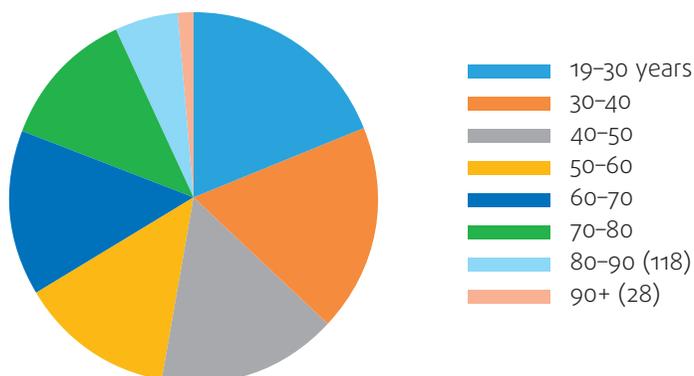
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## 1. The elderly in a general practitioner's care

When preparing my paper, I first asked myself how many retirement homes are there in my area. In the radius of 30 km, I found six: in Pacov, Proseč u Pošné, Chýnov, Pelhřimov, Onšov and Humpolec. Three of these six facilities are equipped with specialised beds (with a special regime) for seniors with Alzheimer's dementia.

I also determined the age structure of my clients.

### Share of the office's clients by age



The chart shows that patients over 60 form 33% of my office's clients.

The scope of a general practitioner's activities is different for each age group. In the younger age groups, approximately up to 40 years, I concentrate on primary prevention. As the age grows, illnesses appear. In addition to curing acute conditions, general practitioners commence secondary prevention, screening for cancer etc. Complications of various illnesses occur as well.

However, the elderly are not characterised merely by their age. People of various ages are in various physical and mental conditions. Sometimes, a 70-year-old is active, rides a bicycle and contributes a lot to his or her family and friends. On the other hand, some people over 50 gradually lose their physical strength or are affected by an illness (a cerebrovascular accident, for example) and a comparatively young person thus becomes dependent on the care of others.

Assessing the situations when my patients leave my care to live in an institution, I see the following reasons:

- Deterioration of health, such as the above-mentioned cerebrovascular accident, progression of a heart failure, diabetic complications etc.
- Progression of simple geriatric symptoms (I witness this very often). The elderly live in a village, in a house, while their children live in the city. In the end, when people lose the ability to take care of themselves as a result of geriatric changes (decreased mobility, tendency to fall, geriatric frailty), they are relocated to a home.
- Loss of a person who took care of the patient up until then, e.g. death of the husband, illness of a daughter who provided care until that point, etc.
- Social reasons. For example, a married couple decide to spend the rest of their lives with less worries and find accommodation in a retirement home. Such cases are extremely rare.

Frequently, I am paid a visit by a daughter with her elderly mother, or even the daughter alone, if her parents are in the hospital, the daughter crying because she thought she would be able to take care of her parents in their old age. But she is afraid to leave her job. She does not know for how long she would be leaving and she does not know whether she would be able to find another job at 58. She considers leaving her parents in an institution a huge failure as she would gladly take care of them. I ask myself whether we, as children, should not have the right to take care of our parents.

As far as my co-operation with an institution for the elderly is concerned, I most frequently work with the retirement home in Pacov. This home has the following structure of beds:

- Nursing home – 56 apartments;
- Retirement home – 52 beds;
- Special regime home – 28 beds.

One general practitioner provides care in the retirement home and the special regime home. Assuming that a general practitioner has 2000 registered patients in total, the 80 patients from the home make up merely 4% of this number. One may say that the group is not particularly large, but it surely requires special time and energy.

## 2. Dealing with pain

Let us assume that pain is indivisible. I am speaking about “total pain”, i.e. pain with not only a physical and mental components, but also social and spiritual components. If an elderly person falls, he or she probably really experiences acute pain in, say, the knee. But let us consider pain in the back. Is it vertebrogenic (somatic) pain, or is it caused by an argument the patient had with his or her daughter last weekend and the problem manifests now in a psychosomatic form? And it may well be that the experience is even deeper and we have to deal with issues that are of even a spiritual nature for the patient.

When assessing deterioration in the medical condition, medical history, i.e. the information the patient provides, is very important. It is not only the issue where the patient experiences pain and the nature of the pain, but also how quickly did the pain appear. What were the dynamics of the whole process? In case of the elderly, especially those suffering from Alzheimer’s dementia, we often cannot completely rely on their medical history. In that case, I attach importance to intimation provided about the patient by a nurse or a caregiver: Did the condition occur suddenly, or was there a long-term progression? What was his or her condition yesterday or a week ago? Can this be an acute intercurrent illness with a quite easy solution which is distorting the overall picture, or is it a progression of the underlying disease? Is it possible to carry out further examination (ultrasound, laboratory, X-ray, EKG) or consult a specialist?

Our approach to the patients ensures, at all times, that they have the possibility to autonomously decide as far as they can assess the given situation. However, it always depends on the quality of the physician and the team what possibilities they can offer to the patient.

The problems also include communication – between the physician and the team or between the physician and the patient’s family. This requires a certain amount of empathy, time and communication skills.

### 2.1 Somatic pain

Many conditions, albeit easily treatable, may significantly deteriorate the overall clinical picture of the patient. Above all, these are infections – symptoms of infectious diseases are quite specific in geriatrics. Fevers are rare, at most a slight increase of the temperature occurs. Symptoms of infections may include headache, dizziness, general muscle weakness, pain in the lower or upper limbs, etc.

Aggravation of a heart disease is very frequently accompanied by cognitive disorders.

The overall medical condition may be significantly aggravated by disorders of glucose metabolism, hyper- or hypoglycaemia, respiratory infections and chronic obstructive pulmonary diseases, and also dehydration, disorders of the internal environment with

mineral imbalance, anaemia, icterus and liver diseases, uraemia, intracranial hypertension, and severe depressions. A separate issue is the interaction between medication and adverse effects of medication.

## **2.2 Mental pain and psychological support**

I am not sure to what extent the psychological needs of individuals may be fulfilled by a physician visiting them by their bed. However, such needs can surely be influenced to a large degree. Let us not forget the power of words. We may hurt deeply with words, but we may also bring hope and encourage the patients, at least by reassuring them that we intend to devote our utmost care to their problems. We certainly are not always in a good shape and we are not always able to consider all aspects of our conduct. There are situations when the patient is hurt for some reason, for example on the emotional level, and is not able to process our rational argumentation at all! When experiencing strong emotions, it is hard to follow the voice of reason. And lying in pain in bed is definitely associated with strong emotions. These are moments when we act with the best intentions, but still remain completely misunderstood.

In spite of the current workload of all medical and social personnel, it is somehow assumed that each caregiver, however small or large his or her professional skills, is able to deal with his or her psychological concerns on his or her own. Few things are less true. Caring for mental hygiene of care in the helping professions is a great challenge for their professional organisations.

## **2.3 Social and socio-economic components of pain**

We must also realize that the elderly are often taken away from their environment and their social ties and relationships on which they relied until then have been torn. It is a pity that there is no system to support family members as caregivers. Families would often be glad to take care of their elderly relatives, but are afraid they would not be able to do so. Caregivers lose their job and contacts with friends, often becoming “socially dead”. It is impossible for them to return to work, keep hobbies and maintain social ties. It would be great if the social system could ensure that the caring person be able to return to work, similarly to the situation after maternity leave. It is very difficult to decide to stay at home with the patient and give up one’s own social relations.

## **2.4 Spiritual pain**

Total pain also includes its spiritual dimension. This means full respect for the patient’s personality within the context of his or her entire existence. What was the nature of the relationships in the family? Long-standing habits? Did the whole family have the habit of meeting one another? What were the family traditions, system of values?

Our own feelings and experience with caring for chronically ill relatives can enhance our understanding of these needs. Each of us grew up in a certain area characterised by the customs of the region and the nature of the landscape. A lot has already been written on the influence of the landscape on the experiencing and shaping of the character of a person as a basic component of society.

## 2.5 Case reports

**Case report I.:** Mrs. L. S., born in 1922. She lives with her family under the exemplary care of her son-in-law. One day, the son-in-law called my office, saying that the patient had not slept at all last night and she had been restless, screaming all night. When I visited her in her apartment and performed auscultation, I diagnosed her with right-sided bronchopneumonia. She had had no fevers, she had not been coughing. The illness manifested itself by acute restlessness. The medication of choice was antibiotics. After one week, her condition improved significantly, the patient slept well, sat on her bed and was cheerful and not at all confused.

**Case report II.:** Mrs. J. N., born in 1926, case history includes an ischemic heart disease and deafness. She lives in a facility for the elderly. One day, the patient became confused, started screaming and experienced visual hallucinations. When specifically asked, a nurse told me that the patient had suffered a myocardial infarction and had been resuscitated. I diagnosed an organic psychosyndrome with acceleration of cerebral atherosclerosis, which occurred due to transient ischemia during unconsciousness. The medication of choice was antipsychotics.

## 3. Practical aspects

After assessing all the symptoms and accepting the whole human dimension and autonomy of an elderly patient, medication is prescribed. It is necessary to honour *lege artis*, taking into consideration and respecting also the prescribing restrictions and limits determined by the tariff. Some groups of drugs may only be prescribed by a specialist (neurologist, psychiatrist), some drugs may be indicated by a specialist and their prescription delegated to a general practitioner under the condition of regular check-ups by the specialist.

When prescribing incontinence aids, we must observe financial limits stipulated for the I., II. and III. degree of incontinence at CZK 450/month, CZK 900/month and CZK 1700/month respectively. Aids for various degrees of incontinence may not be combined.

## 4. Conclusion

To conclude, I would like to highlight that caring for an elderly patient living in an institution is a team work. A physician is only a part of the team. He or she relies to a great extent on information obtained from the staff caring for the patient, especially in case of patients suffering from dementia. He or she trusts this information, relies on it, but must also examine the patient, reveal and find the true cause of the deterioration of the medical condition, if any. The physician becomes part of the care management. It is sometimes difficult in terms of organisation to achieve a panel meeting of outpatient specialists, but if the efforts are successful, this is a welcome help to the team and the specialists can participate in the decision-making.

Provision of care for an elderly patient in an institution is only an infrequent, but time-consuming part of a general practitioner's activities. In the course of time, care for an autonomous elderly patient turns into palliative care. In reality, the elderly do not go to an institution to enjoy their retirement and return back home if their medical condition deteriorates and they become dependent on care. Clients always arrive to institutions when their medical condition and social (not socio-economic) situation deteriorate so much that home care is no longer an option.

The causes and treatment of pain and acute restlessness have their nooks and crannies, secrets and specific features and an active approach is necessary to address them.

Work in a complete team is a dream, and ultimately also a blessing for all concerned, but a continuous care for the team is necessary.

# Co-operation of Employees in Social Services, Communication of Information

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## **Keywords**

Communication of information, team meetings, unit, adaptation period

## **Abstract**

Stating an example of a specific social services facility, this paper concentrates on the necessity of close co-operation between all employees of the facility, especially between nurses and employees directly providing care. The prerequisites include setting up clear rules of communication of information between the individual professions.

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## **1. Introduction**

SENIOR centrum Blansko (Centre for the Elderly in Blansko) is a contributory organisation of the South Moravia Region providing residential care to the elderly since 2002.

Currently, we operate 2 services: a retirement home with the capacity of 70 beds and a special regime home with the capacity of 74 beds. Significant milestones for the activities of the organisation include the year 2007, when a new service, special regime home, was registered upon the effect of the Social Services Act, and the year 2013, when we completed our long-term efforts by gaining the Vážka certificate and the Nutrition Care and Basal Stimulation Facility certificates. Our highest accolade was the Quality Label for Social Services with the highest number of points yet achieved.

This success was the result of a long-term team work on the overall development of both services. We've been through good and bad experiences, which I would like to share.

## **2. Organisational structure of the facility**

Until the end of 2007, the organisation structure included, apart from the economic, catering and administrative units, the health and social care units with three departments – social and health care department, rehabilitation department and mobilisation department. Social workers were managed directly by the director of the facility. In that year, we also started providing another registered service, a special regime home.

In 2008, the health and social care unit was divided into the unit of health care and rehabilitation, where only nurses and rehabilitation workers remained, and the unit of social care, including social workers, direct service care workers (hereinafter caregivers) and mobilisation workers.

Thanks to the founder's understanding, we significantly increased the number of caregivers, because care for patients suffering from dementia is much more demanding, the clients must be guided by the caregiver and must receive care 24 hours a day. It became apparent that the **unit of health and rehabilitation care** functions very well, the nurses were able to devote their time solely to healthcare tasks and administrative tasks with respect to insurance companies and physiotherapists were able to devote themselves only to rehabilitation tasks involving both work with instruments and physical treatment.

The unit of social care had a lot of members and, therefore, in the two years of its functioning, it was divided into the **unit of social care**, including two social workers, a quality manager and a mobilisation worker, and a **direct service care unit**, currently including as many as 46 caregivers.

### 3. Experience with the division of units

I would like to deal with the responsibilities of nurses and caregivers, because it may seem at first glance that this division cannot work and I often hear doubtful voices from other facilities. However, in our facility it proved very useful.

It goes without saying that communication of information between the two units must be seamless and I will concentrate on this topic later. The division of the responsibilities between nurses and caregivers enabled to reduce the number of nurses, who stopped carrying out the tasks of caregivers (feeding, bathing, guidance etc.) and had more time for their professional tasks. Thanks to this reduction, we could increase the number of caregivers, who are now able to actually provide individualised care to our clients.

Caregivers are in constant contact with the clients and they are the first ones to notice any changes in their medical condition, because even if the patients do not communicate verbally, they know their responses. They have a "layman's", family-like approach to medical problems, therefore a change in medical condition is not belittled as something that is normal given the age and illness of the patient.

Co-operation between the two units is now extremely good, but obviously, there have been some problems in the past. Nowadays, individual nurses acquaint the caregivers in regular meetings with the various fields of care and symptoms of illnesses. Nurses are also aware of the value of the feedback from the caregivers on the medical condition of the clients and their response to the chosen treatment.

### 4. Communication of information

However, this would not work without consistent communication of information and functioning of all the units as one team.

Information is communicated as follows:

- morning change of shifts by the nurse on duty at night to the heads of the healthcare and rehabilitation units (10-minute meeting of nurses and rehabilitation therapists on duty);
- daily meeting of co-ordinators of the retirement home and the special regime home services with the head of the direct service care unit (15 minutes);
- mutual communication between heads of the health care and direct service care departments: Monday (after the weekend), Tuesday and Friday (after the visit of the physician);
- regular Monday meetings of the following team: the director, head of the health care unit, the nutrition therapist, rehabilitation worker, head of the direct service care unit, co-ordinators of the retirement home and the special regime home services, head of the social care service and social workers;
- information boards in the departments – recording of important up-to-date information (date, signature, removed after 14 days).

#### **4.1 The CYGNUS information system**

The organisation has purchased all modules of the CYGNUS system, which are thus interconnected. Access rights are granted so that each employee can access all information on the clients required from the perspective of the employee's responsibilities. The overviews of daily records are edited by nurses, rehabilitation workers, the nutritional therapist, caregivers and mobilisation workers.

The following system of notifications proved very useful: caregivers send notifications to the nurses alerting them to a client's problem. The nurse must then send a response stating how she addressed the problem. This prevents accusations as to who forgot to report or address a certain problem. This obviously means that all caregivers must be able to work with a computer, because we also work with readers recording all tasks carried out with respect to the given client.

## **5. The role of social workers before the client is admitted to our facility**

Social workers play an irreplaceable role before the client is admitted to our facility.

Our team has reached a consensus as to what we need to know before the client is admitted to our facility so as to ensure that the care for the client is as close to his or her current habits as practicable. Our goal is to ensure that the client does not need to change his or her habits and his transfer to our facility be as little stressful as possible.

In an ideal scenario, the client comes to visit our facility with his or her family before being admitted, but it is more common that the client knows the life in our facility through photographs and stories. We refute the clients' expectation that they are being trans-

ferred to a healthcare facility with a set regime where their family would only be able to visit them during visiting hours and they will have to accommodate to this.

On the contrary, a social worker will learn as much as possible about the clients' physical capabilities and their preferred way of spending time by asking them and recording their answers in forms. The social worker fills in with the client the Table of the Extent of Support, Assistance and Care, Monitoring of Daily Activities, Monitoring of Catering, General Information for Nurses and hands over to the client the Life Story Outline, where the client may write whatever he or she considers necessary to communicate to us.

