Public Defender of Rights
OMBUDSMAN

RETIREMENT HOMES AND SPECIAL REGIME HOMES

REPORT
ON SYSTEMATIC VISITS CARRIED OUT BY
THE PUBLIC DEFENDER OF RIGHTS 2015

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Pursuant to Section 349/1999 Coll., on the Public Defender of Rights, as amended, the Public Defender of Rights (Ombudsman) protects persons against the **conduct of authorities and other institutions** if such conduct is contrary to the law, does not correspond to the **principles of democratic rule of law and good governance** or in case the authorities fail to act. If the Defender finds shortcomings in the activities of an authority and if subsequently the authority fails to provide for a remedy, the Defender may inform the superior authority or the public.

Since 2006, the Defender has acted in the capacity of the **national preventive mechanism** pursuant to the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. The aim of the systematic visits is to strengthen the protection of persons restricted in their freedom against **ill-treatment**. The visits are performed in places where restriction of freedom occurs ex officio as well as in facilities providing care on which the recipients are dependent. The Defender generalises his or her findings and recommendations concerning the conditions in a given type of facility in summary reports on visits and formulates general standards of treatment on their basis. Recommendations of the Defender concerning improvement of the conditions found and elimination of ill-treatment, if applicable, is directed both to the facilities themselves and their operators and the central governmental authorities.

In 2009, the Defender was also given the role of the **national equality body** pursuant to the European Union legislation. The Defender thus contributes to the enforcement of the right to equal treatment of all persons regardless of their race or ethnicity, nationality, gender, sexual orientation, age, disability, religion, belief or worldview. For that purpose, the Defender provides assistance to victims of discrimination, carries out research, publishes reports and issues recommendations with respect to matters of discrimination, and ensures exchange of available information with the relevant European bodies.

Since 2011, the Defender has also been **monitoring detention of foreign nationals and performance of administrative expulsion**.

The **special powers** of the Defender include the right to file a petition with the Constitutional Court seeking the abolishment of subordinate legal regulations, the right to become an enjoined party in Constitutional Court proceedings on abolishment of an act or its part, the right to lodge action to protect a general interest or application to initiate disciplinary proceedings with the president or vice-president of a court. The Defender may also make recommendations to the Government concerning adoption, amendment or repealing of a law.

The Defender is **independent and impartial**, accountable for the performance of his or her office only to the Chamber of Deputies which elected him or her. The Defender has one **deputy** elected in the same manner, who can be authorised to assume a part of the Defender's competence. The Defender regularly informs the public of his or her findings through the internet, social networks, professional workshops, roundtables and conferences. The most important findings and recommendations are summarised in the **Annual Report on the Activities of the Public Defender of Rights** submitted to the Chamber of Deputies of the Parliament of the Czech Republic.

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FOREWORD

Mgr. Anna Šabatová, Ph.D.
the Public Defender of Rights

The systematic visits to residential social services facilities where care is provided to the elderly which are the subject of this report were carried out during the mandate of JUDr. Pavel Varvařovský, my predecessor in the office. However, the conclusions still apply and I fully identify with the findings and the shortcomings and errors they criticise.

The visits have revealed ill-treatment in **7 out of 14 cases**. Ill-treatment is a term I use when I wish to express the fact that the identified shortcoming not only affects human dignity, but its severity reaches an alarming degree and a remedy must be demanded.

The systematic visits aim to prevent ill-treatment and it is clear **that many areas of dealing with persons dependent on care open up room for ill-treatment**. The rights of people to life, freedom from ill-treatment, personal liberty and the right to private and family life can be threatened even in places which serve to provide care to people, not as places of detention.

In order to raise awareness of topics that are elementary, but of critical importance for the clients, I submit a detailed analysis of topics such as pain, nutrition, malnutrition, excessive use of tranquilising medication (sedatives), neglect of prevention of falls, and restrictions of personal freedom or privacy. I believe that a legal overview can boost protection of persons reliant on care, even though protection must primarily rest in a concerted effort on the part of the facilities to strive for good practice and to systematically create an environment enabling access to good care.

Most of the criticised errors and shortcomings were not committed intentionally by the staff. On the contrary, the staff often did their best and were showing extraordinary empathy. In my opinion, in most cases **it was the management who was at fault due to its failure to set rules and procedures for a certain range of activities**, e.g. it failed to specify the tasks and responsibilities in the area of prevention of malnutrition, pain monitoring, etc. Alternately, these rules existed but the staff in direct care were not properly instructed about them. If the caregivers do not understand the importance of their tasks, this is naturally reflected in their motivation to carry out the tasks properly and responsibly.

Finally, I wish to remind that my predecessor issued recommendations to almost all the visited facilities to increase the number of carers employed. Unfortunately, some of the facilities later informed us that their bad financial situation forced them to reduce the staff even further. **Nevertheless, without adequate staffing, it is not possible to provide good care for people who are highly dependent on assistance of others.**

I) Systematic visits to social services facilities for the elderly

In 2013, the Public Defender of Rights launched a long-term project of monitoring of the treatment of institutionalised senior citizens. The Defender focused specifically on the conditions of provision of care to people with dementia. Considering the demographic developments in the world and especially in Europe, it is clear that the issues related to care for people with dementia will grow in significance in all European countries. The first stage[1] of the project started in spring 2013 with systematic visits to residential social services facilities providing care to people with dementia. These consisted of retirement homes in the sense of Section 49 of the Social Services Act[2] and special regime homes in the sense of Section 50 of the same Act.

The findings obtained during the systematic visits revealed issues which have not yet been properly mapped or discussed. This is why they were addressed in a conference of experts named "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia" organised by the Office of the Public Defender of Rights in 2014. Anybody interested in the issue of the quality of the social services provided is welcome to consult the conference proceedings.[3]

1) Legislation regulating the provision of the "special regime home" and "retirement home" types of social services

The definitions and the primary regulations of the activities of retirement homes and special regime homes are contained in particular in the Social Services Act. In terms of secondary legislation, the implementing decree to the Act[4] is of primary importance, containing the Social Services Quality Standards in its Appendix 2.

My evaluation of treatment of clients in terms of observance of their rights is based on the Charter of Fundamental Rights and Freedoms. Of international instruments with priority of application over domestic law, the Convention for the Protection of Human Rights and Fundamental Freedoms[5] (hereinafter also the

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[1] The project further encompasses visits to health care facilities and also to those residential facilities that lack the registration required by the Social Services Act, despite actually providing social services, albeit illegally.

[2] Act No. 108/2006 Coll., on social services (hereinafter the "Social Services Act").

[3] Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia [on-line]. Brno: Office of the Public Defender of Rights, 2014 [retrieved on: 18 November 2014]. ISBN 978-80-87949-04-7. Available at: http://spolecne.ochrance.cz/fileadmin/user_upload/projekt_ESF/Seniorska_konference/sbornik_EN.pdf Hereinafter "Conference Proceedings 'Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia'".

[4] Decree No. 505/2006 Coll., implementing certain provisions of the Social Services Act.

[5] Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by its protocols No. 3, 5 and 8, promulgated under No. 209/1992 Coll. (hereinafter the "Convention for the Protection of Human Rights and Fundamental Freedoms").

"European Convention"), the UN Convention on the Rights of Persons with Disabilities[6] and the International Covenant on Civil and Political Rights are of primary importance.[7]

Further, I take into account the standards and recommendations formulated by international organisations or non-governmental organisations which, albeit not legally binding, represent a certain framework for assessment of what constitutes good and bad practice in treatment of people with dementia. In the Czech context, the Czech Alzheimer Society's P-PA-IA strategy is to be highlighted.[8] Alzheimer Europe and its recommendations, opinions and declarations are important in the international context.[9] The rights of older persons are also addressed in a number of legally non-binding declarations and charters. The United Nations Principles for Older Persons, adopted by the UN General Assembly in 1991[10], is worthy of attention here as well as the recommendation issued in 2014 by the Committee of Ministers of the Council of Europe in respect of human rights and freedoms of older persons.[11]

2) Course of the visits

The visits were always carried out without prior notice. The facility management was informed upon commencement of the visit. The visits took usually between 2 to 3 days; the duration depended on the size of the facility. In a number of cases, the visit included inquiry during the night.

The visits included an inspection of the facility, especially of the premises where clients were present (personal rooms, dining rooms, common rooms, gardens, etc.) and an inspection of the staff facilities (the nurses station, kitchen, stocks of medical products, etc.). Interviews with the staff, the management and, in certain cases, the clients represented another important part of the visits. The interviews were always carried out in private and their content was confidential. The Office's employees observed the staff at work, inspected the clients' documents, the staff's documentation tools and the facilities' internal rules and regulations.

Aside from the lawyers employed by the Office of the Public Defender of Rights, the Office also invited an external consultant – a health care specialist – to participate in the visits. In order to ensure correctness of the outputs of these visits from the professional viewpoint, the Public Defender of Rights signed a memorandum of **co-operation** with the Czech Alzheimer Society, the Czech Nurses Association, and the Czech Society for Palliative Medicine.[12] A number of consultations as well as selection of the Defender's external collaborators took place on the basis of this co-operation.

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[6] Convention on the Rights of Persons with Disabilities, promulgated under No. 10/2010 in the Collection of International Treaties.

[7] International Covenant on Civil and Political Rights and International Covenant on Economic, Social and Cultural Rights, promulgated under No. 120/1979 Coll.

[8] CZECH ALZHEIMER SOCIETY. Strategie České alzheimerovské společnosti P-PA-IA. Péče a podpora lidem postiženým syndromem demence (Czech Alzheimer Society's P-PA-IA Strategy. Care and Support for People Suffering from Dementia) [on-line]. Prague: Czech Alzheimer Society. Revised 2013 version [retrieved on: 3 June 2014]. Available at: http://www.alzheimer.cz/res/data/000136.pdf, hereinafter the „P-PA-IA Strategy".

[9] See e.g. Alzheimer Europe recommendations on the use of restraints in care for patients with dementia (ALZHEIMER EUROPE. The ethical issues linked to restrictions of freedom of people with dementia [on-line]. Alzheimer Europe 2012 [retrieved on: 3 June 2014]. Available at: http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports).

[10] UN GENERAL ASSEMBLY. United Nations Principles for Older Persons. Resolution A/RES/46/91, adopted on 16 December 1991 [on-line]. New York: UN General Assembly [retrieved on: 5 June 2014]. Available at: http://www.un.org/documents/ga/res/46/a46r091.htm.

[11] COUNCIL OF EUROPE. Recommendation CM/Rec(2014)2 of the Committee of Ministers on the promotion of human rights of older persons, adopted on 19 February 2014 [on-line]. Council of Europe [retrieved on: 5 June 2014]. Available at: https://wcd.coe.int/ViewDoc.jsp?id=2162283&. This represents the first European instrument explicitly addressing the human rights of older persons.

[12] PUBLIC DEFENDER OF RIGHTS. Z činnosti ombudsmana (Ombudsman's Activities) [on-line]. Brno: Public Defender of Rights 2013 [retrieved on: 6 June 2014]. Available at: http://www.ochrance.cz/ochrana-osob-omezenych-na-svobode/z-cinnosti-ombudsmana/.