## 6. Admittance of the client to the facility

If all the above-mentioned information is provided before the client's admittance, the **nurses** know the basic diagnosis and know what care the user will probably need, the **nutritional therapist** knows the client's dietary restrictions and eating habits, the **caregivers** know the life story of the new client and the manner of spending his or her time, needs for his or her support and care, **mobilisation workers** know the client's hobbies, they know whether the person is active or passive, sociable, whether he or she is religious etc. and **rehabilitation workers** are aware of his or her rehabilitation needs.

## 7. Adaptation period

Similarly to other facilities, we also have a system of key workers, where this role is performed by the caregivers. In the adaptation period, the caregivers are responsible for comparing the information provided on the client with the reality, setting up the required care and the daily activities according to the clients' individual wishes and needs. In this phase, the caregivers must visit the client in each of their shifts.

After the adaptation period (3 months), the working team, consisting of the key worker and other caregivers on the shift, the co-ordinators of the retirement home and special regime home services, a nurse, a rehabilitation worker, a mobilisation worker and a social worker, assesses the adaptation.

## 8. Examples of best practice

I would also like to share other manners of communication which proved useful in our facility. These include, for example, Journals for messages between the families and the employees, which are kept in the clients' rooms. We use these Journals, because it is not always possible for the key worker and the family to meet when needed and they can leave written messages for one another. It proved useful for social workers to use e-mail communication, as 80% of the clients' relatives use this manner of communication. On quarterly basis, we hold meetings with the clients' families to assess the past period, showing videos and photos from our events.

Our care would obviously not be of a good quality were we not to co-operate with physicians. By explaining the problems that our clients experience during transportation

for medical examination in ambulances, which is not only stressful for them but also very expensive, we managed to achieve that a general practitioner visits our facility twice a week, a psychiatrist, neurologist, speech therapist and dermatologist once a month, an orthopaedist visits once in two months and a diabetologist twice a year.

# Addictions in Old Age

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## Keywords

Addiction, alcohol, the elderly, harmful use, addiction treatment

## Abstract

Firstly, this paper presents the problem of addiction from the point of view of history and provides the definition and categorisation of addiction. Secondly, it deals with the lack of strategies the society, the families and the employees of facilities for offering the possible solutions to (not only) seniors consuming alcohol. Not every alcohol consumer is already addicted and, in each stage, each consumer needs a different – suitable – form of help.

... addictions sometimes start and never end ... (Reinhard Haller)

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## 1. Introduction

Addiction cannot be belittled as a matter of choice or will, because the illness is a manifestation of a disorder of the biological, mental, and social medical condition of the addicted person and the people closest to the addict (WHO definition).

Dependent or addictive behaviour and consumption of substances usually takes place actively during social occasions. Consumption of alcohol is usually a reaction to dissatisfaction, negative attitudes of other people, a deteriorated mental state and inability to deal with the frustration. The person has a problem, frequently a personal situation that cannot be solved, and looks for something to help him or her to escape (at least for the time being). Ironically, the consumption of alcohol actually does help the person in the beginning. During and because of the consumption the person feels well, relaxed and is looking forward to the next occasion of consumption. We all experience this from time to time, just think about your morning cup of coffee. The situation becomes problematic when the problems remain unsolved for a longer time, they become chronic, consumption increases, doses grow and use becomes an addiction. This process may take years. It appears in all social strata independent of age.

Where in the past addiction used to be connected with the use of various substances, such as alcohol, cocaine, tobacco, medication, hashish, marijuana and others, we unfortunately see today that addictive behaviour and the potential for addiction can be found in a number of other human activities independent of substances. This mainly concerns gambling, workaholism, shopaholism and, last but not least, gaming and the use of the Internet etc. Eating disorders can be included in this list too.

The intensity of addictive behaviour increases in the society and brings along a number of social, financial and interpersonal problems.

Addictive behaviour is a severe mental and chronic illness, not a sign of a weak character – this must be stressed at this point since in the past, addiction was seen as a character flaw, a moral weakness or a fault. From this perspective, overcoming this illness requires professional help and co-operation of the consumer. Such help is only possible in the context of interdisciplinary collaboration between health care and social care.

## 2. Excursion into history

For years, the opinion has been voiced that the drug policy has failed and that an ever-increasing number of people consume drugs (if this were true, we would all be addicts by now) or that the age of the consumers is getting lower. This is not completely true. However, I do not wish to downplay the seriousness of the problem. Therefore, it will be useful to make a small excursion into the history of drugs and their consumption. Generally speaking, every culture at some point in the past accepted one drug and prohibited the others. Problems always arose when new cultures came to the given country and brought along their own (new) drug.

Looking back in history, it is obvious that every substance has its own cultural origin: coca in South and Central America, opium in Mongolia and other Asian countries. Tobacco was originally grown in South and North America.

Alcohol had had a long cultural tradition in Arab countries until its use was prohibited by Prophet Muhammad. But it was also known in China, in ancient times it was known by the Sumerians and old Egyptian sources speak of remuneration for work in the form of bread and beer. We should also mention Bacchus, the god of wine, or the vineyards established by Romans in various parts of Europe. Alcoholic beverages are mentioned in the Old Testament and the Epic of Gilgamesh. The role of alcohol in history is underlined primarily by the manner of drinking alcoholic beverages during religious rites – the “high” helped to achieve a state of ecstasy, meditation, infatuation etc. Such states under the influence of alcohol (or other drugs) played the role of a gateway to the spirit world.

Production of alcohol and its use runs like a red thread throughout history. Alcohol was produced as foodstuff, a drink to quench thirst of the privileged, and the beverage acted as a mediator of social life – this psychosocial function was initially reserved only for some members of society. Even if alcohol was not regularly accessible to many people, the consequences of its excessive consumption and other dangers were known in the past. Already in the ancient times, Plato, Cicero and Seneca warned against excessive consumption of wine. People knew that certain individuals could not stop drinking – for which they were morally condemned. From time to time, the government attempted to introduce measures to curtail the production and spread of alcohol. The first bans on consumption of alcohol are documented by sources from China (8th century B.C.), but Islam and Buddhism were more successful in such efforts. Among the most famous state interventions was the era of Prohibition in the United States in the 1930s. However, the measures did not bring the expected results. Currently, laws regulate where alcohol may be consumed, when and by whom (e.g. in Germany and

Austria, people over 16 may drink beer and only when they reach the age of 18 they may start drinking spirits). In Sweden, the sale of alcohol is in the hands of the state and some types of alcohol are or used to be prohibited, e.g. absinthe. Drivers may not drink alcohol at all or, in some countries, only to a limited extent, etc.)

Europe witnessed the start of an excessive consumption of alcohol in the late Middle Ages and in the beginning of the Modern Era. Alcohol was provided as consideration for work, production was licensed etc. Consumption increased rapidly especially during the times of the Industrial Revolution, associated with the spread of alcoholism as we know it today. Especially beer in various forms belonged (in Central and Northern Europe) amongst the basic foodstuffs. Beer soup was commonly served for breakfast even to children. Nowadays, alcohol is available and accessible almost everywhere – with the exception of Muslim countries – and its production is very important for the economy as well as in terms of tax income.

### 3. Forms of addictive behaviour

Generally, we differentiate between two forms of addictive behaviour. The first is associated with consumption of substances. Legal substances include alcohol, tobacco and medication. Illegal substances include, for example, marijuana, cocaine, morphine, ecstasy etc. Secondly, we recognise addiction without consumption of a certain substance, which is associated, amongst others, with gambling, shopping, media (internet, telephone), addiction to work and, last but not least, eating disorders. Opinions and legislation on the individual forms of substance use differ not only from country to country, but also from one individual to another, ranging from demonization to uncritical acceptance without acknowledging the hazards of consumption. However, it is certain that drugs are substances that affect neurons and have similar effects as poison. It is no wonder that alcohol and drugs used to be sold in drug stores (just like animal poison etc.).

With respect to the influence of the substance on the organism, substances are usually categorised based on three factors:

- the mental and physical effect of the substance;
- how long it takes to induce an altered state of mind;
- how quickly one can become addicted as a result of its consumption.

One fact holds true for all forms of addiction: if the only focal point of your day is the longing for consumption (craving) – when, how, where, what – you are certainly addicted. Addicts are people who are not able to manage their craving for consumption of a certain substance or substances (alcohol, cigarettes, illegal drugs etc.) or are not able to control their craving for excessive behaviour (“addictive behaviour independent of substances”: gambling, eating disorders, Internet, shopping, sex etc.).

A person who learned to manage and co-ordinate his or her feelings through drugs is easily tempted to do this more and more often. Time gaps between individual instances of consumption grow shorter and the positive effect transforms into a strive for ever more frequent possibilities to use the given drug. The ability and willingness to respond to adverse mental states in a “natural way”, i.e. active response and search

for a solution, are transformed into passive consumption. Mental absence with the associated feeling of guilt becomes more frequent. The mental state deteriorates and the person copes with this by consuming more, justifying it by a bad mental and physical state that causes the need for further consumption. The person is caught in a spiral from which there is no escape.

Addicts have one common feature – they have lost personal freedom due to their addiction. They hide their addiction for a long time, deceive their family and friends and respond with aggression if they discover the person's illness (which sooner or later always happens). Why people become addicted to alcohol, drugs, gambling, smoking, etc.? We have yet to find a scientifically grounded answer to this disturbing question.

There is always a number of mutually dependent factors that give rise to one another and develop during this long-term process. The answer to the question why a person becomes addicted (while others do not) requires thorough confrontation with the development of the person and his or her life. Aggravating circumstances which can play a key role include social factors, situation in the family, crises, traumas, violence and heroes and genetic predispositions. In other cases, addiction may be associated with the influence (pressure) of the environment, search for new experiences, boredom, pain, the feeling of being hurt etc.

## 4. The elderly and addictions

Addiction is not unknown in the elderly and loneliness in particular contributes to addiction. Use of illegal drugs is not common among the elderly and neither is addictive behaviour independent of substances. In case of the elderly, addiction usually has the form of smoking, consumption of alcohol and abuse of medication. However, it must be noted that not everyone who gives a drug a go immediately becomes an alcoholic, a smoker etc. Addiction is caused by many factors. Although only a small number of people are addicted – about 5% of the population – the group is large enough given the complexity of the problem.

Smokers among the elderly are usually long-term smokers, bringing their habit to the retirement home. We know that smokers over 60 have twice the mortality rate of non-smokers. Smokers often believe that in their age it is too late to change and stop smoking. A number of longitudinal studies (1987–2011 USA, Australia) show that if long-term smokers over 60 stop smoking, the mortality coefficient rapidly decreases to up to 1.3. This is caused by the fact that the body starts healing immediately after the last cigarette. The carbon monoxide level in blood decreases and blood circulation improves. Even though the risk of lung cancer remains above the average for a longer period of time, the risk of a heart attack is reduced in former smokers already 24 hours after the last cigarette.

Over a quarter of seniors over 65 can be categorised as “risky drinkers” because the consumed volume exceeds “moderate drinking” (data from Germany and Austria). Generally, there are two groups of elderly consumers of alcohol. The first group started drinking a long time ago. Other seniors start later, where we speak of “late manifestation”. They were not addicted in the past but they started abusing the substance as a result of other stimuli: the death of a partner or peers, an attempt to overcome pain,

loss of physical strength, losing interest in their surroundings or in life itself. Or the life is limited by certain rules (in a facility or by pressure of the family). To be more specific, the influences contributing to dependence on alcohol in the elderly can be characterised as either social or individual:

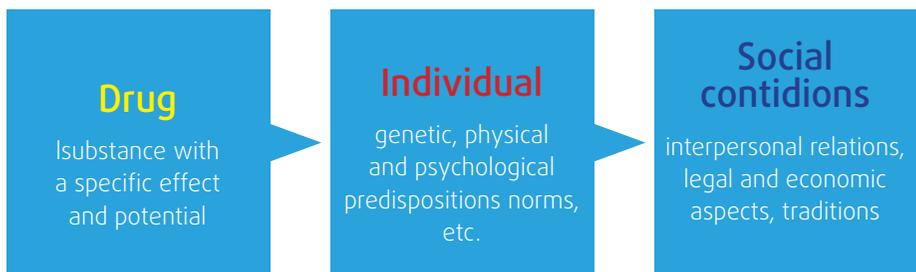
**Social influences**

- the children have become independent
- coping with new circumstances (retirement)
- loss of a partner, friends, peers
- break-up with a partner, family
- inability to come to terms with the change of environment, loss of perspective of one’s life
- influence of family and friends

**Individual influences**

- inherent impulsiveness, aggression, increased sensibility
- genetic predispositions
- traumatic experiences, loneliness
- feeling of helplessness, being subjected to violence by others
- depressions
- loss of interest in personal development, loss of interest in the personal and social life
- comorbidity – depression, pain, internal problems, overall deterioration of medical condition
- incorrect treatment of an illness associated with old age

In summary, three intertwining, mutually dependent factors can be identified in connection with addictive behaviour: a drug or a certain activity, the individual’s predisposition and social conditions.



The basic principle of all addictive behaviour is always the same – be it in people, animals, children or adults – a REWARD. In interaction of all three factors, consumption does provide a certain reward. In consumption, neurons stimulate the hormone dopamine which probably plays a key role – it rewards us and works as the central motivation for addictive behaviour. People mostly reach for the bottle to feel better in the short-term, to forget. Alcohol provides means of escaping the problem as a strategy to overcome it. Alcohol rewards.

Family and friends usually do not notice drinking, the topic is a taboo for both the family and the staff in the facility. Moreover, symptoms of alcoholism, if any, are considered as results of old age, depression, beginning dementia etc., which sometimes irritates even professionals. The main reason is that the elderly do not drink "in public" (as younger people), rather, they withdraw into solitude and drink secretly, discreetly.

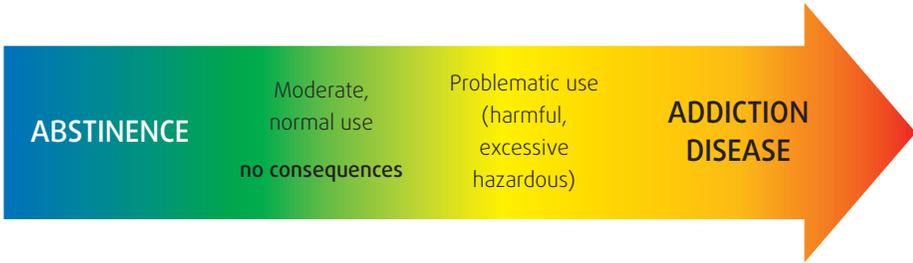
Consumption of alcohol is even more critical because in the elderly the addiction is associated with abuse of medication: in retirement homes, 40% of residents use tranquillisers; psychopharmacologics are prescribed to 2/3 of residents over 65. For the elderly, this means a dangerous cocktail of alcohol and medication, largely prescribed by a physician.

Assessing reasons for addictive consumption, we can easily find what the given person actually needed. However, in each case, there are many interacting factors, the most important being the person as an individual. The choice and effect of the drug plays an important role, just like the attitude and response of the society. However, it must be highlighted that not everyone who drinks alcohol automatically becomes an alcoholic. There are several stages a person goes through before becoming an addict.

Addiction is usually diagnosed if at least three of the following six symptoms have occurred in the past 12 months.

- A long-term, strong, unsustainable pressure, desire or wish to consume alcohol (craving).
- A reduced ability to control oneself and the consumption (its beginning or end) in connection with the volume of the substance consumed.
- If the patient does not consume alcohol, physical withdrawal symptoms appear (e.g. hand tremor, depression, restlessness, insomnia, epileptic seizure etc.).
- Tolerance of the substance increases, i.e. larger doses are required to achieve satisfaction formerly achieved with smaller doses.
- Other interests, contacts, pleasures and activities are neglected due to consumption, more time is devoted to consumption, obtaining the substance, etc.
- Continued alcohol consumption despite the awareness and visibility of negative physical, psychological and social consequences (e.g. lack of money, loss of job, friends, etc.).

Alcohol is a drug with a high hazard potential. In most countries, its consumption is allowed and wide-spread, alcohol is relatively easily and freely accessible, inexpensive, consumption is "hip" in all social strata and at almost all occasions. But it would be wrong to believe that if a person consumes alcohol he or she instantly becomes an alcoholic. The process is not so simple. The "career" of an alcoholic goes through several stages and we can diagnose consumption based on the person's behaviour. The path to addiction is much longer. We usually speak of several stages.



**Moderate use** is a harmless, non-hazardous consumption – this is a situation where the amount of alcohol consumed per day is below the line of low-risk. This line is 20 grams of alcohol for men (16 grams for women) – this corresponds to one beer or two decilitres of wine – there are two days of abstinence a week.

A **problematic, hazardous use** is the consumption of alcohol where the doses exceed 60 g (40 g for women) a day and alcohol serves as a substitute solution – the person has a certain problem and alcohol “helps” him or her to solve it. Hazardous use usually transforms to “**harmful use**” – the person consumes alcohol when he or she has a problem that he or she is not dealing with. If the primary problem is solved, consumption is reduced. If harmful use lasts for a long time (at least one month, or if it occurs repeatedly within several months), it is transformed into chronic use, i.e. addiction. A habit is created together with a certain ritual and regularities. Doses increase to achieve a certain sensation. Excessive hazardous consumption also leads to physical and mental harm to the organism.

**Addiction** – continuous consumption; if the person does not consume alcohol, withdrawal symptoms occur. One thing holds true for addictive behaviour and consumption of dependency producing substances – the longer one consumes the substance, the bigger doses are required to achieve the desired original feeling. This means that the person needs to increase doses and if he or she does not consume the substance, withdrawal syndrome occurs.

The elderly often engage in harmful use. Such situation occurs when the elderly person consumes alcohol because of a certain problem which he or she does not address (e.g. pain, trauma, debt). If the problem is solved, consumption is naturally reduced.

## 5. Treatment of addiction – specifics of treating the elderly

The rule of thumb is that only a very small percentage of addicted patients are able to overcome their illness without professional help of physicians, therapists, social workers, counsellors in the area of addiction and psychologists. But therapy dealing only with the primary problem is not enough – the patient takes steps, the problem disappears (e.g. the patient goes to a clinic, gets cured and everything is fine) and the addict can start drinking again. Treatment generally involves an interdisciplinary co-operation of a team of professionals in various fields. Similarly to other illnesses, alcoholism has various clinical courses and the treatment procedures are complicated.

In addition to professional help, active approach of the patients is also required. Patients are responsible for their own actions and the willingness to change their behaviour and setting up their goals is a necessary prerequisite for a life free of drugs, alcohol etc.

The treatment and therapy is hindered by the fact that a number of alcoholics suffer from mental disorders and two thirds of them live in material need. This is why sometimes the declared (by the therapists) goals of the therapy miss the mark. Everyone needs goals in their lives. But the goals must be specific and realistic. The goals of therapy are always dependent on mutual co-operation: the right method must be offered at the right time. We always work with the patient's YES.

The patient must understand that addiction is not their fault, but rather an illness – and, similarly to diabetes or high blood pressure, this illness must be treated. In an optimal scenario, the therapy is aligned with the patient's environment – partner, family, employer, if any, staff of the home etc. Therapeutic intervention is based on the patient's motivation, which should not be that the patient wants to stop drinking (only a small percentage has this motivation), but that he or she wants to change something in his or her life. The motivation is often the wish to change one's habits, which can be very difficult, because after giving up the substance, the person loses the only thing that he or she trusts and that makes him or her happy.

However, the addicts must primarily realise that they are in fact addicted. This must be stressed at this point since, in the past, addiction was seen as a character flaw and a moral weakness or fault, which leads to a situation when one automatically refuses to admit his or her illness. Addiction is an illness, the addicts are responsible for the rest of their lives and the treatment, counselling and therapy are similar to those offered to younger people. In case of the elderly, we often witness refusal of therapeutic procedures for the following reasons:

- **lack of suitable motivation** and strategies due to insufficient information;
- **overbearing pressure of the therapist in decision-making on further steps;**
- **insufficient communication** with specialised facilities, lack of such facilities and **difficult access** to the facilities (facilities are not widespread enough);
- **negative attitude against alcoholics as patients** (scorn) shown by physicians and the public, politicians, the hospitals' treasury etc.
- **stigmatising stress on own culpability** in comparison to other illnesses not "caused" by the patient (heart attack, cancer etc.).
- **downplaying** of the problem by the public and professionals (2.5 times higher coefficient in case of physicians);
- sixty percent of patients in clinics subsequently state that prior to commencement of treatment they did not consider abstinence as the best solution;
- **lack of suitable treatment concepts.**

Problems include also the alcoholic's picture of his or her live in abstinence. There is often no other option for the addict, or the addicts do not have sufficient strategies to maintain abstinence or they do not want to abstain, because abstinence will negatively impact their subjective quality of life. But there are intermediate stages of abstinence. There is total abstinence, partial (e.g. abstinence from one substance), planned (e.g. fasting) and other types.

But even those who decide to abstain from consumption but later are not able to go through with this (they go through a relapse) need professional help and therapeutic intervention, not judgement. Relapses may occur on individual basis, but this simply is a part of the illness. Nowadays, we know that in the stage of excessive consumption, the priority is to restore the addict's mental balance and possibly reduce the consumption. It is only later that abstinence becomes the main goal.

The motivation to "*change something in my life and find a new aim in life*" plays a key role in particular in case of the elderly. The proposed abstinence is often the biggest problem for the elderly. Therefore, other methods and possibilities must be offered to the elderly to at least reduce the consumption of alcohol if the given patient refuses abstinence. This is important to prevent discontinuation of the contact with the therapist (due to "resistance"). Methods which can be proposed include: psychotherapy, change of diet, intervention in problematic situation at home, in a facility, in contact with relatives etc., treatment of other illnesses, prevention of injuries. Moreover, loneliness can be prevented (alcoholics live in seclusion), the daily life can be structured in another way, contact with other people can be offered, organisation rules can be modified (the issue of to what extent bans make sense) etc.

## 6. Recapitulation

Consumption of drugs and addictive behaviour occurs in the society at numerous levels of human activity. In this respect a problematic aspect of addiction must be underlined, namely that there is no way to completely solve the problem of addiction.

If someone says that there is a universal solution and the person claims to have such a solution and to be able to end the problem of addiction once and for all, the person is simply not telling the truth, is not in touch with reality or does not know what he or she is speaking about. There is no solution to the problem of drugs, addiction and the associated consumption applicable to the society as a whole.

However, regulation is possible on the level of society, just as regulation of road traffic is possible. We are also able to provide individualised solutions.

If we accepted this, we would understand that a drug war taking place in Columbia or Afghanistan or someplace else in the world (nowadays also Mexico) does not lead to the expected result and it does not have any sense, because it does not conceptually solve the problem of an individual in the whole chain. There is no ready-made solution for individuals in the whole chain from the producer to the consumer.

Generally, people do not wish to be addicted to drugs or alcohol. People wish to live happily without worries, but they are confronted with reality – their craving for a drink. In the background of each addiction is the unconscious "I want to live".

It is only when we succeed in dethroning the drug as the solution to conflicts that we are able to break the vicious circle and we have a chance of success. It sometimes takes the patients a lot of time to realise their situation. No sooner than they feel bad do they start questioning the meaning of their life and contemplating changes. Posing these questions at an earlier stage is sometimes only a theoretical dream.

# Individual Approach to Clients Suffering from Dementia Syndrome

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## **Keywords**

Dementia, individual plan, quality of life, the question of why, basal stimulation, orientation, communication, mobilisation

## **Abstract**

The paper deals with the following topics: Basic principles of creating the conditions for a dignified life of clients and providing quality social services, and in particular the importance of individual planning of social services. Description of complications that accompany dementia syndrome. Main principles of communication. Conditions for work with clients suffering from dementia at the author's workplace – organisation of services in the department, two-phase social investigation, care for patients in the adaptation period, manners of mobilisation of clients in the adaptation period and after, basal stimulation as a form of communication with a client unable to communicate otherwise, ways of sharing information on the condition of patients between members of the working teams.

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## **1. The importance of an individualised approach for clients and its meaning**

Individual approach to clients is a basic prerequisite for securing the quality of their lives, building their trust in the staff, maintaining dignity and mutual respect.

By taking an individualised approach, we protect the clients' trust in the people around them and their feeling that they are in control of their affairs. We discover abilities that the clients retained, we search for meaning behind the clients' behaviour, and we maintain and develop partnerships. The staff obtains such information by observing the clients, constantly searching for and discovering the clients' interests even in cases where the clients' communication abilities are limited.

It is useless to take an unprofessional and superficial individual approach where the worker plans the clients' activities and works with them based on his or her idea of what is beneficial for the clients, what the clients need and what brings them the best results and satisfaction. Such approach forces the clients into the role of passive recipients of care. It does not envisage the clients as partners, it does not meet their basic and motivation needs. Employees of the Home serve as guides giving the clients options to choose from, not making the decisions on their behalf.

It is demanding for the caregivers to approach the clients based on their real needs and interests. They deal with people who do not communicate verbally, they cannot keep eye contact and do not resist. They are completely physically and emotionally dependent on their environment. Situations occur where caregivers, although acting in good faith, wrongly make decisions for clients and take charge of them. They do not realise that clients with a cognitive disorder are adults with adult responses, equipped with adult experience and, even after losing some of their abilities, they still consider themselves adults. We must respect that.

We approach the clients knowing that each of our interactions influences their feelings and behaviour and their trust in us. It is easy to lose the clients' trust. Every day, incidents occur that undermine it. For example, we tell the clients that everything is fine while it is not, we address them using a diminutive, we enter their personal space without asking for permission, we remove plates and cups without their consent, we move people in wheelchairs around without them knowing why etc.

We need to ask ourselves the following question: "Would I trust someone who would do this or say this to me?" If the clients stop trusting us, they remain alone and vulnerable. Then they start refusing being dressed and bathed, or they refuse to take their medication. Distrustful people accuse the caregivers or scream that they wish to return home etc. We contribute to mutual trust with the clients by our approach too.

*For example: We are pouring tea. We can either do this without words, without addressing the given patient, without eye contact. Our message is: "I do not have time for you, you are not important to me." But if we address the client, ask him or her to pass the cup to us, the message can be: "I am here for you, you are important to me."*

## **2. Issues that our staff need to take into account in order to work with clients on individual basis**

For the care-giving staff to realise why it is necessary to apply an individualised approach to the client at all times, the staff must be aware of who their clients are.

A person whose life and behaviour is affected by cognitive functions disorders lacks abstract thinking and may feel that he or she has lost control of his or her affairs, feels uncertain and is very vulnerable. We must recognise that his or her altered behaviour is caused by dementia syndrome, the person does not behave in the given way on purpose. We must accept the clients as they are without reservations. Even if the clients clearly do not respond, we may not assume that they do not perceive feelings that are expressed to them, although they did not elicit any response.

To understand the key role of an individualised approach to clients suffering from dementia, it is necessary that the staff of the Home is aware of the following facts and problems caused by dementia.

### **2.1 Components of the quality of life of a person suffering from dementia**

Strict application of an individualised approach at all times, i.e. making use of the person's retained abilities, stereotypical repeating of activities, active participation in daily activities, use of inherent skills (e.g. handshake), maintaining the patient's dignity, expressing recognitions, praising their successes.

## 2.2 Disorders of memory, in particular short-term and working memory

We cannot expect the clients with cognitive disorders to remember our instructions, comments and incidents that just happened. Open-ended questions such as the following are absolutely unsuitable: “What did you have for lunch?” It is much more suitable to ask: “Have you already had your lunch?” The more we explain, the less confident the client will be, because he or she will not understand what we want and will say NO! We must be aware that clients compensate for lapses of short-term memory by repeating questions. This requires immense patience of the staff, as we either have to repeat the answer or turn the conversation in another direction.

## 2.3 Communication problems

It is necessary to minimise dependency on spoken word. People suffering from dementia are still able to understand body language in particular, our moods and our honesty. We should support our verbal communication with suitable gestures. For example, if we are asking the person to sit, we point to the chair, the subject of our communication. The care-giving staff must sometimes accept responsibility for understanding the client and making themselves understood. Whatever the clients say has some meaning. Therefore, the question we most frequently ask ourselves is **Why?** I.e. what the client wishes to communicate by his or her behaviour.

*For example: The client is uptight when being provided services, he or she refuses to be touched. If the caregiver fails to ask **why** the client behaves in this manner, the client is labelled as aggressive and a sedative is prescribed without the cause being eliminated, which may be pain, for example. The client becomes detached and does not trust us any longer. If the caregiver asks “Why?”, i.e. why the client behaves in this manner, the caregiver starts to look for the cause.*

When communicating with clients, one must observe basic principles of communication. Above all, the clients are our equals. We must know how other people, especially their family, communicated with them up until now and to what degree was the communication successful. We must also find out whether it is necessary to use any aids in the communication, whether the clients are suffering from a sensory disability, whether their glasses are suitable, whether their hearing aid works well etc. We must always keep eye contact, speak clearly and slowly, we must not use foreign words, but rather speak in simple sentences, always concentrate on one thing only, ensure that the communication is not disturbed (radio, TV) and the client is not distracted. We must only pose YES – NO questions and pay attention to body language. We should stop the communication if the client is no longer paying attention. The cornerstone of successful communication is active listening.

In order to encourage the clients to communicate, we always approach them in an open, friendly and kind manner, even if we are in a bad mood. At the beginning, we always address the clients using their names to ensure that they pay attention to us. We pay attention to the ongoing conversation too, we do not let ourselves be disturbed by anyone and anything. This helps the clients concentrate. Each time we meet the clients, we introduce ourselves, we do not rely on the clients being able to recognise us. It is necessary to indicate the aim of the visit in simple sentences, using plenty of body language. If the clients respond negatively or are nervous, we do not start an argument

and refrain from reproaching the clients. It is paramount for the clients to see us not as an enemy, but as a source of comfort and safety.

## **2.4 Problems with confusion**

Clients suffering from dementia syndrome can be confused in respect of people, place and time. Clients can be supported with aids indicating the given place (labelling of the bathroom, dining rooms, and lifts). It is necessary to use symbols the clients will recognise. Walls should be equipped with large clocks and calendars. The clients' recent photographs do not reduce confusion at all as the clients may not recognise their own faces any more. One of the most important aids to reduce confusion is to introduce a regular daily regime, repeating the activities in the same manner. It is not suitable to change the equipment of the clients' rooms and move the clients where unnecessary.

## **2.5 Attention disorders**

It should be noted that a person with dementia cannot pay attention to more than one thing. For example, if flowers are on the table when a meal is served, the flowers capture the clients' attention and the clients cannot pay attention to eating. Another example: if we serve all courses at once, the clients do not know on what they should concentrate and they do not eat.

Even the caregivers unintentionally disturb the clients' concentration when serving a meal. For example, if the clients stop eating, the caregivers constantly urge them to eat, explaining why they should eat, that it is healthy etc.; by doing so, the caregivers unintentionally distract the clients from eating. A light touch on the shoulder or hand would be enough to lead the clients in the right direction. Such a gesture does not need a large amount of attention, but can successfully direct the clients' attention to the meal.

## **2.6 Disorders of visual perception**

Visual perception disorders have an impact on a person's ability to function in society and distinguish between objects and the background. Such disorders may cause the person not to see cutlery on a white tablecloth, or a white toilette in a white bathroom, causing men to use a clearly visible bin instead of the toilette. People suffering from visual perception disorders may have trouble recognising familiar objects; for example, they may use a toothbrush to comb their hair or fail to recognise faces. If unable to identify objects in their surroundings, the people tend to suffer from hallucinations and delusions, for example considering shadows as figures etc.

## **2.7 Clients need to feel that they are in control of their own bodies**

Clients wish to feel important and useful. This can be demonstrated on administration of fluids to immobile clients, which can be done in two ways. If the caregiver does not include the clients in the activity, they feel that someone else decides how much water they will drink, how fast they will drink to ensure that their clothes remain dry.

But, performing the same task, the caregiver can put the client's hand on his or her own, enabling the client to control the flow of water and the grip of the glass. The client is no longer a passive recipient of care, he or she has the feeling of being in charge and is satisfied with his or her abilities. Such approach can be applied to all activities, e.g. when performing hygienic activities, the caregiver can ask clients to hold

the soap or sponge, ask them to raise their hands, or look in the mirror with the client and compliment the client's hair.

### 3. Needs of the staff in providing individualised care for the clients

In order for the caregivers to apply an individualised approach to the clients at all times, the caregivers need to have sufficient knowledge about the clients, they need access to a system of continuous education responding to the changing needs of both the clients and the caregivers, and suitable working conditions. This all must be , because only an educated and emphatic employee who has sufficient information on his or her client, knows the client's biography, the client's life story and can guarantee preparation of an individualised plan of social services that is a necessary prerequisite for ensuring a quality life for a person with dementia. Such employees are able to build and keep relationships based on trust, respect and dignity with the clients.