3) Information on the facilities visited

In 2013, a total of 14 residential social services facilities for the elderly were visited; in one case, a repeated visit was carried out to monitor compliance with the Defender's recommendations. In 7 cases, the Defender ascertained ill-treatment consisting of violations of the fundamental rights and freedoms of the clients in various degrees. The table below contains detailed information on the visited facilities.[13]

Facility	Founder	Type of facility	Capacity
Domov pro seniory Třebíč[14]	Vysočina Region	HR[15], SRH[16]	106
Domov Slaný[17]	Central Bohemia Region	SRH	50
Alzheimercentrum Průhonice, o. p. s.	Alzheimercentrum Průhonice, o. p. s.	SRH	159
Charitní dům pokojného stáří, Cetechovice[18]	Regional Charity Kroměříž	SRH, relief care services	42
Domov pro seniory Světlo, Drhovle	South Bohemia Region	HR, SRH	106
Domov pro seniory Uničov, s. r. o.	Domov pro seniory Uničov, s. r. o.	HR	40
Domov pro seniory Kobylisy	Capital City of Prague	HR, SRH	211[19]
Domov pro seniory Pyšely	Capital City of Prague	HR	60
Dům seniorů Liberec-Františkov, p. o.	Liberec Region	HR, SRH	200
Toreal, spol. s r. o. (Královské Poříčí)	Toreal, spol. s r. o.	HR, SRH	177
Domov U Zámku (Ivanovice na Hané)	Domov U Zámku, o. s.	HR, SRH	45[20]
Lázně Letiny s. r. o.[21]	Lázně Letiny s. r. o.	SRH, Healthcare facility	290[22]
Domov pro seniory a domov se zvláštním režimem PAMPELIŠKA (Česká Lípa)[23]	Pampeliška o. p. s., Ústecká 318, 403 23	HR, SRH	72
Domov pro seniory Zlaté slunce (Ostrava)	Agentura Slunce, o. p. s.	HR	62

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[13] Situation as of the date of the systematic visits.

[14] Full name: Domov pro seniory Třebíč, Koutkova-Kubešova, state-funded institution.

[15] Retirement Home (hereinafter also "HR").

[16] Special Regime Homes (hereinafter also "SRH").

[17] Full name: Domov Slaný, social services provider.

[18] Full name: Charitní dům pokojného stáří, Cetechovice 71, 768 02 Zdounky.

[19] Registered capacity: 211 beds, the real capacity: 188 beds.

[20] Location Ivanovice na Hané.

[21] The facility was renamed as "Social services and healthcare facility Letiny, s. r. o.".

[22] 260 of SRH, 30 beds for aftercare (healthcare facility).

[23] Full name: Domov pro seniory a domov se zvláštním režimem, PAMPELIŠKA, Jáchymovská 2352, 470 01 Česká Lípa.

II) Care for people with dementia

1) Dementia

According to Alzheimer's Disease International, there were 44.4 million people suffering from dementia worldwide in 2013. The number is expected to rise to 75.6 million by 2030 and as much as 135.5 million by 2050.[24] In connection with this trend, an increasing number of countries are becoming aware that care for persons suffering from dementia must inevitably become one of the most important topics of national health policies.

Alzheimer Europe, an NGO, and its member organisations have consistently emphasised this problem in the long term. They have jointly urged European governments and the European Union to give the problem of dementia a political priority. These efforts have materialised, for example, in the Paris Declaration adopted in 2006. The Paris Declaration calls, inter alia, for recognising Alzheimer's disease as a major public health challenge and for developing European, international and national action programmes for tackling the disease.[25]

In the Czech Republic, care for people suffering from dementia is included in the National Action Plan Supporting Positive Ageing for 2013–2017, albeit only to some degree.[26, 27] The Action Plan is a rather general, declarative document, which does not represent a comprehensive strategy.

Dementia brings along a wide range of specific client needs to which a social services facility specialising in providing care for the elderly must be able to respond, regardless of the type of service it provides. In this respect, it is irrelevant whether the place is a retirement home or a special regime home. The visits have confirmed that persons with dementia are currently placed in both types of facilities. Not all the facilities, however, were prepared for this type of clients. While a facility may decide not to accept persons with dementia, the syndrome may develop in some of their existing clients over time.

It is important that even retirement homes that have not established the "special regime home" service understand that dementia is a common medical complication in elderly people (and take this fact into account in providing the service). Therefore, its occurrence should not result in termination of the service but rather adaptation to the specific needs of the clients.[28]

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[24] ALZHEIMER´S DISEASE INTERNATIONAL. Dementia statistics [online]. Alzheimer´s disease international [retrieved on: 6 June 2014]. Available at: http://www.alz.co.uk/research/statistics.

[25] ALZHEIMER EUROPE. Paris Declaration [online]. Alzheimer Europe 2009 [retrieved on: 3 June 2014]. Available at: http://www.alzheimer-europe.org/Policy-in-Practice2/Paris-Declaration.

[26] According to the Action Plan, the number of aging-associated diseases is expected to increase and, consequently, specialised care must be developed. The document formulates two general objectives to be achieved. First, to offer the widest possible range of services, and second, to raise awareness among informal carers.

[27] MINISTRY OF LABOUR AND SOCIAL AFFAIRS. National Action Plan Supporting Positive Ageing for 2013–2017 [online]. Prague: 2013 [retrieved on: 6 June 2014]. Available at: http://www.mpsv.cz/cs/14540.

[28] See the PUBLIC DEFENDER OF RIGHTS. Přístup k sociální službě domov pro seniory. Obsahová analýza. (Approach to the "Retirement Home" Social Service. Content Analysis) [online]. Brno: Office of the Public Defender of Rights, 2013 [retrieved on: 18 November 2014]. Available at: http://www.ochrance.cz/fileadmin/user_upload/ochrana_osob/ZARIZENI/Socialni_sluzby/Vyzkum-2013_pristup-k-socialni-sluzbe_web.pdf.

2) Specific dementia-related needs

Dementia is referred to as a syndrome, i.e. a set of symptoms. It is the consequence of a number of diseases, primarily neurodegenerative and vascular, among which **Alzheimer's disease** is the most frequent.[29] It brings memory disorders followed by gradually developing disorientation and speech disorders as well as poor adaptation to new conditions. Soon after that, the impairment of thinking, judgement, planning and organising of certain activities may appear. This brings limited self-reliance and disorientation. In the stage of severe dementia and in the terminal stage, the patients require nursing and assistance in almost all daily self-maintenance activities. The P-PA-IA Strategy provides detailed characteristics of the individual stages of dementia.

Care for people suffering from dementia in residential facilities must be based on professional findings about the disease and the stage the syndrome has reached in an individual; **it must be personalised and performed by instructed personnel**. It must rely on both non-pharmacological approaches and suitable pharmacotherapy if the latter has been prescribed. On the other hand, intuitive and unprofessional approach means not only a missed opportunity to increase the client's comfort, but may worsen his or her difficulties or cause suffering which could have been avoided. In legal terms, this can represent violation of the client's rights or even ill-treatment. T**he requirement for taking consideration of the professional aspects corresponds to the legal obligation of social service providers to ensure individualised approach to client needs** [Section 2 (2), Section 88 (f) of the Social Services Act].

Tests of cognitive functions and self-reliance[30] can be used to obtain a general picture of a person's situation; **however, in most of the visited facilities the condition of the clients was not systematically evaluated on a regular basis**. As a rule, a certified medical diagnose was issued only to those clients who had been hospitalised before admission to the facility or while staying there. As a result, employees of the homes commonly categorise clients as suffering from dementia intuitively, which may result in wrongly interpreted symptoms. Or, to the contrary, the carer does not admit that the client may be suffering from dementia, as a result of which the specific needs of clients remain unmet, or worse still, the carer misinterprets the client's symptom as displayed "out of spite". **Only very few facilities carried out indicative testing of the clients' cognitive functions**. Yet a correct and timely diagnosis is a necessary prerequisite for the setup of individualised care. Therefore, if there is suspicion that a client suffers from dementia, the facility must provide for a professional medical examination.

Each stage of dementia syndrome requires a specific type of care. The client's daily routine and form of support should reflect the current stage of the person's dementia.

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[29] HOLMEROVÁ, Iva. Úvodní stručná informace o problematice demence (Basic Introduction to the Issues Concerning Dementia). In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", pp. 6-13.

[30] Mini-Mental State Examination (MMSE), the Clock Drawing Test.

Needs of people in the P-PA-IA 1 stage:[31]

- *Need for an early and correct diagnosis, introduction of appropriate pharmacotherapy, if prescribed, and acquaintance of the patient with the probable prognosis for the disease.*
- *Need for support and advice in the planning of future treatment and care with the assistance of a physician (previously expressed wishes), including the handling of legal matters.*
- *Support, psychological assistance and advice.*

Needs of people in the P-PA-IA 2 stage (moderately advanced and advanced dementia):

- *Need for supervision and assistance in many daily activities.*
- *Regular and clearly structured daily schedule and participation in activities according to the person's individual abilities.*
- *Scheduled activities which fill the person's day with individual tasks with the aim of maintaining the person's self-reliance.*

Needs of people in the P-PA-IA 3 stage (severe dementia):

- *Need for provision of health (health-social) care, long-term care and palliative care.*
- *Need for individualised assistance and individualised activities.*

Information on the particular type of dementia syndrome and the stage of the illness are crucial for a proper setup of care. The information must be contained in the client's records, which is a basic prerequisite for the specific setup of care and for getting the staff acquainted with the required information. The staff should work further with such information – facilities that omitted this effort often received criticism for a lack of professionalism and individualisation of the care provided.

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[31] P-PA-IA Strategy.

Recommendations

- Work with the client's diagnosis and stage of the disease as a necessary prerequisite for setup of appropriate care.
- In case of suspicion that a client suffers from dementia, take the MMSE test and, according to the result, ask a physician for a diagnosis and appropriate care setup.
- Work together with the client's physician, regularly perform tests of cognitive functions and monitor the stage of the disease.
- Adjust the care for the client and his or her daily routine to the relevant stage of dementia syndrome.
- Note the information on the diagnosis and stage of dementia in the client's records.

The communication abilities of the patients and the ability to understand their situation worsen as dementia progresses and cognitive functions deteriorate.[32] The ability to express their will (and hence to make decisions on themselves) and their likes and dislikes (comments, complaints) diminishes progressively. This problem must be addressed in order to avoid misunderstandings, ignorance of the client's needs and wishes, his or her social isolation and also frustration. *"Proper communication is a good starting point and a pre-condition for good relationships and co-operation. In communication with patients with dementia, it is important to accept them, respect them and support their dignity. Many misunderstandings arise in situations which 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."*[33]

Special training and empathy are required for the staff to be able to detect the wishes of a client with dementia. It is also necessary to shift emphasis to explanations, offers, comments on what is going on, while reducing to a minimum the dependence of the care on verbal communication.[34] In an overwhelming majority of the facilities visited, the standard of communication was a matter of empathy and intuition of the staff, who had received no special support or training.

Recommendations

- Provide the staff in direct care with regular training on communication with clients suffering from dementia.