Information on the clients must be precise and continuously updated. The caregivers have to learn about the clients' lives, their hobbies, customs, and their past professions. All this can be found in the clients' biographies and their life stories.

If the clients are no longer able to provide such information, we can obtain such information from the family. But how many people can safely say that they know everything about their parents? A biography provided by the family may not correspond to the current needs and interests of the clients. Therefore, it is important that the caregiver regularly supplements the biography by observing the client.

*For example: Interest of the family different from the interest of the client. We admitted a client with Alzheimer's dementia who used to be a renowned fashion designer and her work was her hobby. Her daughter, who provided her mother with exemplary care before her admittance to the home, wished that we support her mother in painting. The key caregiver noticed in communication with the client that she had spoken German with her mother and she kept speaking about a doll with which she had loved to play. The key caregiver verified the client's interest – the client responded best to a realistic doll, admired the blue colour of her eyes and put the doll lovingly in her bed. She drew a few pictures, but she kept returning to the doll, which brought her joy. She also enjoyed translation of simple words into German. The biography provided by the family did not correspond to the current interests of the client. Accepting the daughter's wishes would mean that the client would engage in activities in which she lost interest a long time ago and which did not provide her with the feeling of success. She felt successful when translating into German.*

## 4. Conditions for work in our Home

### 4.1 Organisation of services in the departments

The number of employees is not the only decisive factor. Work must also be well organised. Clients' rooms are divided among the staff based on the schedule of shifts. The schedule is available to each member of staff one month in advance. We consider it important that the team in our department holds meetings twice a day, namely

**from 7:00 a.m. to 7:15 a.m.** communication of information from the night shift

**from 2:00 p.m. to 2:30 p.m.** up-to-date information influencing further provision of social services to the individual clients.

Once a week, a physiotherapist and a nutrition therapist attend the afternoon meeting in each department. We do not have time schedules, only recommended times of serving meals. The pace of work depends on the clients.

#### **4.2 We do not separate the social and healthcare activities**

All members of the team must have comprehensive information on each client, they must know the individual plan and submit comments on the chosen care in relation to the changing abilities of the clients.

Direct service departments are staffed with multidisciplinary teams consisting of general nurses, direct care workers and cleaning staff headed by a general nurse.

#### **4.3 No department is closed**

The clients may move freely about the Home, the system of gates allows the clients to leave the Home at their discretion, but prevents confused clients from leaving the premises. If such a client wishes to leave the premises, we try to discover his or her intentions and, if we ascertain any, for example shopping, we allow the client to carry out his or her intention under supervision by the staff.

#### **4.4 Collection of information and knowledge about clients**

In order to ensure that the key caregiver has as much information about his or her client as possible, we carry out two social investigations prior to the client being admitted to the Home. The key caregiver receives the first pieces of information from the application and the participants of the first social investigation in the household of the future client (social worker).

The key caregiver participates in the second social investigation. At this occasion, the caregiver receives the basic biography sheet and life story from the client or his or her relatives. The caregiver sees the client in his or her natural environment, where the client feels safe, surrounded by familiar objects. The caregiver has the opportunity to observe the client's retained abilities and determine the expected form of support. If the key caregiver saw the client when admitted to the Home for the first time, the caregiver's idea of the retained abilities would be completely different and the degree of support could be overestimated.

#### **4.5 Adaptation period after the client's admittance to the Home**

During the adaptation period, the client adapts to his or her new environment. This means that it is necessary to accommodate everything to the settings the client was used to as much as possible. This mainly concerns accommodating the client's room based on his or her wishes – bedding, paintings, photos, small items of daily use such as cups, spoons, etc., we ask the family for co-operation. At the same time, specific planning of social services must be commenced. This must be done with the client's co-operation, with his or her active participation, based on his or her interests, wishes and needs.

During the adaptation period, we observe certain principles allowing the fastest possible adaptation to the Home. The key caregiver remains on duty with the client for two days after the client's arrival to the Home, caring for the client to verify what tasks the client is able to carry out independently, in what activities the client needs support and what is the degree of risk. Based on these findings and information from the social investigation, the caregiver draws up an Individualised Adaptation Plan within five days of the client's admittance and this Plan is binding on all members of the team in the department for the duration of the adaptation period. The Plan is being modified based on findings concerning the changing abilities of the client, which follow from the daily observations of the staff. Each change to this preliminary plan is discussed at team meetings and conclusions are recorded in the Messages for Key Caregivers journal. Information on the client is discussed daily at meetings of the team in the department – reported by the employee who was on duty with the client. Once a week, this information is discussed at a meeting with the head of the Direct Service Care Department – reported by the head nurse, and at the meeting of the management of the Home – reported by the head of the Direct Service Care Department.

Information boards with the regime of the day located by the client's bed ensure that all members of the team proceed in the same manner, conform to a certain form of support and active participation of the client. The client's key caregiver is responsible for updating the board.

The tasks of the staff are facilitated by recording several activities into one form: positioning, skin care, mapping fluids, nutritional care, sipping, food intake, excretion. Information boards in the infirmary provide a clear overview of the areas of rehabilitation and meals and point out the client's allergies. These information boards are updated by the head of the department.

In the adaptation period, the key caregiver prepares, together with the client, a list of the client's eating habits, his or her favourite and disliked dishes, indicating whether the client needs assistance with eating and whether he or she experiences problems with swallowing food. All this information is included in the form titled Nutrition History of the Client, which is then handed over to the nutrition therapist, who determines the client's nutrition status. Clients with a confirmed nutrition risk are provided with an appropriate nutritional care provided by the nutrition therapist in co-operation with the staff of the department, a physician and the client's family.

## **4.6 Serving of meals**

The form of meals is adjusted to the clients' needs. The aim is not only to serve meals, but also to ensure that the clients enjoy their meals, eat with dignity and without difficulties, e.g. finger food, serving on two compartment plates, waiting on individual tables (similarly to restaurants), addressing the clients when serving them food, keeping eye contact, wishing the clients to enjoy their meals. At weekdays, families may have lunch with their relatives. If they wish to do so, they have to inform the head of the Catering department two days in advance.

## **4.7 Mobilisation of clients**

Individual and group mobilisation is carried out based on the clients' biographies and abilities and the observed interests and skills. All caregivers carry out individual mobi-

lisation of clients in the designated rooms by including the client in all daily self-maintenance activities, which is the most natural manner of mobilisation. Moreover, the caregiver on duty in the given room has a 'trunk of memories', i.e. a collection of various small items of daily use (a cup, photo, set of pictures etc.) to which the client has a personal connection and which also provide answers to the question of who the clients used to be in the past, how did they live, what they achieved in their lives etc. Such items are means of establishing communication between the client and the staff and serve as an aid for memory exercises.

#### **4.8 Support for sensory perception**

In case of clients with advanced dementia, we must work with the clients' interests and tastes, i.e. what they used to enjoy (work is not relevant). These may include for example natural flowers, picture books, favourite fruit, etc., so the client can choose, observe, touch, smell and taste. Items of everyday use should be used in mobilisation.

#### **4.9 Outings**

The greatest stimuli are regular walks, sun, natural environments, but even a breeze of cold air can stimulate the clients.

#### **4.10 Group mobilisation**

We divide clients into groups of up to five, aiming at creating homogeneous groups, i.e. not mixing clients with dementia with clients who do not suffer from confusion or mixing clients with various degrees of dementia. We strive for regularity and remind the clients of the activities planned for them so that they can look forward to them.

If the clients are able to read, we ask them to read for us (fairy tales are very popular since in them the good always triumphs over evil). We seek inspiration in the text of the book. For example, if someone is baking bread in the book, we can ask: "You also used to bake bread. What was it like?" The aim is to get the client to reminisce. We have to keep in mind that the clients' biggest problem is loneliness.

#### **4.11 The concept of basal stimulation**

For clients with advanced dementia, a plan of basal stimulation is set-up by the key caregiver, performing by himself or herself a massage stimulating breathing and tranquilising baths. A cage bed proved useful in case of restless clients. Employees providing direct care have gone through a course of basal stimulation.

#### **4.12 Co-operation with the family**

The family co-operates with the key caregiver whom they know in person, fills in the biography and life story, and participates in the preparation of the trunk of memories. The family is approached by the key caregiver, who offers them the opportunity to participate in the decoration of the client's personal space and possibly provide the client's favourite bedding. We use the Journal of Messages stored at an agreed place to boost exchange of information between the family and the key caregiver. Families hold birthday parties in the Home ever more often, inviting also other clients from the department.

### 4.13 Palliative care

With the consent of families, we allow our clients who are in the terminal stage, as determined by the physician, to finish their days in our facility with dignity. When words can no longer be used, we let the client feel our presence by a touch, the tone of our voice, holding the client's hand or even silence and peaceful attention. We offer the client's family to the possibility of spending the night in our new guest room.

## 5. Conclusion

No amount of comfort in housing can replace smiles, words of appreciation, touch of hands and the empathy of nursing staff. No amount of comfort can drive away the hardship of solitude.

To conclude, I would like to share with you the words with which our fictitious client addresses the visitors to our Home.

*"Treat us as people, not as things. Look us in the eyes, do not be afraid to touch us. Treat us with respect – we are unique human beings. We can talk with you through our eyes, we can listen, touch. We can express what we feel, we are only not able to tell you."*

# Autonomy of Will in Clients with Dementia

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## Keywords

Dementia, autonomy of will, dignity, regime, management of needs

## Abstract

One chapter of reports of the Public Defender of Rights on visits to facilities providing care is regularly devoted to autonomy of will of the service user. The term regime is closely associated with this. The Social Services Act and quality standards guarantee a large degree of autonomy of the client's will, but basic principles of provision of social services are formulated so as to ensure that the clients' dignity be observed and the provider uses the individually determined needs of the users as a stepping stone for its activities. What is the role of regime in this scenario? How should we work with the autonomy of will of a person whose intellectual functions are impaired by dementia?

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## 1. Autonomy of will versus human dignity?

Autonomy of will of the service users is one of the topic monitored by the Public Defender of Rights within preventive visits of institutions. The term regime is associated with this topic, even if sometimes overestimated or denied as part of the service providers' activities. Based on a description of the Defender's specific findings, this article will offer modification of the primary position of the autonomy of will with respect to people suffering from dementia syndrome. Several specific recommendations of the Defender will also be offered as a reflection of the findings made in 2013 in the visited social facilities for the elderly.

Article 1 of the Charter of Fundamental Rights and Freedoms guarantees the following: "All people are free and equal in their dignity and in their rights." The concept of autonomy concerns "strong" values that are protected by specific human rights and fundamental freedoms: personality, private and family life, personal freedom, ownership of property. However, in connection with provision of social services to people with dementia, we cannot consider people outside the whole context of their existence defined by values such as life, dignity and safety from abuse. Such values may be determining in the given situation and prevail over others. The Constitutional Court repeatedly stressed that the fundamental basis for interpretation of all fundamental rights is human dignity.<sup>18</sup>

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<sup>18</sup> Award of the Constitutional Court of 14 October 2004, ref. No. IV. ÚS 412/04 (Collection of Awards of the Constitutional Court, volume 39, award No. 223, p. 353).

I shall contemplate the concept of autonomy of will in an illustrative manner. Based on an initial, superficial interview with the staff, a specific social services facility may seem to function as follows:

- the facility always follows the clients' wishes;
- the degree of privacy corresponds to the clients' wishes;
- bed rails are only used based on the clients' wishes;
- people who wish to smoke can do so in front of the building.

## 2. Autonomy of will of people suffering from dementia syndrome

We are faced with a positive picture concocted of the vocabulary of quality standards with its tactfulness and sometimes unfortunately also with its effect of distorting the truth, which becomes apparent when we realise the enormous difference between the individual target groups of social services. It must be noted that we are dealing with facilities providing care to people suffering from dementia syndrome. This is a medical issue associated with the following facts:

- It is extremely difficult to determine the will and likes and dislikes of clients suffering from dementia; the staff must be trained;
- advanced stages of the illness deprive the patients of the ability to make decisions with respect to themselves even as regards every-day matters; the management of these is taken over by the team of caregivers with the required expertise.

In case of people with dementia, the principle of autonomy of will is insufficient precisely due to the disorder of cognitive functions, thinking, memory, orientation in space and time and the loss of the ability to plan and organise one's own life. It is necessary to supplement and "balance" the autonomy of will with the principle of protection of human dignity, i.e. take suitable steps and prevent, by means of "management", infringements of the clients' human dignity.

This rather abstract statement must have specific consequences for provision of care if it is to be valid rather than intended as another meaningless phrase (as is unfortunately the case with autonomy of will of a person who is incapable of any will). Therefore, we raise the following requirements and premises:

- Clients are people diagnosed with the illness by a physician in a standardised way.
- The staff is aware of the diagnosis – i.e. the staff knows that the client has been diagnosed and is aware of the stage of the illness. The staff is also aware of the consequences of dementia and are experts on the problem.
- The staff monitors the needs of the clients, his or her likes or dislikes and risks in the client's situation. This requirement already foresees considerable qualities. Further, it is required that these activities be reflected in the client's documentation.

- Services provided to people with an advanced form of the illness include also the organisation of the client's daily regime and activities, which are tactfully offered to the clients.
- This is accompanied by a decision of the care-giving team reflected in the documentation.

The creation of conditions for meeting basic human needs and human dignity is the responsibility of the social services provider, not of the clients with impaired cognitive abilities. The provider's obligations are derived both from the fundamental principles underlying Act No. 108/2006 Coll., on social services (Section 2 (2)), as well as the definition of basic activities for individual types of social services and the requirements for ensuring proper supervision (Section 2921 of Act No. 89/2012 Coll., the Civil Code).

### 3. Autonomy of will and specific situations of provision of services

Taking into account what has just been mentioned – i.e. the specific needs of people with dementia and the provider's basic obligations – the facility mentioned in the example above may appear in a different light. Tactful assessments can easily change into manifestations of the lack of quality of the service provided:

#### 3.1 Privacy

**Using means of protecting privacy only at request** is an infringement of the dignity of each person living in an institution, clients with dementia especially. When paying preventive visits to facilities for the elderly, the Defender even encountered such "foul play" as the following statements of the staff: "they do not mind using toilet chairs in front of the others or even visitors", "they are used to this and they do not mind, they refuse the use of screens". However, screens should be used automatically.

I quote from the recommendations of the Defender: "I consider it necessary that the privacy and dignity of all users of care be always protected and nobody be exposed to the sight of other users in the situations referred above. Vice versa, none of the users should be exposed to the sight of others performing hygienic activities or the changing of the diapers."

#### 3.2 Mobilisation

The facility claims that it follows all the clients' wishes. But is the staff able to determine the will of the clients? Is the staff able to determine their likes/dislikes, pain and discomfort? It becomes easily apparent that this is not the case when we pose specific questions to the staff in direct care.

As a result, **clients remain in their rooms all day**, because they do not say that they wish to go to the dining room, for a walk or simply, or to have a change of scenery. It is a clear "foul play" if there are no common rooms to spend time outside the bedroom and if there are not even small dining rooms. Another fundamental barrier to the re-

alization of a potentially existing wishes of the clients is that the staff is not around to accompany the clients to their destinations, for example.

What should be the aim in connection with the mobilisation of clients with dementia in order to ensure a correct approach of the facility?

- The staff should be able to communicate, to pick out likes and dislikes; the staff should be proficient in offering activities to the clients;
- a protected environment should be created where people with dementia could spend their days in the presence of the staff;
- an opportunity should be given to the clients to dine in the company of others;
- conditions for accompanying the clients should be created;
- scheduled activities should be prepared for the clients to spend time outside their rooms.

Examples of issues assessed as faults by the Defender include also the situation when the clients **stay in bed the whole day** because they do not say that they wish to be seated in a chair. In reality, this means that it is not possible to find reasons in the documentation **why the clients are not seated for meals**. The Defender recommends that a professional debate be carried out in the presence of a physician/physiotherapist in respect of not seating the clients, serving meals to bed etc. The staff should be familiarised with the result of the debate and proceed uniformly.

This is connected to another extremely serious situation where the clients are **provided with diapers because they cannot go to the toilet on their own**. Such a situation is indicated by the following statement of the staff: “we help them use toilet chairs when they ask us to do so”. The correct procedure would be to determine the bladder voiding regime of the person with dementia. Caregivers (social service workers) should be provided with clear instructions as to which clients should be provided with help using toilet chairs, which clients should be accompanied to the bathroom and how often, where the communication barrier on the part of the client (the client does not ask to be accompanied to the bathroom) should not be the reason for stopping the assistance in use of the toilet.