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[32] The ability to communicate is seriously damaged in a person suffering from dementia, in terms of both sending and receiving a message. The person with dementia is thus losing this "ticket to society". As a result of poor communication, the person can become lonely and isolated even though he or she is surrounded by other people. Yet the ability to communicate is never destroyed entirely in a client with dementia; it is always possible to look for other forms of communication, the ones he or she still possesses. Even messages that appear senseless may in fact make sense. The carers make their life much easier and the care more pleasant for both sides if they learn to reflect on, understand and use communication with people suffering from dementia. HOLMEROVÁ, Iva, JAROLÍMOVÁ, Eva, SUCHÁ, Jitka et al. Péče o pacienty s kognitivní poruchou (Care for Patients with Cognitive Disorders). Prague: Gerontologické centrum, 2007, Vážka series, p. 68. ISBN 978-80-254-0177-4.

[33] HOLMEROVÁ, Iva. Úvodní stručná informace o problematice demence (Basic Introduction to the Issues Concerning Dementia). In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", p. 7.

[34] For more on this, see BÁŇOVÁ, Marie. Individuální přístup ke klientům trpícím syndromem demence (Individual Approach to Clients Suffering from Dementia Syndrome). In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", pp. 76-83.

In some patients, dementia is accompanied by **behavioural disorders** or other psychiatric symptoms (such as hallucinations; on the other hand, spontaneous aggressiveness is rarely observed in people with dementia).[35] Prevention is important in this respect. Thus, care for a person suffering from dementia syndrome may, depending on the circumstances, include management of behavioural disorders including the search for their causes.[36] "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, self-reliance, prevention and mitigation of the patient's behavioural disorders are an inseparable part of comprehensive care for people with dementia. With these measures in place, it is possible to reduce or even eliminate tranquillising medication, especially antipsychotics, which may have side effects dangerous for the patients."[37] For more information, see Analysis of causes of "restless behaviour", prevention, on page 34.

In caring for clients with dementia, it is important to **create a protected environment** where they can spend their day in a normal way. This can be achieved with the use of safe technical means that are unsurpassable for a client with dementia (and, simultaneously, do not limit more able clients in their free movement). Nevertheless, even in such a protected environment, clients must stay together with the carers. It is inadmissible to keep people with dementia in a confined space alone, without supervision and support from the staff.[38] For details, see Leisure areas, Moving in and out of the facility, on pages 19 and 39 respectively.

Further in the text, some other **specific dementia-related needs** observed by me are discussed and placed in categories in connection with the nature of care provided in the facilities:

- Orientation in reality, Leisure areas, Daily routine; [see pages 16, 19 and 26 respectively]
- Issues of nutrition and diet of people with dementia; [see page 41]
- The management of incontinence is discussed in section Bladder voiding regime; [see page 52]
- Management of depression and pain; [see pages 50, 51]
- Autonomy of will of people with dementia. [see page 21]

Trained staff is a key prerequisite for the ability of the facility to provide care reflecting all the above-mentioned specific needs of clients with dementia. **Training of staff**, both medical and non-medical, **must cover the client's disease, stages of dementia, communication specificities, associated medical complications, behavioural disorders**. Staff training was always examined during the visit to a facility. In most of the facilities visited, the staff had no systematic training and relied exclusively on intuition.

Recommendations

- Provide the staff in direct care with regular training on care for clients suffering from dementia.

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[35] HOLMEROVÁ, Iva. Úvodní stručná informace o problematice demence (Basic Introduction to the Issues Concerning Dementia). In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", p. 8.

[36] HÝBLOVÁ, Pavla. Zvládání poruch chování spojených s demencí (Management of Behavioural Disorders Connected with Dementia). In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", pp. 14-15.

[37] HOLMEROVÁ, Iva. Úvodní stručná informace o problematice demence (Basic Introduction to the Issues Concerning Dementia). In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", p. 8.

[38] See P-PA-IA Strategy.

3) Facilities for elderly people operated without proper registration

There is a considerable demand for residential social services facilities providing care to people with dementia syndrome, which registered social services facilities are not always able to satisfy. In this respect, it is necessary to emphasise the danger coming from various facilities that promise professional care for people with dementia but in fact lack authorisation for its provision under the Social Services Act.

Such unregistered facilities usually present themselves as guesthouses and accommodation facilities and they most often operate on the basis of a trade licence for the provision of accommodation and meals. They provide care services illegally, which constitutes an administrative offence under the Social Services Act. **They are not bound by any requirements for quality, the care provided is not subject to inspections by the Inspectorate of Social Services and they do not respect the maximum amount of monthly payment** stipulated in the Social Services Act for registered social services facilities. The Public Defender of Rights has emphasised this risk before. More details on this problem are available on the Defender's website.[39]

The Defender performed a series of visits to such facilities in 2013 and 2014. Ill-treatment was found in all seven facilities visited. More information is provided in the summary report from visits to accommodation facilities providing care without authorisation.[40]

It is not easy to address the problem of the lack of duly registered social services. However, it follows from the Social Services Act that the Regional Authorities are responsible for ensuring availability of social services (see Section 95 (g) of the Social Services Act). If a citizen who needs a residential social service is refused by the existing facilities, he or she may turn to the Regional Authority for help. Yet the Regional Authorities address the application according to their own discretion and the application in itself does not constitute legal entitlement to provision of the service. At present, however, it is the simplest path to take. In cases where a person is in a situation where failure to provide immediate help (in the form of social service) would put the person's life or health at risk, the duty to provide the social service to the necessary extent lies with the municipal authority of a municipality with extended competence.

4) Detention in social services facilities

Since 2011, the Defender has been pointing out the absence of legal provisions regulating involuntary stays in social services facilities. Some progress has been made through the Special Court Proceedings Act[41] effective since January 2014, which regulates the proceedings of courts in declaring inadmissibility of detaining clients in social services facilities in cases where the person concerned has been placed in

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[39] PUBLIC DEFENDER OF RIGHTS. Za inzerovanou péčí o seniory se může skrývat špatné zacházení (Advertised Care for Elderly People may Hide Ill-treatment) [online]. Brno: Public Defender of Rights, 2012 [retrieved on: 6 June 2014]. Available at: http://www.ochrance.cz/tiskove-zpravy/tiskove-zpravy-2012/za-inzerovanou-peci-o-seniory-se-muze-skryvat-spatne-zachazeni/.

[40] PUBLIC DEFENDER OF RIGHTS. Ubytovací zařízení poskytující péči bez oprávnění. Zpráva ze systematických návštěv veřejného ochránce práv (Accommodation Facilities Providing Care Without Authorisation. Report on systematic visits carried out by the Public Defender of Rights) [online]. Brno: Public Defender of Rights, 2015 [retrieved on: 20 March 2015]. Available at: http://www.ochrance.cz/fileadmin/user_upload/ochrana_osob/ZARIZENI/Socialni_sluzby/SZ-Neregistrovana_web.pdf.

[41] Act No. 292/2013 Coll., on special court proceedings.

the facility on the basis of his or her curator's decision (Section 84). However, the regulation is inadequate because the Act fails to specify the grounds on which a client may be held in a facility against his or her will. It only vaguely assumes that the court will assess whether detention in a facility is necessary or clearly disproportionate. This makes decision-making of courts unpredictable, which contravenes the requirement for legal certainty and opens up room for entirely arbitrary deliberation of courts.

In this arrangement, persons with limited legal capacity who are placed in a social services facilities against their will on the basis of a decision of their curators are not sufficiently protected against unlawful intervention in their fundamental right to personal freedom, which is at variance with the Charter of Fundamental Rights and Freedoms as well as the obligations following from the Convention for the Protection of Human Rights and Fundamental Freedoms (the European Convention).[42]

Where a client of a residential facility, for whom the contract on the provision of social services was concluded by his or her curator, shows disapproval[43] of his or her stay, the provider should inform the court of this fact.[44] Based on that notice, the court should initiate proceedings on declaration of inadmissibility of further detention in social services facilities.

5) Healthcare in social services facilities

It is time to abandon the outdated understanding of clients of retirement homes and special regime homes. It is no longer valid that they accommodate healthy, self-reliant elderly people who wish to spend their old age among their peers. The very admission to a facility is conditional on a certain degree of dependence on care. **At present, most clients of retirement homes are elderly people with serious health problems**. Their medical condition requires nursing care provided directly in the facility. This applies without exception to clients who suffer from advanced or terminal dementia syndrome. The care involves a wide range of nursing tasks such as the administration of medication, acts related to addressing of the risk of malnutrition and its manifestations, prevention and treatment of decubitus ulcers and addressing of unrest.

The visits revealed that full reimbursement of this care by health insurance companies is problematic. **While the clients of the facilities have paid health insurance premiums properly all their life, now, near the end of it, insurance companies often refuse to pay for the necessary care**. The facilities must fund the nurses' work from their own resources, to the detriment of other social care tasks. Some entrust the task of nursing care to non-medical personnel and employ fewer nurses, quite obviously to the detriment of the clients.

Thus, although the Social Services Act anticipates that retirement homes and special regime homes will provide the clients with nursing care and rehabilitation care primarily through their own employees (see Section 36 of the Act), the funding of such care is not satisfactorily addressed.

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[42] For more information, see PUBLIC DEFENDER OF RIGHTS. Nedobrovolný pobyt v zařízení sociálních služeb (Involuntary Stay in a Social Services Facility) [online]. Brno: Public Defender of Rights, 2014 (retrieved on: 6 June 2014]. Available at: http://www.ochrance.cz/ochrana-osob-omezenych-na-svobode/aktuality-z-detenci/aktuality-z-detenci-2014/nedobrovolny-pobyt-v-zarizeni-socialnich-sluzeb/.

[43] The disapproval may be displayed other than just verbally – the person concerned may attempt to leave, or indeed leave the facility without returning spontaneously. However, it is always necessary to take into consideration the person's health. A person in an advance stage of dementia who is disoriented and has limited cognitive abilities is unlikely to perceive his or her situation as a restriction of personal freedom and his or her leaving of the facility need not necessarily indicate unwillingness to stay there.

[44] Specifically, the district court within whose jurisdiction the social services facility is situated.

For example, reimbursement of the administration of medication is a major problem (facilities are currently not permitted to request reimbursement of oral but merely parenteral administration). The General Health Insurance Company of the Czech Republic is notorious for refusing to reimburse the administration of medication, with the substantiation that the task does not take 10 minutes. Although there are many rulings by courts of first and second instance that the time of 10 minutes should be considered an average, and its reduction does not constitute grounds for refusal to provide reimbursement for the task, the insurance company insists on its policy as a rule of thumb and complies only when it loses a dispute.

In 2014, a **Memorandum of Agreement on Reimbursement Mechanisms** was concluded among the General Health Insurance Company of the Czech Republic, the Association of Social Services Providers and the Association of Regions of the Czech Republic.[45] Individual social services providers who enter into a Special Agreement with the General Health Insurance Company, thereby agree to terminate any litigations they may be holding against the General Health Insurance Company. In return, the General Health Insurance Company pays reimbursement for nursing care provided in the past years. This, however, is only a partial solution of the pending disputes regarding reimbursement for care provided.

In June 2014, the Public Defender of Rights invited the General Public Health Insurance Company to provide a statement inter alia on what the Company saw as current shortcomings in the provision of nursing care to users of residential social services. The answer of the Company was that it *"sees as absolutely unsatisfactory … the tendency of some residential social services facilities to release qualified medical staff (nurses) and to replace them with staff in direct service care"*.

The statement gives the impression that the **General Public Health Insurance Company has an understanding for the demands placed on nursing of clients of social services facilities**. In that case, however, it should not refuse an agreement with the facilities that would be primarily in the interest of clients who need health (nursing) care.

In addition, I see a major issue in the fact that **health insurance companies do not conclude agreements with nutritional therapists** as often so as to allow them to become active also in facilities for the elderly and participate in care for individual clients. All this despite the fact that they possess a separate qualification which cannot be fully covered by other employees, not even registered nurses. Persons suffering from dementia are extremely exposed to the risk of malnutrition. If a facility wishes to address this medical problem effectively, it needs a nutritional therapist and, in the present arrangement, has no other option than to pay him or her from its own resources. Malnutrition is a health- and life-threatening condition accompanied by human suffering and clients are entitled to proper healthcare preventing, or effectively addressing, malnutrition.

Failure to **reimburse rehabilitation** is a problem of equal gravity. It is impossible to place rehabilitation under activation, which constitutes one of the basic activities of the service. Only qualified staff can ensure that it is provided to a high standard and safely for the client.

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[45] ASSOCIATION OF REGIONS. Memorandum o dohodě na úhradových mechanismech 2012 – 2014 a o dohodě na smírném ukončení soudních sporů (Memorandum of Agreement on Reimbursement Mechanisms 2012–2014 and Agreement on Amicable Settlement of Court Disputes) [online]. Association of Regions 2014 [retrieved on: 1 August 2014]. Available at: http://www.google.cz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCAQFjAA&url=http%3A%2F%2Fwww.asociacekraju.cz%2Fdownload%2F101%2F&ei=SUg=-VebyBIKcsgHrroCYBw&usgAFQjCNHdnGRC6rojWT6qwHEa-BMnvbXB7w&bvm=bv.91665533,d.bGg.

III) Defender’s findings and recommendations

The visits aimed, generally speaking, to ascertain whether or not the rights and dignity of clients reliant or dependent on care provided by the staff were being respected. Therefore, the focus was on the clients’ living conditions, the care provided, the information whether or not this care was suitable to their needs, and also the manner in which the staff treated the clients. The inquiry addressed a whole range of issues, from conditions for ensuring privacy, to the nursing care provided and the daily routine. The inquiry’s agenda was similar in all the visited facilities. Special attention was devoted to the specific needs of people with dementia.

1) Environment and equipment

a) Orientation in reality

Good practice

Distortion or loss of one’s orientation in reality represents a specific issue related to dementia. The care provided must include a well-considered support of orientation in reality and reduction of factors that hinder it. The facility should be suitably adjusted for the needs of clients with dementia in terms of equipment. The inability to orient oneself may cause behavioural disorders or even aggression.[46]

A number of elements assist the client in orientation in place, person and time. People with dementia are at risk of getting lost even in familiar surroundings. The space where they dwell thus has to be well-arranged, the clients should be able to see the staff and the staff should have good view of the clients. The individual rooms (personal room, social facilities, the day room, dining room) should bear clear markings to attract attention. A client’s orientation in space needs to be supported e.g. through the use of pictograms, colour differentiation, various kinds of reflective bands, direction indicators, and signs.[47] The fact that many people with dementia fear darkness or have troubles recognising uneven terrain also has to be taken into account. Orientation in time should be assisted e.g. by the use of large wall clocks, visible colour-coded indication of days of the week, months and years.

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[46] HOLMEROVÁ, Iva, JAROLÍMOVÁ, Eva, SUCHÁ, Jitka et al. Péče o pacienty s kognitivní poruchou (Care for Patients with Cognitive Disorders). Prague: Gerontologické centrum (Gerontological Centre), 2007. ISBN 978-80-254-0177-4 (hereinafter also “HOLMEROVÁ, JAROLÍMOVÁ and SUCHÁ”), p. 174.

[47] “Labels, colours and symbols alone are definitely not sufficient to ensure spatial orientation in the facility for patients with dementia. Clients must be patiently taught how to orient themselves in the facility. They need to be taught the colour of their room, where the common premises are located (…). Patients with dementia are sometimes able to find their own reference points which may not be obvious to others. This is why the carers should remain attentive and observe what attracts the attention of patients with dementia and what they use to orient themselves.” (HOLMEROVÁ, JAROLÍMOVÁ and SUCHÁ, p. 177).

During the visits, the Defender focused on whether or not the environment was suitable for the needs of clients with potentially impaired orientation (e.g. inability to find their rooms, cabinets, beds, lavatories, or confusion as to what day or season it is, etc.).

Findings from the visits

The Defender found shortcomings concerning unsuitable environment in practically every singly facility visited; often, the clients' orientation in space and time received only a token attention or was not supported at all.

The Defender pointed out the unsuitable practice of **insufficient marking and differentiation of rooms of clients suffering from syndrome of dementia**, where the individual rooms were marked only by (black and white) name tags. The Defender also criticised the lack of instructive pictograms on doors to toilets, showers and common rooms (in some places there was a simple "WC" tag, which may be illegible to clients with cognitive impairment). In some cases, the Defender encountered long, dark corridors where door markings were practically indiscernible (due to the uniform-looking black and white name tags).

In some facilities, markings and pictures were used, but not to support the clients' orientation, but for decorative purposes. In these facilities, certain spatial elements (light switches, power sockets) were marked, but the markings were distributed around only sporadically, and in other cases the pictures used to mark the door lacked a connection to the rooms they led to (e.g. a big flower on a toilet door).

The Defender also criticised the facilities if the environment lacked any kind of stimuli and clues for the clients to help them orient themselves in time and space (big letters, variety, colour contrast, information on the time of the year, recurring presence of the information over multiple places).

Recommendations

- Adjust the interiors to the needs of clients with dementia, who may have trouble with orientation.
- Mark toilet, shower and kitchen doors with clearly visible pictograms, not only with text.
- Mark the doors to the rooms where clients with dementia live distinctly (use colours) so that the clients can find their rooms.

b) Individualisation of the rooms

Good practice

The client's room represents his or her home. This is why it should not look "sterile", but reflect as much as possible the client's personality in terms of personal belongings, pieces of furniture from home (a chair, a cabinet etc.) or pictures. Personal belongings and photographs can help a person to remain aware of who they are, and to help them better deal with changes and potential feeling of isolation.

With **bedridden clients**, increased attention must be paid not only to the environment and the room furnishings, but also to their field of view. Seemingly trivial matters can have massive implications on the quality of the client's life.

Findings from the visits

The Defender considered inappropriate that some rooms were completely "sterile", without decorations or personal belongings, and resembled hospital rooms.

In some cases, not even **bedridden people** had any personal belongings around, or these were not placed in their field of view. In some cases the beds were placed so that the clients could only stare at bare walls. In some places a client could not look out the window due to furniture blocking the view or the window being placed too high.

Recommendations

- Pay increased attention to individualisation of the room.
- Pay special attention to the environment in rooms with bedridden clients and their field of view.

c) Safety

Good practice

Adjusting the environment encompasses also providing for a safe movement of the clients within the facility. Not only clients with dementia are at risk of falling. For this reason, it is vital to actively work to mitigate the risk and introduce preventive measures.

Findings from the visits

The Defender criticised that some facilities **lacked hand rails** for support while moving through corridors, lavatories and showers. There often were **long, dark corridors with no places for rest**. In some places, the corridors were further obstructed by storage boxes and medical material, which made them more difficult to navigate. Sometimes the obstacles blocked access to the hand rails. The Defender also criticised the practice where **furniture (beds, bedside tables) was fitted with wheels that were not secured**. Corridors sometimes contained obstacles in the form of **unsecured wheelchairs or walkers**, which the clients often wanted to use for support. This lead to a needless increase in the risk of falls.

Problems were sometimes caused by **inadequate timer-controlled lighting** in the corridors. A client with reduced mobility was often unable to walk through the corridor without the light going out. In one of the facilities, entrances from the corridors to the rooms were blocked by **high thresholds or inclined floors without any kind of sign or colour-coding**. In another facility, the **door to a client’s room were too narrow for a bed to move through**. In case of a fire, it would be very difficult to evacuate the clients.

Recommendations

- **Adjust the environment and equipment of the facility to the needs of clients with dementia in terms of the increased risk of falls and reduced mobility of the clients.**

d) Leisure areas

Good practice

Clients, not only those with dementia, should not be forced to spend time exclusively in their rooms. Such a situation could lead to social isolation and violates **the principle of normality**. It is normal and natural for human beings to go through various environments according to the activities they engage in during the day: a space for eating, rest, leisure activities and work. A person with dementia has the same right as others to change environments and benefit from the change.

The facility should have a **dining room** available to enable the clients to eat elsewhere than in their rooms [see the chapter “Prevention of malnutrition”, p. 41]. There should also be a **common room for social interactions**. A common room enabling social interactions may represent an important element supporting activation. The common room should be furnished in a fashion similar to a typical household.[48] These spaces (the dining and common room) should serve approx. 15 people and help create a domestic, community feeling. They should not resemble high-capacity, noisy cafeterias typical for large institutions. Furthermore, the facility should have a **safe outside area** with clearly marked pavements and a plenty of spaces to sit.

Findings from the visits

The absence of suitable common leisure time spaces in the visited facilities was an often-criticised shortcoming. Some facilities **completely lacked a common room or a dining room** that could serve this function. The clients were thus **forced to remain in their rooms the whole day**, or to wander aimlessly around the corridors.

In one facility, there was only one large canteen (with a capacity of 150 people), which was not divided into smaller sections. It also served as a day room, where large TV screens were always on. Such an arrangement is likewise unacceptable for a social services facility.

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[48] P-PA-IA Strategy, p. 5

In another of the visited facilities, there were common dining rooms, but they were not situated on the floors where the clients lived. This was despite the fact that the clients were often mobility-impaired and unable to independently move from floor to floor. At the same time, the staff were unable to move the clients to another floor for the daily meals. As a result, the clients were forced to eat and spend most of their time in their rooms. The same problem was noted in facilities which had a smaller common room, which was nevertheless far from the clients' rooms, or otherwise too small to serve all the clients at the same time.

The Defender often recommended to adjust the facility's outdoor spaces to suit the needs of clients with dementia. He pointed out uneven lawns, the absence of benches, no pavements and lack of sheltered areas.[49]

Recommendations

- Establish smaller common rooms in the facility for the clients and smaller, accessible dining rooms for groups of approx. 15 clients.
- Adjust the facility's outdoor spaces to suit the needs of clients with dementia, with a view to ensuring their safety.

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[49] "Memory gardens" are a current trend in care for people with dementia. These special gardens are designed to remind the clients of their youth – showing period signs, building replicas, etc. The gardens serve to help clients recollect experiences and support their memory.