Another problem ascertained in this respect is also an **early bedtime** (5:30 p.m.) determined so because the clients do not protest. In this connection, another instance of “foul play” occurs when breakfast is served at 8:00 a.m. For clients not provided with snacks after dinner, this means 11 or more hours without food. Moreover, it is expected that they will spend this whole time in bed without any further demands. Good practice includes respect for the natural daily rhythm of human beings and especially the natural daily rhythm of individual clients.

### 3.3 Bed rails

Let us now review the statement that bed rails are only used based on the clients’ wishes. Should a person with impaired intellectual abilities decide on measures preventing falls, i. e. measures connected with his or her safety? If the problem is formulated in this manner, the absurdity of the “client’s will” becomes more apparent. In connection with this, the Defender often found out that the staff did not know which clients should be equipped with bed rails and each caregiver applied the bed rails intuitively. This is only possible in case of healthcare workers competent to assess the risk of a fall; otherwise, each caregiver proceeds in a different manner and the underlying problem

is not monitored. In view of the current staffing of most of the visited facilities, the Defender demands that the issue of prevention of falls be resolved by the care-giving team including a nurse and each caregiver be informed on the resolution.

### **3.4 Management of the client's needs**

I will quote from the P-PA-IA strategy: "People with advanced dementia benefit from a tactful individualised care and assistance in those self-maintenance activities which they can still perform. A significant reduction in verbal communication occurs, which presents challenges to the ability of the staff to maintain communication with the person with dementia non-verbally." In practice, this means that the staff should determine which abilities and rituals are beneficial for the clients and tactfully offer them such activities. As the mental functions deteriorate, the caregiver naturally takes over the organisation of the patient's day, working with rituals, regime and planning of daily activities. This replaces the management of the day and needs which healthy people ensure on their own. It is paramount that the staff be familiarised with this approach. Otherwise, there is risk of neglecting quality care for the person with dementia.

In this respect, a comparison of the facility and an informal environment is a false argument: "How can the client with such a regime feel 'like in normal life'?" The person with dementia started using the service because he or she is no longer able to live a normal life. Similarly, it is inappropriate to compare the life in a social service facility with the life at home, if this consists in a simplification ignoring the causes and nature of the person's social situation. I would point out here that the concept "social service=like at home" is valid if we compare social services with a hospital and it was of an importance at the time when social services had yet to go through primary humanisation; this however is a historical fact which is no longer relevant.

Unfortunately, I encounter this "confusion of languages" most frequently in confrontation with people ideologically justifying the following approach: "the lady did not want to get up from bed, so I left her there," "the lady is not hungry (note: at the occasion of dinner served at 5 p.m., snacks were served at 4 p.m.) so I am taking her dinner away", "we respect the wishes to the clients - if a lady suffering from diabetes wants 10 escalopes, she will get them".

The provider is responsible for matters concerning basic human needs of people with impaired cognitive functions and volition, otherwise there is a threat of negligence. In this connection, we must reiterate the legal opinion that the creation of conditions for meeting basic human needs and human dignity is the responsibility of the social services provider, not of the clients with impaired cognitive abilities.

### **3.5 Smoking**

I quote from one of the reports of the Public Defender of Rights issued after a visit to a retirement home: "The facility is not equipped with smoking rooms and if a client wishes to smoke, he or she has to go in front of the building. According to the direct care staff, smoking was not allowed even on balconies. All sources of ignition (matches, cigarettes) have to be stored with the caregivers for the purposes of fire protection. A social service worker stated that they are generally against clients drinking alcohol or smoking and if the accessibility of cigarettes is reduced, the clients cease to request them after a certain time. I would like to point out that the fact that a client needs

a social service does not mean that the facility providing the service will decide on the priorities and the client's way of life. It is neither the mission nor the right of social services to introduce more suitable habits to clients – adult people in their old age.

I recommend that a smoking area be reserved in the facilities and cigarettes kept with the clients unless the management of the client's needs in this respect is included in the agreed aim of the service (in that case, cigarettes should be provided based on the individually ascertained needs of the client)."

### 3.6 Regime

As far as regime is concerned, I once again refer to the Defender's report: "According to the internal documents of the facility, the daily regime is based on the recommended time of meals. One of the clients stated that she needs an incontinence aid for the night and thus she must be in her room at 7 p.m. at the latest so that the nurse can provide her with a diaper. She cannot go back to the common room after that and she does not have a TV in her room, which does not suit her.

This shows that the clients' daily regime does not reflect individualised approach. The regime is designed to allow the staff to carry out all their tasks; the needs of the clients, such as peace and ease and, for example, watching TV in the evening are secondary. For operational reasons, dinner is served relatively early, at 4:30 p.m., and breakfast is served around 8 a.m. There is large time gap between the meals. Only clients suffering from diabetes receive snacks after dinner, others must use their own resources. If a client is hungry, he or she cannot get a second helping after dinner and he or she even cannot ask the staff for bread. A number of clients answered the questions of the employees of the Office to the effect that they are hungry in the evenings and eat biscuits or sweets to fill themselves up. The facility does not respect the natural daily rhythm and the operational rules are given priority over individualised care for patients. It was established in interviews with the staff of the facility that the clients are woken up before 5 a.m. so that the staff can change their diapers. Waking up clients to change their diapers interferes with their sleep and represents a large burden for the clients. The natural rhythm of the clients' day is disturbed and this disturbance can cause restlessness or aggressive behaviour. It is obviously necessary to reflect the specific situation and the client's needs and ascertain whether the change of the diaper is really necessary (intestinal problems, infection, etc.). However, this issue cannot be addressed indiscriminately based on a schedule of work, waking up all clients to change the diapers. Regular waking up at night, or several times per night, can be considered prevention of sleep, which alone can be considered an instance of ill-treatment. Only clients who are used to waking up this early and have been doing so their whole life may be woken before 5 a.m. However, this is only possible in individual cases of people whose individual plans include such information and who wish to be woken up to have their diaper changed.

I recommend respect for the natural daily rhythm and taking account of the client's individual needs and wishes. In particular, I recommend that clients' bedtime correspond to the time when they are used to go to sleep. I recommend that clients not be woken up during the night indiscriminately and incontinence aids be changed only after the clients wake up on their own accord. Aids should only be changed based on a justified need or request of the client."

## 4. Conclusion

It follows from the above that the main problems of residential care facilities for seniors with dementia with respect to autonomy of will and dignity of the clients include: (i) insufficient awareness of the staff and management of the facilities; (ii) lack of management of the clients' needs; (iii) ignorance of the principle that from a certain stage of dementia a professional team must make decisions for the client; (iv) interference with the client' personal sphere is only intuitive, chaotic and proper documentation is missing.

A solution can be found only in improving both the theoretical and practical expertise of the team. In an absolute majority of the visited facilities for the elderly, the answer to the question "which of your clients suffer from dementia" was not readily available, rendering it impossible to determine the stages of illness of the individual clients. The third step is to prepare the staff for the requirements for their work resulting from the clients' medical condition. Facilities may not rely on the statement that "they have done this or that forever".

The provider is responsible for matters concerning basic human needs of people with impaired cognitive functions and volition, otherwise there is a threat of negligence. In case of people with dementia, the principle of autonomy of will is insufficient precisely due to the disorder of cognitive functions, thinking, memory, orientation in space and time and the loss of the ability to plan and organise one's own life. It is necessary to supplement and "balance" the autonomy of will with the principle of protection of human dignity, i.e. take suitable steps and prevent, by means of "management", infringements of the clients' human dignity.

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# The Issue of De-institutionalisation of Residential Services for the Elderly and the Right to Live in the Community

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Institutions, the right to live in the community, disability, de-institutionalisation

## Abstract

Social services in the Czech Republic are currently provided on a contractual basis. However, the lack of choice of providers offering community care often makes institutionalisation the only alternative. This paper analyses the legal position of the elderly and deals with the definition and specification of the term 'disability' in the UN Convention on the Rights of Persons with Disabilities. It analyses the contents of the rights stipulated in Articles 4 and 19 of the Convention in terms of the four specific commitments of the States, i.e. the right to respect, protect, fulfil and promote.

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## 1. Introduction

For a long time, the issue of institutionalisation of people with disabilities was not considered a matter of human rights. The rights of persons with disabilities have become emphasised only since the 1990s, resulting in the adoption of the landmark UN Convention on the Rights of Persons with Disabilities in 2006 (hereinafter also abbreviated as "CRPD"). The issue of institutionalisation is considered in Article 19 of CRPD.

This paper is concerned with institutions, therefore the definition of the institution as a term is crucial. For this purpose I will use the definition provided by non-governmental organisations advocating the rights of persons with disabilities and also the definition included in the court decision in case DAI v. Paterson. Non-profit NGOs define the institution as a facility, where: i) a person cannot decide where to live, with whom to room, what and when to eat, or when and how to come and go; ii) a person loses individuality and becomes part of a system that they have no control over; iii) a person does not leave the institution to go to the doctor, the barber, school or work; everything happens inside the institution; iv) a person seldom sees their family; v) because everything takes place inside an institution and away from the public eye, a person is more vulnerable

to sexual, physical and/or emotional abuse. The court deciding in the *DAI v. Paterson*<sup>19</sup> case in New York, USA, used a similar definition. The court defined the term “institution” on the basis of several criteria: i) most of the inhabitants’ daily lives occur inside the institution; ii) visits to nearby facilities such as parks, shops, restaurants, libraries, houses of worship or cultural facilities are sporadic; iii) contact with people without disabilities is very limited; iv) public mental health programmes and case management do not contribute much to their integration; v) stay in the institution dissuades the residents from taking part in normal daily activities and promotes “learned helplessness”.<sup>20</sup>

Accepting this definition of an institution, I believe many residential care facilities for elderly people can be subsumed under it.

## 2. On the (non)definition of disability

The right to live in the community is stipulated in Art. 19 of CRPD. To answer the question whether this applies also to the elderly and therefore the residential care services, it is first necessary to deal with the issue of defining a disability according to Art. 1 of CRPD. The issue of (non)definition of disability in CRPD has not yet been solved by the US Committee on the Rights of Persons with Disabilities, or rather the Committee, which is the only body having the authority to interpret the Convention, has not yet dealt with defining disability and only issued a recommendation to the States to adopt a definition that is in compliance with CRPD. Nevertheless, professional literature [1,2]<sup>21</sup> offers some hints as to how Art. 1 of CRPD should be interpreted. The elementary question is: Does the UN Convention on the Rights of Persons with Disabilities include a definition of disability?

The issue of inclusion of the definition of disability in CRPD long remained unsolved during the preparatory work for CRPD. In 2005, the Chairman of the preparatory committee expressed in his letter to the members his preference that the CRPD should not contain a definition. The reason was the complex nature of the issue and the danger of accidental exclusion of some groups from protection. Directive 2002/73/EC of 28 September 2002 does not contain a definition either.<sup>22</sup> On the other hand, the inclusion of a definition was supported by groups of persons with disabilities, which formed a coalition for talks over CRPD, the International Disability Caucus (the “IDC”). Without a definition, there is a risk that the States would interpret CRPD narrowly and thus make it essentially meaningless. In the end the opinion that CRPD should include at least some specification prevailed, however, it soon turned out to be a very difficult issue.

Some specification appears in Art. 1 of the final CRPD wording, which contains a stipulation of the “purpose” of CRPD. Art. 2 of CRPD containing definitions does not provide for a specification of disability. This is very important since it indicates a willingness to specify disability without defining it. Therefore, it is better to conclude that CRPD does not offer any **definition**. Concerning the **specification** of disability itself, it does not contain an exhaustive list of all types of disability. The specification of the term is *19 Disability Advocates, Inc. v. Paterson (“DAI I”), 598 F. Supp. 2d 289 (E.D.N.Y. 2009)*  
*20 Ibid., paragraphs 27-46.*

<sup>21</sup> These sources will not be quoted in the text below.

<sup>22</sup> In this connection, see ECJ decision in case *Chacón Navas v Eurest Colectividades SA*, No. C-13/05, *Coleman v. Attridge Law*, No. C-303/06.

not closed, which is stated in recital (e) of the Preamble, according to which: “*disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.*” Connection with recital (e) of the Preamble is also inferred from the phrase “*various barriers*” as a specification of disability. It is therefore advisable to read the specification together with recital (e) of the Preamble.

## 2.1 The issue of specification and the problematic Czech translation

The wording of the specification itself is another matter. The Czech translation: „*Osoby se zdravotním postižením zahrnují osoby mající dlouhodobé fyzické, duševní, mentální nebo smyslové postižení, které v interakci s různými překážkami může bránit jejich plnému a účinnému zapojení do společnosti na rovnoprávném základě s ostatními.*” In English: „*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*”

This specification can be criticised for the following reasons: Firstly, the original English version contains the word “*mental*” (the correct Czech translation should be “*psychosociální*” (psychosocial). For example, the IDC suggested to replace the word “*mental*” with the terms “*intellectual, psychosocial, neurological, neuro-diverse*” since this is a part of the language which persons with disabilities and their organisations use and understand. The Czech translation of “*mental*” as “*duševní*” is more or less accurate. “*Psychosociální*” would be preferable, but that is not a common term in either the professional legal or lay language in the given context. Similarly, the expression “*mentální*” is a good translation of the English term “*intellectual*”.

“*Impairment*” is a problematic word because the specification should rather use the term “*condition*” (translatable into Czech as “*stav*”). This term is more inclusive and less stigmatising. The Czech translation is very imprecise in this case since “*impairment*” is usually translated as “*porucha*” and not as “*postižení*” (“*postižení*” means “*disability*” in English; also used as “*disabilita*” in Czech). “*Impairment*” is defined by the International Classification of Impairment, Disability and Handicap (ICIDH) of 1980. [3]

The third problem is the expression “*long-term*”, correctly translated into Czech as “*dlouhodobé*”. This implies that the given condition must be of a permanent character, meaning persons whose medical condition (“*stav*”) is transient are excluded from protection. The condition of permanence should not be interpreted narrowly even in the absence of an authority able to provide a definitive interpretation.<sup>23</sup>

<sup>23</sup> Up until now, no general statement of the UN Commission was issued with respect to rights of persons with disabilities.

## 2.2 Who falls under the specification of disability?

The issue of who falls under the specification of disability cannot easily be answered if only because of the *evolving concept of disability* (see recital (e) of the Preamble). However, some answer can be found if we interpret recital (e) of the Preamble together with the Article 1 of CRPD, which contains a non-exhaustive specification. The fact that the CRPD is construed on the 'social model' of disability emphasising the role of interaction between the individuals with disability and their surroundings must be taken into account. This interaction is incorporated in the very term "disability", which means „ *decrement in functioning at the body, individual or social level that arises when an individual with a health condition encounter barriers in the environment* ". [4] This is why the specification in Art. 1 of CRPD can only be understood as a non-exhaustive list of the types of disabilities (in this part the Czech translation incorrectly uses the term "*postižení*"), which should be interpreted broadly in order to make protection available also to the persons who face social barriers as a result of their medical condition. This specification might thus cover also other vulnerable groups which initially may seem do not fall under the protection of CRPD, e.g. the elderly.

## 3. The right to live independently in the UN Convention on the Rights of Persons with Disabilities

The basic document regulating the right to live independently and the right to live in the community is the UN Convention on the Rights of Persons with Disabilities. It is one of the quickest-prepared conventions whose preparatory work in the UN took only 5 years, from 2001 to December 2006. The Convention was open for signature in March 2007 and entered into force on 3 May 2008. The Czech Republic ratified the CRPD in 2009.

The whole Convention is based on the principle of independence, which is the cornerstone of all rights of persons with disabilities. According to recital n) of the CRPD, the countries "*[recognise] the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.*" Independence is also stipulated as the first [sic!] general principle of the CRPD. According to Art. 3 (a) of the CRPD, the Convention is based on the principle of a "*respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*". Furthermore, independence is underlined in Article 9 (Accessibility), which is very important, and in all the other provisions.