2) Dignity and the autonomy of will of the clients

Human dignity is a value that has to be respected and protected unconditionally. Violations of human dignity cannot be justified, particularly not by organisational problems or a lack of time on the part of the staff. **Regardless of quality, care cannot meet its intended aim if the clients' dignity is not respected.**[50] Human dignity is a common denominator of all fundamental human rights and as such it is protected by the Charter of Fundamental Rights and Freedoms. It is closely associated with the right to decide about oneself, i.e. with the "autonomy of will".

Autonomy of the clients' will may seem to be an abstract term. However, its violation in practice entails very significant impacts on the clients' quality of life. A violation consists in decisions being taken for the clients by others even in situations where, in consideration of the degree of their disability, the clients are able to make their own decisions. There is a risk that, towards the end of their lives, the clients may get into a position where their own will is ignored, which leads to a gradual loss of the sense of their own importance. **The client then becomes a mere subject of care.**[51] Such an experience can be very frustrating and may lead to aggressive behaviour. Despite the fact that life in an institution by itself carries certain limitations, **the client should be able to make his or her own decisions to the maximum possible extent**.

There is a number of occasions where the will of the client can manifest. These range from the fundamental decision concerning admission into the facility to various situations within the facility. Everyday decisions include the possibility of deciding if and when the client will go out to get fresh air, either in the garden or outside the facility's premises, the choice of foods and the selection of daily drinks (water, tea, sweet tea, etc.), choice of leisure activities, the option to choose a TV channel to watch, make decisions about the daily regime (wake up time, bedtime). The most significant choices concern the selection of the key staff member and the possibility of choosing roommates.

Recommendations

- **Respect the clients' dignity and involve them as much as possible in decision-making on everyday matters.**
- **Regularly record the clients' will, or the fact that a client is unable to make his or her will in a certain area, in the client's individual plan.**

a) Staff's attitude to the clients

Findings from the visits

In a number of facilities, the Defender criticised the fact that the **staff treated clients with dementia as if they were children** (baby talk, use of diminutives, pointing out the client's lack of self-reliance, generalised use

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[50] This rule was included in the conclusions of the Alzheimer Europe conference titled "Living Well in a Dementia-friendly Society" organised in Malta in October 2013.

[51] See e.g. the Judgement of the Constitutional Court of 22 February 2008, File No. II. ÚS 2268/ 07 (N 45/ 48 SbNU 527), available at http://nalus.usoud.cz, par. 44: "... human dignity has become the foundation for interpreting all fundamental rights; this i.a. excludes a human being treated as an object ...".

of first names in addressing people, etc.). Such conduct is inappropriate and undignified, even if the intentions behind it are good. Labelling the clients by the staff (e.g. "hypochondriac", "drama queen") is similarly inappropriate. Such an attitude can negatively reflect on the provided care.

The Defender has long criticised the practice of **using baby bottles to serve drinks** to the clients. According to the staff, the clients prefer it in this way, or alternately the relatives wish so. Although there may be individual exceptions, when e.g. a client got used to a certain bottle in home care and its removal would stress the client out, facilities should generally look to other ways of serving drinks to the clients.

Recommendations

- Systematic education of the staff in direct care concerning the necessity of treating the clients with respect, as adults, and non-tolerance for any signs of inappropriate behaviour.

b) Example of disrespect – "rationing"

Findings from the visits

The Defender has criticised the absence of toilet paper in lavatories. He pointed out that the clients pay for the accommodation, which unambiguously includes access to a toilet and a shower, and that toilet paper cannot be considered an above-standard amenity. In one of the visited facilities, **toilet paper was "rationed"** to the clients. If they could not manage with the ration, they had to buy more. Alternately, clients could ask the staff for toilet paper. One of the explanations given was that the clients would clog the toilets with the toilet paper. The clients were thus treated as if they were naughty children. Moreover, they were forced to involve the staff in very intimate tasks, such as going to the toilet.

The Defender likewise criticised **the "rationing" of cigarettes**. All clients' cigarettes were mandatorily kept by the staff and the clients only received one cigarette three times a day. To get their cigarettes, the clients queued in front of the nurses stations and a nurse handed one cigarette to each client. The whole procedure gave an impression of severe humiliation.

In both cases, the staff get into a position of great power, which invites abuse. **Any kind of a "rationing" system only reinforces the impression of being in an "institution".** The aim of social services is to provide the client with a substitute domestic environment and meet his or her individual needs to the greatest degree possible. The aforementioned practices thus have no place here.

c) Management of the client's needs

Good practice

Dementia as a health problem entails two basic facts: (1) ascertaining the will or dissatisfaction on the part of clients with dementia is difficult and the staff have to be trained in that; (2) advanced stages of the disease deprive people of their ability to make their own decisions, even as regards everyday matters, which then have to be managed by a team of carers with the required expertise.[52]

Proper care for persons with cognitive disorders means that responsibility for their everyday decisions needs to be partially assumed by the carers. In this context, "partially" means that this happens only in those areas where the people are no longer able to make their own decisions due to their illness. People with advanced dementia benefit from 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.

Professional literature mentions "activity planning"[53] or assuming management of the patient's needs. In terms of the duties of the social services provider, the basic principle states that "the scope and form of help and assistance provided through social services must maintain the human dignity of persons" (Section 2 (2) of the Social Services Act); further, the duty to provide due **supervision needs to be reflected** (Section 2921 of Act No. 89/2012 Coll., the Civil Code). Good attitude also means observance of the basic principle that **assistance must be based on the individually-determined needs** of persons and has to be provided so that **human rights and fundamental freedoms are not violated** [also Section 2 (2) of the above-quoted Act].

The service provider has the duty to ensure adequate management of the needs of a person with dementia. In order to prevent arbitrary violations of the clients' rights, the **following principles** need to be observed:

- the client must be diagnosed with dementia by a physician;
- the staff must be aware of the diagnosis, they must know stage the illness has reached and the specific challenges brought by the given stage (i.e. the staff must be properly trained);
- the staff must map the clients' needs, the things they like and dislike (the staff must be trained in communication with people with dementia), the clients' risks and their abilities, and record this information in the clients' documents (individual plans, risks plans);
- the service must include organising the clients' daily activities based on the principle of normality, their individual needs and their history;
- needs must be managed by the team of carers and reflected in the clients' documents.

Findings from the visits

Staff in most of the visited facilities were not aware that a team of professionals has to start making decisions for the client in a certain stage of dementia. It is, however, crucial for the staff to know about the principle, otherwise there is a risk of neglect of the patient with dementia or excessive care and arbitrary interference with the individual's autonomy of will.

The examples included completely intuitive and inconsistent decisions by the individual members of the staff concerning whether or not a client might leave the ward or the facility; arbitrary decisions

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[52] LUKASOVÁ, Marie. Autonomie vůle u klientů s demencí. (Autonomy of Will in Clients with Dementia.) In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", pp. 84-89.

[53] "The carer plans suitable activities for the clients who are no longer able to make decisions and their own plans. Establishing contact often takes long and the carer must continuously strive to succeed. A client should be calmly lead to perform a certain task, e.g. the client should be assisted in eating and be lead to eat. Every activity must be accompanied with suitable words." HOLMEROVÁ, JAROLÍMOVÁ and SUCHÁ, p. 65.

as to whether or not an elderly person was allowed to smoke, eat sweets, or accept visits from certain persons; or leaving the client completely immobile if the client did not ask for activities; accelerating the onset of incontinence if the client did not ask for assistance with the use of a toilet; and exaggerated comments that *"a client will get 10 slices of meat if he so desires"*.

Recommendations

- **Ensure management of needs of persons who are prevented from autonomous exercise of their will by the advanced stage of their illness.**
- **Approach persons as individuals, map the abilities and needs of clients, keep proper records and make decisions as a team.**
- **Observe the other principles of protection against arbitrary violations of the clients' autonomy.**

d) Clients' wishes

Good practice

Individualised approach (which is mandatory for social services facilities) presumes that the staff know the clients, their wishes and the ways in which they express their will. In order to achieve fulfilment of the clients' wishes, but also to respect the autonomy of their will, it is necessary for the expressions of desire and displeasure to be reflected in the individual plans. This alone enables sharing of information and verification of correctness of the chosen approach. This is obviously impossible without the staff being able to communicate with persons whose communication skills have been impaired or minimised as a result of their illness [see the chapter "Specific needs as a result of dementia", p. 9].

Findings from the visits

In a number of cases, the Defender criticised the lack of specificity in the individual plans and their formal nature. Even if the staff had tried to find out about the clients' wishes, it was not reflected in any documents and, therefore, the information could not effectively be shared among the team of carers. Any potential for satisfying the clients' wishes thus depended on the will and ethics of the individual staff members.

Recommendations

- **Regularly identify the wishes and the expressions of will of the clients and record them in the individual plans.**
- **Share the information among the team and record whether the wishes are fulfilled, or why they are not.**

3) Daily rhythm

a) Daily regime

Good practice

The daily regime in a facility should both respect the principle of normality and a natural daily rhythm as well as accommodate as much as possible the individual habits and needs of the clients; in other words, it should reflect an individualised approach to clients. The client's need should be the most important and they should not be overruled by operational reasons or the effort of the staff to do everything on time.

The **replacement of incontinence aids very early in the morning**, before the start of the morning shift, often represents a problematic point. The Defender noted that waking up clients to change their diapers interferes with their sleep and represents an unnecessary stress 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, e.g. intestinal problems or special medical condition requiring a higher frequency of diaper changing. Only clients who are used to waking up this early and have been doing so their whole life may be woken up at these hours. However, this is only possible in individual cases of people whose individual plans include such information. **Work schedule cannot take precedence over the clients' sleep and their individual needs**.

Findings from the visits

In several facilities, the Defender criticised the practice where all immobile clients were **put to bed immediately after dinner** (around 6 p.m., sometimes even earlier). He also considered inappropriate if clients were indiscriminately woken up between 4 and 5 a.m. so that the night shift employees could manage changing their incontinence aids.

Such a daily regime is associated with **long time gaps between the individual daily meals**. In some facilities, dinner was served at 4:30 p.m., while breakfast only at 8 a.m. While diabetics were served a second dinner, the other clients who wanted to eat had to either rely on their own food or wait until the morning. Such a practice is completely unsuitable especially in case of clients suffering from Alzheimer's disease, and may again be seen as one of the causes of restlessness on the part of the clients, which is subsequently dealt with through the use of sedatives [see chapter "Prevention of malnutrition", p. 41].

Recommendations

- Set a daily regime so that it adheres to the principle of normality and reflects an individualised approach.

b) Daily routine

Good practice

In each stage of their illness, clients with dementia benefit from a different set of activities and the facility's offer of activities should reflect that. While in the stage of moderately advanced or progressed dementia, the clients are able to perform especially the activities they have done routinely throughout their lives and benefit from scheduled activities,[54] persons with severe dementia primarily require individualised assistance. Participation in scheduled activities is of no benefit for these clients; on the contrary, it could cause them discomfort and be unnecessarily burdensome.[55]

In order to adhere to these principles, the staff must know the clients' diagnosis, their current stage of dementia, and the number of staff must be sufficient.

Findings from the visits

The visits revealed that instead of well-trained and informed staff, the facilities had an insufficient number of staff providing direct care and these were unable to ensure meaningful activities and programmes.

Some facilities provided the clients with a broad spectrum of activities. However, these often did not correspond to their abilities and potential in view of the specific stage of their illness and thus failed to achieve sufficient activation and therapeutic effect.

In a number of cases, the Defender encountered a completely inappropriate practice of having the clients watch TV in the common room the whole day.

In some homes, the quality of care for the clients was good, the daily routine served a purpose and was individualised to a certain degree; however, such cases were exceptional and made possible only as a result of utmost efforts by motivated staff.

Recommendations

- **Offer activation activities so as to support the daily routine in accordance with the principle of normality and the individual's need in the given stage of dementia.**

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[54] Scheduled (programmed) activities are an individual's daily tasks planned with a view to maintaining his or her self-sufficiency. These include especially self-maintenance activities and other activities which improve the quality of the person's life and fill up the day (P-PA-IA Strategy, p. 5).

[55] P-PA-IA Strategy, pp. 4–5, 8.

c) Getting outside

Good practice

The provided social services should also include the possibility to get outside, even for immobile clients if they want to. The facility should put in place a rule providing for systematic records of the instances of the clients' time outside. If this is not the case, the clients' possibility to get outside depends solely on the volition, time and goodwill on the part of the staff; this state of affairs is unsuitable, easily exploitable and cannot be subjected to proper checks.

Findings from the visits

In a number of visited facilities, if a client was less mobile or immobile, he or she would get out only when accompanied by relatives. The clients' documents showed no record of how often immobile clients had got outside, whether they had expressed the wish or how the staff reacted to such a wish.

In a number of facilities, the Defender was told by the staff that the clients themselves did not want to go out. It would, of course, be impermissible to force people to go out. However, such an argument hardly applies in case of persons with dementia who said they do not want to go out; it cannot be automatically assumed they are capable of efficient verbal communication. Getting outside should at least be tried, and if, then, a client shows signs of displeasure, this should be recorded in the documents.

Recommendations

- Ensure that all clients, including those who are unable to do so themselves, have the possibility to get outside regularly (i.e. every day, if possible), and record this in the clients' documents.

- Set rules for the clients' stay outside, do not leave the decision solely up to the staff members in direct care.

- Regularly check and monitor how often individual clients do get out, and if they do not get out, find the reason why.

4) Privacy

The right to privacy is a fundamental human right protected not only by the Charter of Fundamental Rights and Freedoms, but also by a number of international human rights treaties. Many of its aspects are closely related to human dignity. The Defender thus always inquired whether or not the clients’ privacy was respected, especially in tasks of personal hygiene, in toilet use and during individual nursing tasks. He also inquired whether the clients’ right to privacy was ensured in their rooms, i.e. whether their rooms were really substituting a home for them.

a) Privacy in personal hygiene, toilet use and nursing

Good practice

In personal hygiene or toilet use, care must be taken to ensure that the clients’ dignity and privacy is respected. The very assistance with personal hygiene by another person is a very sensitive task and the staff should ensure sufficient intimacy, whether in bed baths in the clients’ rooms, in showers, or during use of portable toilet chairs. It is of paramount importance that nobody in such a situation be exposed to the sight of others and that none of the clients have to watch others.

In some cases, the Defender was told that the clients did not mind if a screen was not used with the bed or toilet chair. Even if the client does not show disagreement, it does not mean such a practice is permissible. It only means that, through their disrespectful approach, the staff have managed to gradually “condition” the clients to disregard their own dignity, which violates the basic principle of provision of social services [see Section 2 (2) of the Social Services Act].

Findings from the visits

In case of immobile and partially mobile clients, personal hygiene, nursing and changing of diapers were often carried out in the clients’ rooms. In most of the facilities, screens were not used and the tasks were thus performed in plain sight of the roommates, or with door to the corridor open. In a number of cases, it was found that clients in multi-bed rooms had to use portable toilet chairs without a screen or another kind of a barrier blocking the view.

The employees of the Office witnessed a client with dementia pulling down her trousers at the nurses station where a nurse was about to give her an injection. This happened with the door open to the corridor where other clients were present. A case was also witnessed where the staff supervised showers even of oriented and self-sufficient clients. In two cases, more persons were showering together in common showers which were not separated into individual shower enclosures; in one case, there was even a door open to the corridor so that the staff could see the clients there.

The Defender also criticised the practice where the cabin doors in common lavatories lacked locks, door chains or bolts, and there were no means to indicate the cabin was occupied. He advised that there were locking systems enabling to open the cabin also from the outside in cases of emergency. In one case the Defender criticised that two rooms had a common shower accessible from both rooms, but the door could not be locked.

Recommendations

- Always carry out personal hygiene and nursing tasks in the room, as well as showering in bathrooms, with the door closed.
- In rooms with multiple clients present, use a screen or another barrier to block the view during tasks of intimate hygiene, nursing or during use of portable toilet chairs.
- Provide means of indicating the occupancy of a lavatory or ensure the possibility for its safe locking (with the possibility of its being opened from the outside).
- Do not automatically supervise showering of all clients, but assess each individual's self-sufficiency and the degree of assistance needed.

b) Privacy in rooms

Good practice

Each client should be able to **store his or her personal belongings independently and securely** and, if the client's mental abilities permit, the client should have the possibility to deposit his or her belongings **in a lockable storage** and manage this storage freely. Depending on the degree of their orientation, the clients should have the **possibility to lock their rooms**. For the clients, the rooms represent their homes where they live for years on end. They should thus be able to protect their homes and privacy. The possibility of locking one's room or at least one's personal belongings is an exercise of the fundamental right to privacy.

However, the right to privacy must not outweigh the need to ensure the client's safety. Therefore, the medical condition has to be objectively evaluated and it always has to be assessed whether giving the key to a particular client represents a risk to safety; the decision to give the key to the client should be based on this assessment. Such an assessment must of course be reflected in the client's individual plan.

Findings from the visits

During the visits, a case of clients having to share a common cabinet was witnessed. The Defender also witnessed situations where the clients did not have a sufficient space for storage of their personal belongings, which were lying about on the floor. In another facility, the clients' personal belongings were stored in plastic bags on the floor at the staff changing room, with no security at all.

In five facilities, the clients (not even those capable of using keys) had no option to at least lock away their personal belongings in their rooms. In a number of visits, it was found that even fully self-sufficient clients were not allowed to lock their rooms.

In one case, the Defender criticised an excessive number of clients in one walk-through room (6 beds). The room was very small, making it impossible to use screens around the beds. Personal hygiene on the bed, changing of diapers and nursing tasks was thus carried out in plain view of the other clients.

Recommendations

- Ensure that all clients have their own locker or another suitable lockable storage space for storing their belongings.
- If the cognitive state of a particular client makes this possible, give him or her the key.
- Set up a suitable manner of locking the clients' rooms, based on an assessment of risks and their subsequent mitigation in each individual case.
- Address the risks of manipulation with the keys (to the locker and the room) and always document this.

c) Personal data protection

Good practice

The facilities collect certain information on the clients which is considered personal data in the sense of the Personal Data Protection Act.[56] In addition, they often have the clients' personal identity documents and process information on their medical condition using a number of documentation tools. Pursuant to the aforementioned Act, these data are sensitive and all materials where they are contained need to be properly secured.[57]

Dealing with identity cards is subject to special rules. An identity card is a public document. Section 15a (1) of the Identity Cards Act[58] forbids taking away identity cards upon entrance into any premises. The facility may thus only offer to take the identity card for safekeeping; however, forcing the patient to surrender his or her identity card or denying the patient a free choice is unlawful. Keeping the identity cards away from the clients is permissible only in cases of clients with a mental disorder to whom the facility provides this as a service. However, it should not be applied indiscriminately.

Findings from the visits

During his visits, the Public Defender of Rights encountered problems especially with indiscriminate removal and inadequate safekeeping of identity documents, or with disclosure of sensitive data (i.a. information on the medical conditions) to unauthorised persons.

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[56] Act No. 101/2000 Coll., on personal data protection and on amendment to certain laws (hereinafter the "Personal Data Protection Act").

[57] Pursuant to Section 13 of the Personal Data Protection Act, social services providers must adopt i.a. measures preventing the loss, misuse or other kinds of risk to the personal data.

[58] Act No. 328/1999 Coll., on citizen's identity cards, as amended.

In some facilities, all the clients' identity cards were kept by the facility's staff (at nurses station and the social worker's office). Aside from the indiscriminate removal, the problem was that the documents were not secured in any way and practically any members of the staff could access them.

In one case, the Defender criticised the practice where a note was placed at the entrance to the facility containing information on clients who were to be transported by an ambulance to a hospital. Aside from other data, there was information on the planned medical interventions, i.e. often also about the diagnosis. These sensitive data were available to anybody who walked through that entrance.

Recommendations

- Set up a regime for manipulation with materials containing the client's personal data and ensure their proper security pursuant to the Personal Data Protection Act, i.e. especially take measures preventing unauthorised or accidental access to these data, their destruction loss or misuse.

- Do not indiscriminately take away the clients' identity cards.

- If clients hand over their personal identity documents to the staff for safekeeping, the documents should be kept in such a way as to prevent the staff from freely disposing of them; the documents should be kept in a separate lockable storage space with special access authorisation and access records.

5) Freedom of movement

Restriction of the clients' freedom of movement may result from the use of restrictive measures as well as from other nursing interventions legitimately carried out to ensure the clients' safety and comfort.

It is important that the adopted measures, if they are part of specific care, should not be arbitrary, unprofessional or result from intuitive decisions by the staff. They must be carried out as a result of co-operation between a physician, nurses and the facility's team of carers. It is also necessary for the facility's management to set up clear rules for the use of measures restricting movement.

a) Measures restricting movement (restraints)

The Defender devoted special attention to the use of measures restricting movement in the sense of Section 89 of the Social Services Act. Their incorrect use (e.g. incorrect administration of sedatives) may have grave consequences for the client. It can represent a threat to the clients' health or life and violate their fundamental human rights and freedoms (right to personal freedom, right to human dignity, autonomy of will, right not to be subject to ill-treatment). Finally, incorrect use of a restraint may be classified as administrative offence pursuant to the Social Services Act, or even as a criminal offence.

Section 89 (1) of the Social Services Act stipulates that **restraints may not be used** in provision of social services with the exception of special cases where there is a **direct risk to health or life** of the clients or other persons; in that case, they may only be used for **the necessary period of time** and other conditions have to be met as well (see below).

The measures that may be used to restrain a client in social services facilities in these exceptional circumstances are listed in Section 89 (3) of the Social Services Act. Physical grips should be used primarily; if they are not sufficient, the person may be placed in a room specially equipped for safe accommodation. If needed, a physician may be called in to order the use of medication, which has to be administered in his or her presence.

i) Survey – prevalence of the use of restraints

In connection with the visits to facilities for the elderly, the Public Defender of Rights contacted Regional Authorities with a request for information concerning the use of measures restraining movement in retirement homes and special regime homes in 2011 and 2012. The Social Services Act, in the wording effective until the end of 2013, required the providers to report, on a half-year basis, to the Regional Authorities as the registering authorities the number of instances when restraints were used.