Independent life within the meaning of deinstitutionalisation of institutional care and the right to live in the community is guaranteed by Article 19 of the CRPD. The first draft of this provision entitled "Living independently" was submitted to the delegations for discussion in January 2004. Some commentators note that this first draft underlined the aspect of choice. [5] Looking at the discussion on the proposal at the UN, it is clear that the free choice of the place of living actually echoed throughout the discussion, including the possibility of choosing a life in an institution. However, the German delegation emphasised that the right to live in the community entails 2 aspects – the freedom of choice, and the right to an adequate standard of living as set

forth in Article 11 of the ICESR. The implications of this for persons with disabilities are they do not necessarily have the choice to live outside of an institution even if they are not committed to an institution by state authorities. The question of forced institutionalization is a separate issue. Therefore, the German delegation proposed that Paragraph 1 should be reformulated as follows “persons with disabilities have their equal freedom to choose their own living arrangements. This freedom includes the right not to reside in an institutional facility.” In view of Article 11 of the ESCR, paragraph 2 should clarify that the States recognise of the right of persons with disabilities to an adequate standard of living “*which enables persons with disabilities to live independently.*”<sup>24</sup>

On the fifth session, the Working Group did not come back to the right to live independently and returned to its wording and proposals submitted in particular by the European Union<sup>25</sup> and representatives of the non-profit sector<sup>26</sup> on its sixth session in August 2005. The sixth session saw the impetus for emphasising the aspect of the liberty of movement and freedom of choice<sup>27</sup>, the remaining text was composed at the seventh session held in the beginning of 2006, where particularly the comments of non-profit organisations were reflected.<sup>28</sup> In this respect Leibowitz states that the older formulations had one thing in common, namely the lack of any “*right*” to form the core of this provision. Therefore, an unambiguous right of all people to live in the community was supplemented based on targeted efforts of civil society and some countries. According to their argumentation, this provision should deal with a “*right*” just like the provision of any other convention. Specifically, this Article should include a right which is essentially connected to the right to liberty of movement or choice, but is not identical; rather, it should be an inalienable right to live in the community regardless of proving the person’s “*ability*”, “*eligibility*” or “*authorisation*”. [6] This was a significant position which also influenced the final text of Article 19 of the CRPD, concerned with both a “*right*” and equality of all persons with disabilities with respect to living in the community.

From the perspective of institutional care, this provision is interpreted to the effect that it prohibits forced institutionalisation: “Persons ... have the opportunity to choose their place of residence and ... and are not obliged to live in a particular living arrangement” (Article 19 (a) of the CRPD). However, in addition to forced residence, the Article also prohibits life in institutions as such, regardless of formal forcing. As a matter of fact, institutions are different from communities in their nature, thus contributing to isolation and segregation. According to Leibowitz, this is at variance with the obligation to provide “*access to ... services ... necessary to support living and inclusion in the community, and to prevent isolation or segregation*” (Art. 19 (b) of the CRPD). We can agree with this interpretation, because institutions are definitely particular living arrangements, they are defined by control, by power over the lives of the inhabitants or clients. They

24 With respect to the discussion and proposals of the German delegation see: <http://www.un.org/esa/socdev/enable/rights/wgsum15.htm>.

25 Governments’ proposals are available at:

<http://www.un.org/esa/socdev/enable/rights/ahc5contgovs.htm>.

26 Proposals of international organisations are available at:

<http://www.un.org/esa/socdev/enable/rights/ahc5contngos.htm>.

27 Cf. the Report of the Chairman with respect to Art. 15 (originally) (14) The Report is available at: <http://www.un.org/esa/socdev/enable/rights/ahcstata19ssrepchair.htm>.

28 Cf. the comments of International Disability Caucus (IDC). The comments are available at: <http://www.un.org/esa/socdev/enable/rights/ahcstata19sevscmts.htm#idc>.

are inherently more or less closed systems with a tendency towards totalitarianism, isolating the internal life from the outside world.<sup>29</sup>

## 4. What obligations can be inferred from Article 19 of the CRPD?

The right to live in the community is a subset of the right to live independently, which is in contrast with institutionalisation and institutional care. The Convention on the Rights of Persons with Disabilities was adopted only recently, in 2006, and the manner of interpretation of obligations of the State Parties following from the right to live in the community under Article 19 of the CRPD is not quite clear. However, in view of Article 4 of the CRPD, which provides for the obligations of the States, we can attempt to determine the individual components of the right to live in the community and even specific obligations of the States following from this provision. According to Art. 4 (1) and (2) of the CRPD:

*“States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.*

[...]

*With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.”*

The original draft Article 4 of the CRPD did not refer expressly to economic, social and cultural rights. This was discussed in the UN, namely on the third<sup>30</sup> and fourth session<sup>31</sup> of the working group. In the fourth session, the working group agreed that Article 4 should include the principle of progressive realization of the economic, social and cultural rights balanced in view of the need for immediate implementation of those obligations that *can* be immediately implemented. It was also highlighted that non-discrimination is not subject to the doctrine of progressive realization.<sup>32</sup>

Article 4 of the CRPD emphasises that the States are obliged to ensure and promote the “*full realization*” of all human rights. Full realization is also emphasised in the Convention on the Rights of the Child (Article 2); older international conventions on human rights do not use such resolute vocabulary. As far as the specification of the obligations to “*ensure*” and “*promote*” are concerned, the original draft of Article 4 only provided

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29 Institutions have been described as “total institutions” by Erving Goffman, cf. Goffman, E. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Anchor Books: New York, 1961.

30 Cf. the debate available at:  
<http://www.un.org/esa/socdev/enable/rights/ahc3sum4.htm>.

31 Cf. the debate available at:  
<http://www.un.org/esa/socdev/enable/rights/ahc4sumarto4.htm>.

32 Cf. report of the *ad hoc* committee available at:  
<http://www.un.org/esa/socdev/enable/rights/ahc4reporte.htm>.

for the obligation to “ensure”<sup>33</sup>, obligation to “promote” was added based on the initiative of a group of African countries on the seventh session of the group.<sup>34</sup>

The obligation to “ensure” is expressly provided for in Article 2 of the International Covenant on Civil and Political Rights. This is a positive obligation, which according to Nowak covers the above specified obligations to protect and fulfil. In Nowak’s opinion, this can be inferred both from the Covenant itself and from the case-law of the Human Rights Committee. [7] The CRPD emphasises the obligation to “support.” This obligation is expressly provided for in Art. 7 (2) of the Bill of Rights of the Constitution of the Republic of South Africa. According to this provision “the state must respect, protect, promote and fulfil the rights in the Bill of Rights”.<sup>35</sup> This categorisation was adopted also by the African Commission on Human and Peoples’ Rights with reference to the work of Asbjørn Eide<sup>36</sup>.<sup>37</sup>

Article 4 of the CRPD does not unambiguously include the obligation to *respect*, i.e. the obligation to refrain from interfering with rights of people with disabilities. This obligation can be inferred from the general principle of the Convention specified in Art. 3 (1)(a), according to which the State is obliged to “[r]espect (...) dignity” of persons with disabilities and also the individual rights guaranteed by the CRPD. This includes, for example, the right to life under Article 10 of the CRPD or the absolute prohibition of torture under Article 15 of the CRPD.

To conclude, we can state that four specific obligations of the States can be inferred from the Convention on the Rights of Persons with Disabilities, namely: (i) to respect the rights of persons with disabilities; (ii) to protect their rights; (iii) to fulfil the rights of persons with disabilities; and (iv) promote the rights of persons with disabilities.

Subsequently, in view of the right to live in the community, we can infer specific obligations of the States even in the field of institutional care for the elderly. The obligation to **respect** the right to live in the community means that the States may not institutionalise persons with disabilities, including the elderly. On the national and regional level, this means that the State and the self-governing units must abandon the systematic policy of institutional care for people with disabilities and may not introduce such policy. The States are obliged to respect the opportunity of persons with disabilities to choose their place of residence and where and with whom they live on an equal basis with others and persons with disabilities are not obliged to live in a particular

33 Cf. the original draft version of Article 4: “States Parties undertake to ensure the full realisation of all human rights and fundamental freedoms for all individuals within their jurisdiction without discrimination of any kind on the basis of disability.” Original wording available at: <http://www.un.org/esa/socdev/enable/rights/ahcwgreporta4.htm>.

34 Cf. proposals with respect to Article 4 presented on the seventh session. The proposals are available at: <http://www.un.org/esa/socdev/enable/rights/ahcstata4sevscomments.htm>.

35 Original wording of Art. 7 (2): “The state must respect, protect, promote and fulfil the rights in the Bill of Rights”.

36 Eide did not include the obligation to “promote”. The Commission pointed directly to the following work: Asbjørn Eide, “Economic, Social and Cultural Rights As Human Rights” in Asbjørn Eide, Catarina Krause and Allan Rosas (Eds.) *Economic, Social, and Cultural Right: A Textbook* (1995). pp. 21-40. The obligation to promote was included by van Hoof (see above).

37 In the decision in the case of the *Ogoni* people (Communication 155/96, Report of the Commission), the African Commission on Human and Peoples’ Rights connected the obligation to promote with the obligation to protect. The Commission stated that, in view of the obligation to promote, the State should make sure that individuals are able to exercise their rights and freedoms, for example by promoting tolerance, raising awareness and building infrastructures

living arrangement, as emphasised in Art. 19 (a) of the CRPD. While social services in the Czech Republic are currently provided on a contractual basis, the lack of choice of providers offering community care often makes institutionalisation the only alternative.

On the level of individuals, the State and the municipality or region have the obligation not to institutionalise individuals. Institutionalisation may be forced, i.e. involuntary, or voluntary. It is necessary to prevent “forced” institutionalisation, which can be either overt or covert. Covert forced institutionalisation means that the State or the municipality or region failed to meet their obligation to provide community services and, therefore, the only option is institutional care. In such cases, voluntary choice is pure fiction.

The obligation to **protect** gives rise to the State’s obligation to protect persons with disabilities against third parties, in case of social care in particular against non-governmental providers of services. This obligation includes the adoption of legislation or other measures ensuring equal access to community services provided by third parties. It is necessary to inspect the provision of the service and ensure that these services are provided by professionals who meet reasonable standards for education, skills and ethical behaviour. The State should ensure that third parties do not limit people’s access to information.

The obligation to **fulfil** means that the State transforms the care provided in institutions. This obligation is expressed, *inter alia*, in Art. 19 (b) of the CRPD, which guarantees access to in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community, to persons with disabilities. The obligation to fulfil foresees deinstitutionalisation, or more specifically the transfer of care from institutions to services in the community. In the preferred scenario, this process should be provided for in legislation and a national policy for transformation of institutional care should be adopted with a detailed plan of realisation of the right to live in the community. The State is obliged to ensure the right to live in the community for all persons with disabilities; no group of persons with disabilities may be excluded from the obligation to transform institutional care. The State is also obliged to ensure a sufficient volume of quality and appropriate services in the community.

The obligation to *fulfil (facilitate)* requires that the States take specific positive measures, which will allow persons with disabilities to use their right to live in the community. If individuals or groups are not able to exercise this right using their own means through no fault of their own, the State is obliged to *fulfil (provide)* the right to live in the community.

## 5. Conclusion

To conclude, we can point out certain statistics. In 2010, there were 485 retirement home services with 37,696 beds [8] in the Czech Republic; a simple calculation shows us that there are approximately 77 beds in each service. I believe this number is horrific and testifies to the fact that residential services for the elderly are large services and I fear that it would be rather daring to describe such services as community services. In view of the flexible definition of disability, amongst other things, one can argue that the UN Convention on the Rights of Persons with Disabilities applies also to the elderly and,

therefore, the protection offered by the CRPD, specifically by Article 19, should apply also to this target group. Therefore, the transformation (deinstitutionalisation) should not be limited to homes for persons with disabilities and psychiatric hospitals; rather, the State should make specific and targeted steps to transform residential services for the elderly and create a network of available and accessible community services for this target group.

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# Protection of Rights of the Elderly in Institutions, Focusing in Particular on Persons with Dementia, Social Work and Social Services

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## Keywords

Social work, social services, the elderly, dementia, rights, dignity

## Abstract

This paper addresses certain problematic aspects of provision of appropriate care for seniors with dementia in view of the fact that this is one of the most vulnerable target groups in residential care facilities. The paper reflects selected rights of the users of care and the most frequent discrepancies in their implementation in practice. Subsequently, the authors move to the description of activities performed by a qualified social worker when engaged with seniors with dementia.

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## 1. Introduction

Protection of the rights of the elderly and ensuring appropriate care for persons suffering from dementia are ever more topical and ever more debated in the Czech Republic. Most developed countries are faced with the problem of demographic aging and the associated expected increase in prevalence of age-related diseases, including dementia. In practice, this means an increasing demand for appropriate care for persons suffering from dementia, especially for institutional provision of such care. Demands for care for persons with dementia at home are so high and exhausting for the caring persons that one cannot expect a significant increase of the share of people cared for in their natural environment by their relatives, even if we assume that the current trend aimed at an increased support for field and outpatient services will continue.

Even though experts strive to achieve accessible and quality care for persons with dementia regardless of whether care is provided at home or in an institution, this paper focuses primarily on care provided in institutions, or more specifically in residential social services facilities.

The elderly suffering from dementia are the most frail and vulnerable target group in residential care facilities (retirement homes, special regime homes) for which a high level of risk can be identified, consisting in violation of the right to human dignity. The (lack of) respect for this fundamental right is influenced to a large degree by the ap-

proach of the staff in the institutions, be it social or healthcare workers, direct service care personnel and management of the organisation. Care for persons with dementia is demanding in particular with respect to individual assessment of the specific situation of the given person, or rather his or her current social and medical condition, and prediction of progression of the disease in the context of the client's future life. The increased demands are associated with the fact that care for persons suffering from dementia requires close co-operation of and interconnection between the social and healthcare components of the care, especially in the assessment of the clients, where it is important that representatives of both the social and healthcare component be included.

When striving to support the quality of care for persons with dementia in residential social services facilities, we definitely need to address the rights of users/clients and the dilemmas associated with their realisation.

## **2. Rights of users and their realisation within the framework of care for seniors with dementia**

The following list includes the most common discrepancies between the defined rights of users and their actual realisation (the list does not take into account extraordinary cases of extremely serious violations of human rights, such as inhumane and degrading treatment).

### **2.1 Right to dignity**

The right to dignity is a fundamental human right defined in key national and international documents and its observance is an elementary prerequisite of any kind of care. It includes the right to privacy, self-determination, respect and acknowledgement, safety and generally everything that protects the integrity and autonomy of an individual. In practice, the interpretation of the right to dignity is to a large extent subjective, similarly to the boundaries of violation of dignity. In residential social services facilities, the decisive factor is the expertise and personal talents of the staff, who should be able to define the risk of violation of the right to dignity. Nowadays, the personnel of residential care facilities strongly voice demand for a clear definition of "dignity" of the users and practical specification of implementation of this right for the purposes of care of users, as the current definition following from quality standards for social services is considered vague and subject to interpretation.

### **2.2 Right to be addressed in a dignified manner**

Addressing users in a dignified manner counts among the basics of the personnel's approach to users. This does not necessarily mean that a caregiver may not address a user as "grandmother/grandfather", which is sometimes given as an example of bad practice; the underlying requirement is that users be addressed as they wish. This wish must be recorded and observed by the personnel.

### **2.3 Right to privacy**

The subject of the right to privacy is the intimate sphere of an individual's life and includes the right to decide whether one's private affairs will be disclosed. In a healthy

person's household, the right to privacy is easy to implement and, in case of a violation, a remedy can be ensured relatively easily. The situation is different in residential social services facilities, especially where seniors suffering from dementia are concerned. Most frequently recorded are violations of the right to privacy in the given person's own room and the right to privacy of clients accommodated in multi-bed rooms. A typical example of an issue often faced by the personnel of institutional facilities is (not) giving the keys exclusively to the given user with dementia.

## **2.4 Right to privacy in personal hygiene**

When using the toilet or the bathroom, users have the right to lock themselves. Users who need assistance in personal hygiene must be covered at all times on the way to the bathroom. If personal hygiene is performed in a multi-bed room, privacy must be ensured for example by closing curtains. Violation of the right to privacy in personal hygiene is a material breach of the right to dignity.

## **2.5 Right to free choice and decision-making**

All users have the right to decide freely on matters that concern them. It is not clear what share of users of retirement homes and special regime homes have decided on their own and freely that they would spend the rest of their lives in a residential facility. The wishes of seniors with dementia are usually not ascertained; the decisive factor is usually the situation in the family (increased demands on the caregivers, progression of the disease, etc.).

The users have the right to choose what support and assistance they need from the personnel at the residential social services facilities. The users are supported in free decision-making by individual planning.

Discrepancies in realisation can be found for example in case of users who refuse any mobilisation techniques. They are entitled to this choice and may not be forced to perform the activities against their will, even if the staff is convinced of their positive effect (the staff actively offers the activities and motivates the users in an appropriate manner).