The results were surprising. Generally speaking, the Regional Authorities recorded very few reports of the use of restraints. In three of the Czech Republic's self-governing regions, no such report had been filed in the previous 2 years. In another two regions, there were 1 and 2 cases of use of restraints, respectively.

There are several possible explanations: Either clients in residential social services facilities did not suffer from any serious behavioural disorders, perhaps because the facilities were sufficiently staffed with employees in direct care, there were good risk plans and individual plans in place addressing the causes of restless behaviour and steps were taken to ensure prevention. Such an explanation would be a good news. Nevertheless, it does not correspond to reality as encountered by the Defender during his visits.

The other explanation is that the facilities do use measures restricting the clients' movement, but they do not classify them as "restraints". The latter explanation seems much more likely. During the visits, **even senior employees were often unable to name the measures that can be used to restrain the client's movement pursuant to the Social Services Act**. Given this fact, it is no surprise that they often fail to observe the rules set for their use.

It is also possible that the facilities circumvent the Social Services Act and administer sedatives on the basis of a pre-made medical prescriptions or on the basis of a physician's orders given on the phone. Although the purpose of such administration of drugs is to restrain the client's movement, it is not considered a restraint precisely due to the involvement of the physician. The Defender frequently encountered this problem.

ii) Statutory conditions for use of restraints

In use of restraints, the conditions stipulated by Section 89 of the Social Services Act must be met. Firstly, restraints may not be used unless there is a **risk to health or life of the person** or other persons [Section 89 (1)]. This means e.g. that it is not possible to administer a sedative on a one-off basis (i.e. not on a basis of a prescription) simply because the client is "restless" (see below).[59] Secondly, measures restricting movement of persons, including sedatives used against restlessness, can only be used if **all the other measures listed** in Section 89 (2) **were used without success**. Thirdly, medication may only be administered **on the basis of a physician's order and in his or her presence**! This means that in a conflict situation, sedatives may never be administered by a nurse or other members of the staff on the basis of their own discretion or on the basis of a telephonic consultation with a physician. Personal presence of a physician deciding on the use of medication is always necessary. Non-compliance with this procedure represents an administrative offence pursuant to Section 107 (2)(e) of the Social Services Act, for which a fine up to CZK 250,000 may be imposed [see Section 107 (5)(d) of the Act].

iii) Administration of sedatives – when do they represent a restraint?

The situation may sometimes be ambiguous in case of administration of sedatives to a "restless" client. This may either be a form of restraint or an ad hoc administration of drugs prescribed by a physician for certain anticipated situations. If administration of drugs is aimed at restricting the freedom of movement of a client (walking, getting up from bed, touching objects or persons, etc.), this as a rule represents a measure restricting the freedom of movement (restraint) under the Social Services Act. Administration of drugs to a client due to aggressive behaviour is also a form of restraint. It is not relevant here whether or not the sedative was prescribed by a physician for cases of "restlessness" or "aggression".[60]

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59 See also GERONTOLOGICKÉ CENTRUM (GERONTOLOGICAL CENTRE) Doporučení Alzheimer Europe k použití omezovacích prostředků v péči o pacienty s demencí (Alzheimer Europe Recommendation on the Use of Restraints in Care for Patients with Dementia). Madridský plán a jiné strategické dokumenty (The Madrid Plan and Other Strategic Documents) [on-line]. Prague: Gerontological Centre, p. 101 et seq. [retrieved on: 15 July 2014]. Available at: http://www.alzheimer.cz/res/data/000062.pdf.

60 For more details, see HRADILOVÁ, Adéla. Nepravidelná medikace s tišícím účinkem v praxi zařízení sociálních služeb pro seniory. (Irregular Use of Medication with Sedative Effect in the Practice of Social Service Facilities for Senior Citizens.) In: Conference Proceedings "Protection of Rights of the Elderly in Institutions, with an Emphasis on People Suffering from Dementia", p. 17.

The provisions of the Social Services Act on the use of restraints may not be circumvented by a physician prescribing a certain sedative in advance for cases of "aggression" or "restlessness" without further considerations. Even if the physician does so, **the facility must still comply with Section 89 of the Social Services Act**. If all the conditions stipulated there are not met (including the presence of a physician), the facility becomes liable for non-compliance, including liability for any potential administrative offence.

However, administering a drug in order to relieve a certain unpleasant condition (perceived in the given case as "restlessness") does not represent a restraint where the physician has anticipated that the condition could arise on account of the manifestations of the client's illness. In this situation, the drug may be administered by a nurse without the presence of a physician. **It is, however, necessary for the physician to clearly state the situations where the prescribed drug may be used**. Based on the knowledge of the client's medical condition and the manifestations of his or her illness, the physician should specify what constitutes "restlessness" in each particular case. If the prescription only states "in case of restlessness" without further details, the responsibility for assessment of the client's condition is shifted to the facility's nurse in a completely unacceptable manner. Aside from the fact that non-medical staff are not authorised to do this, they are much more involved in the care for the lients and thus their decisions may be unduly influenced by their own needs instead of the needs and interests of the clients.[61]

iv) Analysis of the causes of "restless behaviour", prevention

It is always necessary to first look for the causes of the restlessness and consider how to address it and prevent its occurrence in the future. Holmerová et al. notes that it is primarily necessary to **consider all the available non-pharmacological solutions**, where the basic steps in this approach are always as follows:

1. identification of problematic behaviour;
2. determination of its causes;
3. and taking suitable steps in terms of nursing, communication, attitude and environment which will result in mitigation or elimination of this problematic behaviour.[62]

The principle of prevention is likewise included in the Social Services Act, which in Section 89 (4) stipulates that *"a social services provider has the duty to provide social services in a way ensuring that the methods of provision of the services prevent situations where use of restraints becomes necessary"* (emphasis added). In this context, it is useful to refer to Section 88 (c) which stipulates the duty of the provider to provide social services in such conditions that enable their clients to exercise their human rights.

With respect to behaviour of people with dementia, professional literature warns that it is not completely accurate to speak of "aggressiveness". Volicer uses the term "resistiveness" instead. This means that clients may respond aggressively to certain situations (nursing tasks) due to a lack of comprehension and understanding on the part of the staff. In that case, it is the carer who is perceived by the client as the aggressor.[63]

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[61] ALZHEIMER EUROPE. The ethical issues linked to restrictions of freedom of people with dementia. Luxembourg: Imprimerie Centrale, 2012, ISBN 978-2-9599755-6-1, p. 62.

[62] HOLMEROVÁ, JAROLÍMOVÁ and SUCHÁ, p. 84.

[63] VOLICER, Ladislav, BLOOM-CHARETTE, Lisa. Assessment of Quality of Life in Advanced Dementia. In: Enhancing the Quality of Life in Advanced Dementia. 1st ed. Philadelphia: Taylor and Francis, 1999, p. 15–16. ISBN 0-87630-965-1.

v) Findings from the visits

In a vast majority of the facilities visited, the staff stated that they were not using any kind of restraints in the sense of Section 89 of the Social Services Act. A record of the use of a sedative as a form of restraint was filled only in few cases. Nevertheless, in almost all of the facilities visited, some clients had been prescribed sedatives for cases of restlessness or aggression. In some facilities, there were records of administration of sedatives to clients on the basis of such previous orders. This is documented by the following examples:

- "Around 7:30 p.m.; the client is verbally aggressive, raging. Verbally calmed down, Tisercin 1 amp IM applied on the basis of the order of the examining psychiatrist."
- *"Very restless over the morning, harassed clients, wanted to go home. Could not be calmed down verbally, resulting in application of Tiapridal 1 amp IM at 2 p.m.; situation repeated 2 hours after application."*
- "Applied Apaurin 1 amp IM, 5 –7 drops of Haloperidol – no detectable effect. Situation usually resolved by making promises."
- *"20th of January – Haloperidol Richter 1 amp, refuses medication, aggressive."*
- *"Bed rails kicked out 2 times, a sedative pill administered."*
- *"Constantly tried to get out of bed following replacement of diapers and bed linen – a sedative pill administered."*
- *"Restless, called the Police, threatens to run off – HALOPERIDOL 3 amp IM applied."*
- *"Restless, noisy, kicks the door, wants to go to the bathroom – does not respond to words. Haloperidol R 1 amp IM applied at 10 a.m."*

The purpose of administering the drugs in these cases was to alleviate the aggressive behaviour, to restrain the client. The drugs were administered by the staff (in some cases it was not clear whether by a nurse or a social services worker), no physician was present. The documents did not contain data on whether or not the situation represented a threat to health or life and, therefore, whether the conditions for the use of the drug as a restraint were satisfied. The records of such uses did not manifest the requirements pursuant to Section 89 (6)[64] of the Social Services Act (there were no other records in the facility).

In a number of cases, there was serious suspicion that sedatives were used by the staff to restrain the clients' movement, although formally these measures are not considered restraints. The Defender subsequently sent the obtained information to the regional branches of the Labour Office to investigate the possible administrative offence.

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[64] Pursuant to the Act, records of the cases of use of restraints must contain information such as:
  a) name, surname and date of birth of the person;
  b) date, time of commencement and place of use of the restraint;
  c) reason for the use of the restraint;
  d) name and surname of the person who used the restraint;
  e) description of the situation immediately preceding the use, description of the course of the event and its assessment, and description of the situation immediately following the use.

Recommendations

- Carefully differentiate between administration of drugs as a measure restricting movement and administration of drugs that represents a realisation of previous orders given by a physician.
- Comply with the conditions for use of restraints pursuant to Section 89 of the Social Services Act.
- Insist that the physician states precisely the situations for which the ad hoc medication is prescribed.
- Subject administration of such medication to systematic review by superior employees.
- Insist on documentation of the conditions that led to administration of medication, record its effects.
- Look for the causes of restless or aggressive behaviour and try to eliminate them.

b) Handling of sedatives

Aside from ad hoc administration of medication with sedative effect for the purposes of restriction of the client's movement, there were **further serious shortcomings** involving sedatives which represented a risk to the clients. The Defender criticised especially the following:

- hazardous storage of sedatives;
- storage of unassigned ("general-issue") packages of sedatives without any record of the stock;
- incomplete prescriptions lacking data on the drug's potency or on the dosage;
- ambiguous prescriptions from which it was not clear when a particular medication was to be administered;
- orders for medication from which it was not clear for which situations the particular drug was ordered;
- failure to keep records of ad hoc administration of sedatives.

When the **physician's prescription is not complete or unambiguous**, the dosage or the selection of the drug is, in fact, determined by the nurse. In this case, the drug is not ordered by a physician, but a nurse, who is, however, not authorised to do so pursuant to the Decree on Activities of Health Care Workers.[65] The responsibility for (incorrect) administration of drug is thus unacceptable transferred to the nurse, or rather the facility.

Hazardous storage of sedative medication consisted e.g. in that the package was freely available to any member of the staff, without the total amount remaining being recorded. The drugs were "at hand" (freely on the shelf at the nurses station or in the staff common room) and the facility management could not have had any control over the handling of the drugs by the staff in direct care.