## **2.6 Right to safety**

The right to safety and its realisation is very demanding in practice, especially in case of people suffering from dementia, and makes large demands on the staff and the organisation of their work. The responsibility for the safety of users on the premises of the facilities is always borne by the providers.

# **3. Activities of a social worker when engaged with seniors with dementia**

Prior to defining specific activities of a social worker, it is necessary to define social work in residential social services (retirement homes, special regime homes). Social work is a highly qualified work with a specific nature, contents, prestige and defined qualification required for its performance. This fact is often forgotten in practice, especially in the two above-mentioned types of residential social services. In the best scenario, the

activities of social workers are supplemented with other activities which can be performed by other staff. In the worst scenario, the activities of social workers are reduced to these other activities and the homes often forget to perform social work itself. Most frequently, the other tasks include administrative tasks, shopping, administration of deposits etc. Performance of these activities by social workers not only belittles the role of social work, but it also violates the principle of “due managerial care”, as qualified, specialised experts perform activities which could be performed by other staff, and thus human resources are being wasted.

In the whole scheme of care for persons suffering from dementia, the key role is played by the **social worker**. Qualified social workers are “watchdogs” with respect to the clients’ dignity and their rights and provide contact with the families and the social environment; they work with all the clients’ needs in the context of their life stories.

When performing their responsibilities, social workers focus on the following tasks:

- Screening (finding clients for social services, or the clients seek the social service themselves)
- Assessment of the clients’ specific life situation
- Contracting = setting up the contractual relationship between the clients and the providers
- Individual planning, drawing-up intervention plans
- Assessment of the individual plans (fulfilled/not fulfilled)
- Assessment of the impact of intervention on the life situation of individuals (clients)
- Networking (creation of condition for mutual co-operation)
- Strategic and conceptual planning in the area of public social and related policies
- Ensuring that the clients’ rights are observed
- Other professional activities (e.g. specialisation in work with clients unable to communicate, work with the clients’ biographies and other techniques).

We speak about a **process of provision of social services** (horizontal activities of social services).

**Basic activities and tasks** to be ensured by residential social services are stipulated by Act. No. 108/2006 Coll., on social services, and the Implementing Decree No. 505/2006 Coll. (vertical activities of social services). They include:

## 1. Assistance in every-day self-maintenance tasks and personal hygiene

1.1. Assistance in personal hygiene and provision of conditions for personal hygiene.

1.2. Assistance in personal hygiene and grooming, assisted toileting.

1.3. Assistance in daily self-maintenance tasks: Assistance and support in eating and drinking, assistance in getting dressed and undressed, including special aids, assistance in moving to a bed or a wheelchair, assistance in spatial orientation, independent movement both indoors and outdoors, assistance in getting up from bed, laying down, shifts of position.

## **2. Mobilisation and training activities**

2.1. Mobilisation activities: Training and improving motor, mental and social abilities and skills.

2.2. Leisure time and recreational activities, assistance in restoring or improving contact with the natural social environment.

## **3. Assistance and support in serving or preparing meals and drinks**

3.1 Provision of food: Provision of daily food appropriate to age, the principles of proper nourishment and specific dietary needs, comprising of at least 3 main meals a day.

3.2. Provision of food or assistance in ensuring food; in case of residential services: Ensuring conditions for independent preparation of meals or provision of daily food appropriate to age, the principles of proper nourishment and specific dietary needs.

3.3. Provision of food or assistance in ensuring food: Assistance in preparing meals, provision of the daily food appropriate to age, the principles of proper nourishment and specific dietary needs, comprising of at least 3 main meals a day.

## **4. Mediating contacts with the community**

4.1. Assistance in restoring or improving contacts with the family and assistance and support in other activities supporting social inclusion of persons.

4.2. Activities enabling enhanced orientation in relationships in the community.

4.3. Accompanying the persons to schools, educational facilities, physicians, work, to leisure-time and recreational activities, to public authorities and institutions providing public services and other associated social services, and accompanying them on the way back, help in restoring or improving contacts with the families and assistance and support in other activities promoting social inclusion of persons.

4.4. Support and assistance in use of commonly available services and information sources.

4.5. Assistance in restoring or improving contacts with the family and assistance and support in other activities supporting social inclusion of persons.

## **5. Social therapeutic activities**

5.1. Socio-therapeutic activities, the provision of which leads to development or maintenance of personal and social skills promoting social inclusion of people.

5.2 Socio-therapeutic activities, the provision of which leads to permanent abstinence, prevention of relapse, development or maintenance of personal and social skills promoting social inclusion of people.

## **6. Assistance in the exercise of rights and legitimate interests and in running personal errands**

6.1. Assistance in communication aimed at exercise of rights and legitimate interests.

6.2. Assistance in restoring or improving contacts with the family and assistance and support in other activities supporting social inclusion of persons.

6.3. Assistance in running every-day errands.

**Social work** is a necessary part of each social service and quality social services cannot be provided without qualified social workers. Work with seniors with dementia makes high demands on the **expertise of social workers** in view of the frailty, vulnerability and definite diversity of the target group. We can legitimately ask whether social workers specialising in this target group should not have certain “above-standard” knowledge and skills that are necessary for correct assessment of the specific situation of clients with dementia. Moreover, in case of seniors with dementia, social workers primarily play the role of “defenders” of rights and legitimate interests, very often against other personnel in the facilities.

The intention of the Act on social workers and professional chamber prepared by the Ministry of Labour and Social Affairs proposes, in addition to basic requirements for “general” social workers, also the possibility of **specialisation** obtained in a special education programme. If the substantive intention of the Act on social workers is enacted with this proposed provision, we will have new means of improving social work with seniors with dementia, amongst others.

# Nursing as a Part of Residential Service (Workshop)

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## **Keywords**

Scope of care provided, nursing

## **Abstract**

Nursing is necessary in residential social facilities, just as social approach is necessary in healthcare facilities. The theme of the workshop was the scope of care provided and examples of best practice and bad practice.

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## **1. Scope of care provided**

The conclusions of the working group clearly indicate that nursing is necessary in residential social facilities, just as social approach is necessary in healthcare facilities.

The participants consider it an unwritten rule that if over 50% of all tasks are healthcare tasks, the client is considered a client of healthcare services and vice versa. One cannot argue that healthcare activities in social care facilities should be analogous to those performed in-home. However, insurance companies pressure providers and general practitioners to decrease the scope of the services to the minimum; the procedures differ in individual regions.

## **2. Nursing in residential services**

Physicians should be available at least to the same degree as when the clients live at home. We need medical procedures paid by insurance companies that are meaningful for the quality of life of our clients. Examples: rehabilitation, physiotherapy, basal stimulation, general palliative care, treatment of pain, nutrition care. Registered nurses are wanted in social services.

When is health care provided in social services? Nowadays, it is provided in all social services. Can health care be separated from social care? The conclusions of the working groups indicate that this is impossible.

Let us open a passageway between the almost neighbouring Ministry of Health and the Ministry of Labour and Social Affairs and let us deal together with our common issues.

# Workshop of National Preventive Mechanisms and Ombudsman Institutions

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## Keywords

Ill-treatment, restrictive measures, retaliatory measures

## Abstract

The aim of the workshop was to share knowledge and practical experience relating to the supervision of places where persons restricted in their freedom are, or can be, found. Discussion centred on a number of topics which the monitoring teams currently address in their activities.

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## 1. Introduction

On 21 February 2014, representatives of the Czech, French, Slovenian and Polish national preventive mechanism (NPM) and staff of the offices of the Slovakian and Hungarian Ombudsman offices met under the auspices of the Czech Public Defender of Rights. This round table was organised at the occasion of the international conference entitled “Protection of Rights of Elderly People in Institutions, with an Emphasis on People Suffering from Dementia” in which all the foreign guests actively participated too. The Conference and the subsequent round table were held as part of the project Together for Good Governance (CZ.1.04/5.1.00/81.00007).

The aim of the workshop was to share knowledge and practical experience relating to the supervision of places where persons restricted in their freedom are, or can be, found. Discussion centred on a number of topics which the monitoring teams currently address in their activities, including the problematic issues addressed in some of the papers presented at the conference.

Participants:

- The Office of the Public Defender of Rights (Marie Lukasová, Adéla Hradilová, Zuzana Kameníková, Ladislav Tomeček, Ondřej Vala)
- The Office of the Public Defender of Rights of the Slovak Republic (Lenka Bodnárová, Petra Fúrková, Drahoš Navrátil).
- Alapvető Jogok Biztosának Hivatala - The Office of the Commissioner for Fundamental Rights (Tímea Csikós, Katalin Haraszti).
- Contrôleur général des lieux de privation de liberté (Vincent Delbos)

- Varuh človekovih pravic RS (Ivan Šelih, Jure Markič)
- Rzecznik Praw Obywatelskich (Aleksandra Iwanowska, Marcin Kusy)

## 2. Topical questions and issues on the agendas of NPMs and Ombudsman institutions

In the beginning of the meeting, debate was held on topical problems with which the individual monitoring teams currently struggle. Particular attention was paid to the existence and monitoring of unregistered social services facilities. The reactions of the foreign guests revealed that this issue is topical not only in Czech Republic but also in other European countries. Participants from Hungary, Poland and France confirmed that in their countries there are also facilities that provide accommodation and comprehensive care for vulnerable persons without the license required for health or social services and, therefore, without any guarantee of quality and respect for the clients' human dignity. In spite of this, monitoring bodies in the above-mentioned countries do not visit this type of facilities yet.

Responding to a question of their foreign colleagues, the representatives of the Czech NPM stated that they visit unregistered facilities providing social services, since persons restricted in their freedom are found in these facilities due to their clients' dependence on the care provided. They were able to do so as the Czech law implementing the OPCAT stipulates that even such facilities fall under the competence of the NPM ("*restriction of freedom as a result of dependency on the care provided*"). A series of these visits is currently under way and the findings are very serious with respect to ill-treatment of elderly clients suffering from dementia or another mental disorder. When visiting these facilities, the Czech NPM had no problems so far, the employees were always let in. One can assume that it is only a matter of time before the Czech courts rule, under the influence of the case-law of the European Court of Human Rights which is now being settled, that placement in an unregistered facility falls into the category of detention in social services; national case-law is only being developed now and the NPM intensively works with the legislative bodies to improve the statutory framework with respect to the conditions for restriction of freedom in social services facilities.

Mr Ivan Šelih, a representative of the Slovenian Ombudsman, stated that a person recently died in one Slovenian facility providing social services and, therefore, the topic is now in the spotlight. Mr Šelih also pointed out that Slovenia has yet to see an unambiguous solution of the issue of how to assess situations where a person with restricted legal capacity or deprived of legal capacity is placed in a facility based on the consent of the person's guardian. Up until now, the consent of the guardian has been deemed equal to the consent of the person under guardianship. Therefore, the Slovenian Ombudsman contacted the Constitutional Court two years ago with request for a statement on this issue, which has not been issued yet.

Mr Vincent Delbos pointed out that the French NPM is not authorised to visit social service facilities, because its competence is limited to facilities in which people are placed based on a decision of a public authority. Therefore, the issue of operation of unregistered facilities providing social services is more of a societal problem in France and its solution should arise from debates on that level.

With respect to this topic, our Polish colleagues stated that in their country courts are obliged to inspect social services facilities once or two times a year.

Our colleagues from Slovakia added that the Public Defender of Rights so far implemented several systemic investigations in institutions such as corrective facilities, schools, prisons and police detention departments for foreigners. A systemic investigation in institutions for the elderly has not been carried out so far, even though the rights and freedoms of the elderly have been investigated on numerous occasions individually on the basis of complaints even in social service homes, retirement homes and similar facilities. A number of recurrent deficiencies in the protection of fundamental rights and freedoms of the elderly were identified based on these investigations, inspiring the Public Defender of Rights to direct the systemic investigations in 2014 to this area on her own accord. Specifically, the issues concerned include: determining real availability of social services for the elderly with an emphasis on observing human dignity and reasonable material support in view of the offer and price of social services on the one hand and the financial possibilities of the elderly on the other hand.

### 3. Methods of work of NPMs and Ombudsman institutions

Subsequently, the debate turned to methods of investigation used by individual teams in visits. The topics mentioned included the manner of interviewing, observing and obtaining necessary documents. Photographing during visits, communication with authorities and other entities and training of certain target groups were also discussed.

As far as interviewing during visits is concerned, the participants agreed that it is often very difficult to ascertain the truth about the observed phenomena. Therefore, it is advisable to ask the same questions repeatedly to verify the statements of the interviewed persons, compare the answers of the interviewed persons and contrast the information gained with the findings of colleagues. The representatives of the Czech NPM pointed out that it proved very efficient to visit the monitored facilities not only during the day, but also at night. At night, the staff is often more open and less busy and it is thus possible to gain further valuable findings which could not be necessarily obtained in previous visits. Visits at night are also frequently implemented by the French NPM, who inspired the Czech NPM to introduce the method.

The Slovak delegation stated that when implementing their investigations, they carry out individual interviews with persons placed in institutions (anonymously in the form of an unstructured interview using a list of questions prepared in advance) as well as with the personnel and the management of the institutions. They obtain key information in particular during the first interviews after they arrive in the facilities (they found out that the interviewees subsequently communicate with one another and their answers are prepared in advance and tendentious). In addition to interviews, they focus on obtaining all available written documents when performing investigations in institutions. They also inspect all parts of the facilities, creating photographic documentation.

The Polish delegation contemplated the question of whether individual or group interviews with the interviewed persons are more advantageous. The participants agreed that individual interviews are usually more valid.

The Czech NPM complements observation, as a necessary part of visits, with taking a large number of photographs, which are an indispensable tool in the subsequent preparation of reports on the visit of the facility. Other participants confirmed the use of this method. Katalin Haraszti, a colleague from Hungary, stated that the Hungarian NPM stores the photographs taken on a CD and includes them in the file. The French NPM currently uses the services of a professional photographer, who participates in some visits as a member of the monitoring team. Photographs taken by the photographer do not only have an information value, they also serve as means of raising public awareness of the NPM's activities. They can be used in press conferences, reports etc. More and more frequently, the Czech NPM too includes photographs which capture the reality in the given facility in the text of its reports.

The participants focused on other challenges which they face during their visits. One of the topics was the situation when the staff of the facility is not willing to let the personnel of the monitoring body in the facility and allow the visit. The Czech NPM encountered such situations rarely, for example during a visit to a police cell and alcoholic interception centre, the French NPM encountered such situation when visiting a children's psychiatric ward in a hospital. The Polish delegation pointed out that waiting for a long time and negotiating before the visit can impede the fulfilment of the goal of the visit, as evidence of ill-treatment may be covered up in the meantime; they primarily had in mind visits to police cells. The participants agreed that these problems can be prevented by a sufficient awareness of the NPM's mandate among the public and the specific types of facilities. In the Czech Republic, there still are groups of facilities not visited by the NPM so far and thus not aware of the NPM's activities. The Slovenian delegation emphasised that many problems on the NPM's agenda can be efficiently prevented by keeping informal contact with the competent authorities (in particular the ministries) – it is important to have a telephone number and, in case of problems in the field, to be able to flexibly deal with them on the level of the competent authority.

The participants stated that education of some of the important target groups is a key element of the work of monitoring bodies. Both the Slovenian and Polish NPMs regularly hold seminars at police academies. The Czech NPM also plans to offer a seminar for policemen this year.

The Slovak delegation added that investigated entities were more willing to co-operate with investigators if the Public Defender of Rights participated in the investigation in person. It has proven useful to hold an *ad hoc* meeting during the lunch break, during which the lawyers exchanged their findings and determined priorities for the visits.

## 4. Co-operation with experts and NGOs

The topic of co-operation with NGOs and experts was introduced by Mr Šelih, who outlined the Slovenian model of the institution of Ombudsman in his presentation. The "Ombudsman +" model in place in Slovenia is specific in its broad co-operation with selected NGOs. Experts delegated by these NGOs participate in the preparation and implementation of systemic visits together with the NPM team. In addition to co-operation with experts from NGOs, the Slovenian NPM also engages independent experts. The typical composition of the visiting team is one member of the NPM, one representative of an NGO and one expert. This whole team participates in the preparation and realisa-

tion of the visit and preparation of the final report, managed and supervised by the NPM member. The team discusses in advance the topics of the planned visit, the method of work and assessment of the findings.

The Slovenian delegation stated that the choice of experts within individual NGOs is problematic. Under the current arrangements, the NPM selects only the organisation, but not the specific expert. It depends on the NGO whom it assigns to the work. The representatives of the Slovenian NPM stated that it is more advantageous to be in charge of the selection of the individual persons and, therefore, they wish to change the system in the future.

Mrs Haraszti from the office of the Hungarian Ombudsman pointed out that when co-operating with NGOs it can be challenging to check and ensure that they maintain confidentiality. She underlined the fact that NGOs are not independent and the NPM must closely supervise their work.

As Mr Delbos stated, the French NPM shares its findings with NGOs by means of its annual reports. When performing visits, the NPM is in contact with local NGOs and it shares its findings with some of them after performing the visits. After presentation of the NPM's annual report, a meeting is held with, *inter alia*, representatives of NGOs. Even though experts from NGOs are not directly included in the NPM team, some members of NPM worked for NGOs in their former professions.

As far as the role of independent experts is concerned, the Polish delegation stated that the institution of Ombudsman employs psychiatrists, psychologists and a general practitioner. Responding to a question, representatives of the Slovenian NPM stated that from the financial point of view it is more efficient to hire external experts than to employ them.

The Slovak delegation stated that when preparing and subsequently processing individual topics of systemic investigations, they used the help of NGOs (depending on their specialisation) on numerous occasions, in particular with respect to their findings, experience or manner of carrying out investigations. However, in view of the funding of the Office, the help of NGOs and experts has never been used in the realisation of field investigation itself. A psychologist employed by the Office usually participated in investigations.

## 5. Reprisals against people communicating with NPMs and Ombudsman institutions

The debate moved on to the issue of reprisals with which (not only) the French NPM currently struggles. The French NPM frequently encounters situations where persons who contact the NPM or communicate with the NPM in any other way (e.g. during visits) are persecuted by the facility in which they are placed. This problem is typical of prisons. France has seen a case of death of a person who was placed in solitary confinement for provision of information to the inspection body. Numerous suspected cases of immediate relocations of the persons to other facilities or withdrawals from projects are also of serious concern. Letters from persons restricted in their freedom are often delivered to the French NPM opened.

As Mr Delbos stated, it is very difficult to estimate the frequency of these reprisals. However, it is very important to address this issue, as it very negatively interferes with the work of the NPM. The French NPM noted that the interviewed people often do not wish to talk to the members of the monitoring team out of fear of reprisals. In one case, prisoners stated that the guards threatened them with relocation to another prison if they speak to the representatives of the NPM.

The Polish delegation also mentioned one specific case where they strongly suspected reprisals: a prisoner was relocated to another prison very shortly after he spoke to the NPM representatives. However, it is difficult to prove that relocation (or other negative consequences) occurred in connection with communication with the inspection body. This was confirmed by Mrs Haraszti, who pointed out that victims of the reprisals include not only persons restricted in their freedom, but also the personnel of the facilities.

The Slovak delegation added that when implementing systemic investigation, they never encountered a proven case of reprisal against the employees or persons who provided them with information. However, they encountered many cases where employees were afraid to provide information due to a potential loss of their jobs or other negative responses of the management. In repeated visits, persons in facilities stated that the management of the facilities (especially in facilities housing children) pressured them in connection with provision of information.

Neither in Slovenia nor in the Czech Republic are there many indices of reprisals of persons communicating with inspection bodies. However, as Mr Šelih said, this does not mean that the problem does not exist and if the NPM learns of any reprisals, it should visit the given institution more often.

To prevent this problem, confidentiality of all interviews must be ensured both with respect to persons placed in the facilities and their employees. The French NPM meets, within the framework of a visit, a representative of the unions of the prison and discusses this topic with him or her. Ms Lukasová from the Czech NPM noted that reprisals are inadmissible acts for which liability is borne by the inspected facility. The NPM must deal with such acts in the best possible way. However, Ms Lukasová proposed maximum co-operation with representatives of the inspected entities and putting pressure on these representatives so that they actively take steps against reprisals and clearly condemn them and guarantee a proper prevention of ill-treatment to which the State agreed.

## **6. Use of restrictive measures in healthcare facilities and social services facilities**

At the end of the meeting, there was space for a problem specific to monitoring healthcare facilities and social services facilities, namely the use of restrictive measures.

The representatives of the Czech NPM outlined the legal framework of use of restrictive measures and the practice ascertained in visits of both of the above-mentioned types of facilities. The Czech NPM pointed out that employees of social services facilities often do not know which practices are legal and use measures that are not permitted by law. They often use tranquillising medication at variance with the statutory procedures.

Inspection bodies are unable to appropriately respond to this problem. In reports from visits, the Czech NPM not only criticises, but also actively communicates with inspection bodies and the ministry to improve the practice in the whole system.

The Polish delegation stated that they too encountered situations where the personnel of the facilities did not know what measures are considered restrictive. In Poland, seminars on the use of restraining measures are provided to policemen, but they are lacking in other professions. Representatives of the Polish NPM witnessed incorrect and inhumane methods of use of restrictive measures. In the past, the Polish Ombudsman dealt with cases where persons were preventively sedated during transportation, for example.

In Slovenia, restrictive measures may only be used in specialised departments. Therefore, social services facilities must obtain licenses to establish special units; psychiatric hospitals usually have special closed departments. Use of tranquillising medication is not considered a restrictive measure, but rather a type of health care and, as such, it is not subject to inspection with NPM's visits.

The Czech NPM emphasised that the use of restrictive measures should be regularly inspected by the management of the facilities. For this purpose, the Czech Ombudsman recommends (above the scope of statutory requirements) to keep a central registry of use of restrictive measures in the given facility. The NPM also pointed to a specific type of restrictive measures which is (legally) used in Czech healthcare facilities, namely the cage bed. The use of cage beds was ascertained even in one of the visited alcoholic interception centres. This measure is very controversial, as strangling of patients located in cage beds occurred in the past (accidentally). Other participants did not indicate that it is possible to use cage beds in their countries.

The French NPM currently deals with a specific problem, namely the use of masks in transportation of persons suspected of involvement in organised crime. The Czech NPM has not encountered this problem so far.

The Slovak delegation added that they only carried out this type of investigation in corrective facilities (with respect of minors), where they found excessive and insufficiently justified use of the isolation room. The staff of the Office was not able to verify the purpose of use of tranquillising medication.

## Conclusion

The workshop of national preventive mechanisms and staff of Ombudsman institutions could not deal by far with the entire spectrum of topics which members of the monitoring teams face within their work. However, it proved to be an efficient means of mutual sharing of experience and best practice and warning against any unsuitable or unsuccessful practice. The representatives of the Czech NPM have gained valuable knowledge at the workshop, which they will strive to use in their future activities.

# Dementia – It Will Soon Open Our Eyes

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## **Keywords**

Dementia, Functional Assessment Staging Test, early diagnostics

## **Abstract**

This paper contemplates the statistical data forecasting a demographic development which will multiply the share of people suffering from dementia in the Czech society. It points out the advantages of early diagnostics and adoption of systemic measures to achieve better quality of life of the patients and their families.

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In 2013, healthy life expectancy in the Czech Republic was approx. 60 years. Life expectancy with the presence of an illness was 80 years. During the past 15 years, the gap has widened by approximately 5 years on both sides. And it keeps growing. This means that we all have to assume that we will live longer, but with a disease. In many cases, we will live with a disease for years.

Dementia is a typical example of a “modern” disease of this century. In the Czech Republic, there are about 150 thousand people with dementia and some forecasts predict that this number will double or triple in the next twenty years. This increase is obviously associated with a significant increase in the percentage of the population aged 75 to 80, amongst other factors. From the age of 70 onwards, the number of patients with dementia doubles every five years. In Europe, there are 14–16% people suffering from dementia among people of 80 (men – women) and 33–48% among people aged 95 or older. In the Czech Republic, the percentage is similar or higher, we are among the countries with the oldest population in Europe.

Several months ago, I was very pleased to hear of a very interesting idea coming from Germany. Municipalities will build barrier-free apartment buildings, where on the same floor there will be an apartment for an elderly person or an elderly couple and next door there will be an apartment with significantly reduced costs which can be occupied by the grandson, granddaughter, a young married couple (priority will be given to family members of the elderly inhabitants) under the condition these younger occupants will take care of the aging spouses or the lonely senior a few hours a day. It was calculated that this will be cheaper for the government than to pay for various home care services or institutional substitute social care while intergenerational solidarity will be maintained. This solidarity is extremely important and, about 20 years ago, it used to function well even in the Czech Republic.

According to some scales for testing the stage of dementia syndrome (in particular the most frequent Alzheimer's dementia) – for example the FAST scale (Functional Assessment Staging Test)[1,2] included in the references – it is possible to define the temporal prognosis of untreated dementia based on large sets of patients. In 6a-d stage, the prognosis may be as short as 3-6 months in case of untreated complications of dementia (behavioural and eating disorders). In a later stage, however, the prognosis in case of untreated patients may be up to one year.

What does this tell us? Dementia must be diagnosed at an early stage, it is necessary to recognise the need for specialised palliative care and support of the family of the caring persons already in stage 3-4 (or P-PA-IA 2-3 according to the Czech Alzheimer Society). A plan of care must also be drawn up and discussed with the family.

Who should do this? The healthcare system, general practitioners, geriatricians, internists, psychiatrists, and physicians in other fields.

According to the modern approach to dementia diagnosing, this plan should be drawn up upon the diagnosis of moderate dementia, i.e. at the very beginning. In this case too, early diagnostics in the Czech Republic is not satisfactory, but even if it was, only few professionals in the Czech Republic speak with their patients about the whole course of the disease from the outset.

Unfortunately, in the second stage of dementia (according to the Czech Alzheimer Society) it is often already difficult to establish such relationship with the patients that they can decide whether they wish to receive artificial nutrition, acute care, ventilation care etc. in the end of their lives. Our legislation recognises previously expressed wishes, but, as a society, we still do not feel the need to address the human life as a whole. With all the pluses and minuses.

I believe that dementia can be one of the factors of the modern era which will open our eyes. I am convinced of this because according to research there will be over 0.5 million patients with dementia in the Czech Republic in 2035. This means that if a standard family with 3 or 4 generations has about 10 or more members, every other family in the Czech Republic will have to deal with the question of how to take care of their relative(s) with dementia syndrome.

And because people with dementia are not confused or stupid, but simply “behave differently”, we “healthy people” do not understand them much, according to professor Böhms' psychobiography, and we must learn to understand them, I believe that dementia will open our eyes also with respect to values other than those addressed by the healthcare and social systems.

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# I Sometimes Cry over People, I Often Cry for People, and at times I Cry in Front of People

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## **Abstract**

This paper is a personal testimony of a physician – head of a palliative medicine facility.

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The World Health Organization defines health as a state of well-being. Everyday, I meet people who have experienced our healthcare system, but the system was not able to provide them with well-being in the sense of curing. But it also was not able to provide them with anything else, anything valuable. It did not want to hurt them and it could not refuse them and it did not even wish to do so. And thus it did what it seems to be able to do: it “treated” them. But it had no idea as to why, what and how.

It is easy to complain about how horrible everything is. I do not like it when people are spoiled. This country is one of the best places on Earth. We could do even better. But to do so, we would have to stop crying for ourselves and start doing something for people, or at least cry for them.

Let me tell you a story.

Telephone – a young woman, request for admitting her husband in coma in the hospice. Complicated case, about 3 months after a cardiological surgery, during which arrhythmia occurred, cardiac arrest, long resuscitation and a significant loss of brain activity, coma. 37 years of age. “Can I bring the application in person?” Of course. A good opportunity to get to know her, attempt to gain her trust, which is necessary for future support.

Next day, I am on duty, she arrives at 6 p.m. Short, quiet, but resolute, she is not the type who cries when a problem occurs either because of fear or for herself. “The worst thing is that my 5-year-old son has been crying every day since it happened. What do I tell him? Can I bring him along? In the hospital, they do not want to talk about this, they will not advise me.” The eyes seem to have sunken. “I think you can bring him along, or rather you have to. We will help you. We will have a free bed after the weekend. If the hospital fills in clear categorisation (therapy without any changes) in the documenta-

tion, there will be no problems with admitting him." I will inform the head physician of the intensive care unit in the hospital.

Two days later, a phone call from the patient's wife: "They transferred him 50 km away to a long-term care facility and they refuse to fill in anything." I call to the long-term care facility, the head physician is great: "Yes, from our point of view, hospice care is suitable for the patient, we will hold a meeting of neurologists and we will transfer the patient to you on Monday. This will surely help the wife and the family." Bless you, sir. There should be more people like you in our profession.

The patient has been with us for 4 weeks, his condition is deteriorating, the son came with his mother once, but then refused to come again. But the mother is calmer; she can see that we take care of the husband. But she also knows he can die any minute. On Thursday morning, the patient's condition gets worse, his heart fails, it is clearly terminal pulmonary embolism, so I call the wife. At 11 o'clock, a nurse calls me: "The patient's wife is in the patient's room, please go see her."

I enter the room, the woman and her son by her side are standing by the bed, the son talking to his dad as if in a conversation. I look at the patient and I see at the first glance that he has just breathed his last. The wife immediately sees in my eyes what happened, and she starts to cry. The son is standing by her, helpless. I am helpless for a couple of seconds too. Then I kneel beside him: "I am so very sorry, your father has died..." A tear comes into my eyes and my voice is trembling. He does not respond at all, his eyes are frozen, then he embraces his mother; I think of my own children. Our psychologist is with us too, we are just standing near to be available.

"What can we do for you?" - "I cannot drive, I will try to get someone from my family to drive us." - "Do not call anyone, I am going to Brno by car, I will take you there and you can pick your car tomorrow." She agrees.

On the way, I stop several times, the boy is sick, he is choking, then has a coughing fit. His mum is great, but clearly exhausted. In their apartment, there are both her and her husband's parents, two of them suffering from a serious oncological disease. She and her husband had a mortgage for their apartment to repay, but she is on maternity leave with her young daughter. What happens now? The parents also did not know that the husband had passed away, I offer my condolences, I explain what is needed; I cannot leave immediately and leave them alone. I say my goodbyes half an hour later - I will come back the next day at 8 o'clock to take the wife to the hospice and we will deal with the necessary issues.

I am driving home, it is only about 5 km, but I am almost unable to drive. My thoughts are wandering. It is my middle daughter's birthday, I was supposed to be home two hours ago. They are waiting for me in the kitchen. I sit down wearily and start crying. This was the first time in the 16 years I have been working in healthcare that I brought my work home like this. "Dad, what happened?" I tell them everything, my children kiss me and I feel a little better. I am lucky to have them.

I pick her up the next morning. She is brave, does not talk much and just firmly shakes my hand when we part. "Thank you, I will never forget what you have done for us." She does not have to say any more and I feel a little better again. Three months after that, I received an e-mail: "Thank you, it is hard, but my son started going to the kindergarten again and things are looking up." Thank you, Jana, I feel a little better.

The moral of the story is this: I do not think it is wrong to cry from time to time, but it is necessary to cry for people, for a reason. Apart from this, we need to do something for people – so that we can all laugh heartily from time to time. I will never forget one of my colleagues, a general practitioner, who died in my arms from pulmonary haemorrhage associated with lung cancer. She knew everything, she knew how her disease will develop, she had a great family and she supported them. A week before she died, she had a picture taken of her and her two daughters in the hospice bed. It is an amazing picture, you would not tell how seriously ill she was. The picture is so full of smiles and joy that they could be together, full of courage.

We praise ourselves for having one of the best healthcare systems in the world. In some acute fields this may be true for a small group of patients. But our population is aging, the expectancy of life with a disease and the one without it differs as much as by 20 years, many of us are already living through these years with a disease and in future the number of such people will be even higher. In many cases, people will live fully dependent on others for months or years. We will die of these diseases. Within three weeks in January 2014, nineteen patients died in our hospice. Nineteen stories, nineteen families, about eighty people. Some of them had to accept as a part of their life story that their relatives suffer from a disease, but frequently also from the stupidity, ignorance, unwillingness or even vulgarity of the society, and even the healthcare system, in which we live and work. I do care about it because one day I will be one of them.

I sometimes cry over people, I often cry for people, and at times I cry in front of people. Maybe I am a hopeless humanist, but though I might cry again, I will never run away from a dying patient. I do not like the way we make our lives easier. Being spoiled. This is the problem of this society and this age. Seeking easy solutions. At any cost. I do not like this because this does not work as a strategy for life at all. Just like any act of selfishness.



## Protection of Rights of Elderly People in Institutions, with an Emphasis on People Suffering from Dementia

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