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[65] It follows from Section 4 (3)(a) of Decree 55/2011 Coll., on activities of health care workers and other professionals (hereinafter also as "Decree on Activities of Health Care Workers") that a general registered nurse may only administer medicinal products based on a physician's prescription.

A similarly serious shortcoming consisted in that drugs were stored at the facility without being assigned to any specific client. **Unassigned sedatives are easily exploitable** as a tool of unlawful restriction of the clients' movement. Unless there are records of how much remains in the package, any control on the part of the senior employees (of whether or not drugs are administered to the clients in accordance with the medical prescription) is impossible.

These drugs were left over by clients who had died, and were freely available to the staff, e.g. at the nurses station (unlocked drawer, refrigerator) with no records being taken as to how much of drug was left in the package. In some places, packages of drugs with the names of the dead clients inscribed on them were found in baskets with medication for the clients present in the facility at that time. The staff "forwarded" the packages on, but nobody felt any need to change the inscriptions. This unnecessarily raised the possibility of mix up of medication. In one facility, people from the area were bringing in drugs left over by their deceased relatives. In some cases the freely available medication was recorded as "general-issue". When asked how **"general-issue" Tiapridal** drops were used, the staff said it was used if a client had troubles swallowing the drug administered in the form of pills. The amount of the drug administered in a different form was not addressed. This created ideal conditions for misuse of these drugs. In one case, a physician allegedly prescribed 1 box of medication for 2 clients simultaneously, allegedly in order to save money. No records were made of administration of the drugs.

The suspicion that sedatives were misused by the staff for excessive sedation of the clients arose in multiple facilities. In one of the facilities, a senior employee even stated that sleeping pills were getting lost and that he suspected specific employees in direct care of arbitrarily sedating some of the clients during the night shift.

Recommendations

- Ensure safe storage of drugs. Only allow authorised employees to access the drugs.
- Do not store drugs in the facility that are not assigned to any particular client. Destroy any existing stock of such medication.
- Set up records of the remaining amounts of drugs in individual packages of sedatives which are administered ad hoc, i.e. irregularly.

The problem of hazardous storage of drugs or stockpiling non-client-specific sedatives is, in a vast majority of cases, not a result of individual errors on the part of the staff members. This is again primarily the fault of the facility management, which failed to set up rules for safe handling of sedatives.

The Defender further criticised the practice where preparation and administration of drugs was based on **incomplete prescriptions**, which lacked vital information – the drug's potency, form, dosage, the possibility of repeated use. The following prescriptions were found, for example: "if restless, use up to 3 x 1 pill"; "Haloperidol IM if aggressive." The Defender often encountered **ambiguous orders** which did not clearly show which drug was to be administered.

- *"Tisercin in case of restlessness, Prothazine in case of restlessness and insomnia, Tiapridal in case of insomnia."*
- *"Prothazine in case of insomnia, or Buronil or Tiapridal."*
- *"Prothazine 1 pill in case of mild restlessness, Tisercin 1 amp IM in case of severe restlessness."*

The Defender saw the most common and most serious problem in the **vague prescriptions of sedatives, which were not to be administered regularly** but only in certain situation – typically in cases of "need", "restlessness", "aggression" or "insomnia". This is documented by the following examples:

- *"Haloperidol richter in case of restlessness, as needed."*
- *"Apaurin, Tisercin 1 pill in case of restlessness."*
- *"Prothazine 1 pill in case of mild restlessness, Tisercin 1 amp IM in case of severe restlessness."*
- *"Apaurin and Haloperidol in case of restlessness."*
- *"Lexaurin in case of problems."*
- *"Tisercin 1 amp in case of seizure."*
- *"Risperdal – in case he refuses to take medication in the evening."*

The above is not a selection of the worst examples, but a randomised selection from various facilities. Similarly vague prescriptions were used **in 13 out of 14 of the facilities visited**. Such "orders" were found in various tools used to prepare medication, e.g. on lists on bulletin boards, in the clients' medication files, in the clients' baskets with drugs, etc.

However, "restlessness" is a very vague term which may manifest differently in each client, depending on his or her medical condition. The above-described prescriptions did not sufficiently specify what constituted restlessness with respect to a specific client and his or her medical conditions, and how it could have manifested. The staff were thus given a considerable leeway in interpreting "restlessness", "mild and severe restlessness" and "seizure". Similarly, if a drug prescription contains phrase such as "as needed", it may not be clear to everybody whose needs are being addressed – the client's or the staff's.

Recommendations

- Insist that the physician states precisely the situations for which the sedative medication is prescribed.

- Require that the physician exactly specifies the dosage, potency and frequency of use of a given drug in the given time period.

In a number of cases, the Defender criticised the fact that r**ecords were not kept of ad hoc usage of sedatives**. In one of the facilities, the staff made records only of administration of medication via injections. The Office's employees have also encountered cases where clients with ad hoc medication prescribed in case of restlessness, aggression or insomnia had these drugs stored in a basket with the other medication. Some packages were open and pills were missing. At the same time, records on the administration of these drugs were nowhere to be found. In one bottle of Tisercin, there were only 5 pills left out of 50. Nobody was able to explain when and to whom the missing pills had been administered, for what reason and based on whose decision.

Insufficiency of records was a common problem. The records were usually included in the records book, or in the records book and in the clients' documents (there was no rule as to where to make the record); they often gave only scant information, such as "Tiapridal applied because of restlessness" or "the client was restless, Apaurin administered", without specification of how the restlessness had manifested or what the administered drug's dosage or potency had been. Sometimes, it was not even clear who had administered the drug. Sometimes the record only included the name of the drug and the date, with no other information provided. Moreover, the facilities often lacked a comprehensive system of record-keeping (e.g. the Cygnus system). Therefore, there was no way of finding out how many times a specific client received ad hock sedatives other than going through the records book.

Recommendations

- Make consistent records of the use of ad hoc sedative medication, containing the following data:
  - who administered the medication;
  - when;
  - to whom;
  - for what reason (description of the situation);
  - what drug (name, form, potency);
  - dosage;
  - the client's condition prior and after use;
  - if and when was a physician informed.

c) Moving in and out of the facility

Good practice

The fact that a client is accommodated in a special regime home or the fact that he or she suffers from dementia do not by themselves constitute a reason to restrict the client's free movement, i.e. violate his or her fundamental rights.

On the one hand, the social services provider is obliged to ensure the clients' safety and protect their health and lives, but on the other hand the clients must not be restricted in ways that do not correspond to potential risks. This is why the **risk factors**[66] **and the need for supervision must be individually assessed in each individual client**, who must be assigned an individual regime recorded in his or her individual plan.

Depending on the assessment of risks and needs, the client should either be allowed to leave the facility independently, or an option should be given to the client to stay e.g. within the facility's garden in a safe space without supervision, or supervision or company during stay outside should be ensured (this then constitutes one of the basic elements of the service). Restriction of the client's free movement (which must only be carried out in the interest of his or her safety) can only be implemented in

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[66] In the Report from the Visits to Institutions of Social Care for Physical Disabled Adults, the Defender expressed his understanding of reasonable diligence and the related reasonable risk. Reasonable diligence means that, under normal circumstances, an average client of the institution is not threatened by unanticipated risks. Each client should have a specific plan which identifies the risk factors and situations that could occur with this particular client with respect to his or her medical condition and character. After identification of such risks, measures to eliminate them should be specified. PUBLIC DEFENDER OF RIGHTS. Zpráva z návštěv ústavů sociální péče pro dospělé (Report from the Visits to Institutions of Social Care for Adults) [on-line], par. 69. Brno: Public Defender of Rights, 2006 (retrieved on: 17 June 2014]. Available at: http://www.ochrance.cz/?id=101614.

individual cases, after assessment of the risks, justification and a proper recording of the fact in the client's individual plan.

Findings from the visits

The visits revealed that some wards or parts of the facilities providing the "special regime home" service were locked up. Clients, not even those with good orientation, could leave the ward on their own. The possibility of getting outside in a safe space was likewise not ensured.

In one of the visited retirement homes, the whole building was always locked up. If a client wanted to leave, he or she had to ask the staff for a key. This was so even though the facility housed clients whose medical condition permitted safe stay outdoors. No individual risk assessment to serve as a guideline for the staff had been carried out. The decision as to whether a client would be allowed to go outside was left to the staff members' intuitive discretion.

In some facilities for the elderly, the fact that a client had left for a nearby restaurant on their own was considered an emergency situation. The records book stated that the client *"wilfully left the home without notifying the carers"* and was found in a pub.

Elsewhere, a client's outing required consent of the curator, despite the fact that outings or getting outside do not represent a legal act and the curator is not competent to decide for the client. In one case, the facility's psychiatrist was the one deciding whether a client could leave the facility. Even clients who were allowed to go out and were fully oriented were subject to an arbitrary decision on the part of the nurse as to whether they would be allowed to leave the facility (the building was constantly locked).

Recommendations

- Assess the risk factors and the need for supervision in each client (the knowledge of the diagnosis is a prerequisite here) and set up an individual regime for going out.
- Ensure that oriented clients have the option to leave the ward on their own if this is permissible with regard to their medical condition; ensure that they have the possibility to freely leave the building.
- Ensure conditions for the clients' safe stay in the facility's outdoor areas (garden, park, etc.).

6) Care provided

The facility management often responded to the Defender's criticism of shortcomings in nursing care with arguments that the facility serves as the client's home and that certain practices are common in domestic environment as well.

While the fact that the facility serves as the client's home and provides substitute domestic environment can serve as an appropriate measure of the quality of accommodation and equipment, it cannot be used in assessment of nursing and other professional forms of care. Registered social services facilities have the duty to provide **professional social care**. **Professional care excludes the intuitive approach** typical of family-like environment, which is antithetical to quality in social services.

Facilities of the "special regime home" type or the "retirement home" type can and should also provide **professional medical nursing care of the appropriate quality**. Considering the clients' medical condition, such medical care is essential in these types of facilities. Section 36 of the Social Services Act stipulates that clients are provided with nursing and rehabilitative services in particular through **members of staff who have the necessary professional competence** to be employed as health care workers. Therefore, there is no room here for an unprofessional, inexpert and intuitive approach. **The team of carers in the facility should always include a nurse** who would deal with prevention and dealing with issues such as malnutrition, decubitus ulcers, pain, and depression.

a) Malnutrition prevention

Good practice

Clients in residential facilities are often permanently bedridden, have limited communication skills and suffer from a progressive stage of dementia. This makes them reliant on the care provided by the facility's staff. The care must include **basic nutrition and nutritional care.** For this reason, the Defender also inquired during the systematic visits if the facilities were aware of the risks associated with malnutrition and whether a system of malnutrition prevention was set up.

Insufficient nutritional care may result in malnutrition, which may cause further complications such as worsening medical condition, prolongation of treatment, increased risk of bedsores, deteriorated self-sufficiency and increased mortality. The need to devote adequate attention to the risk of malnutrition is underscored by latest research, which points to the connection between proper nutrition in dementia patients and maintenance of their cognitive functions. [67]

The basic principles of nutritional care for patients with dementia are summarised e.g. by Pidrman: [68]

- *"Timely identification the patient's lower interest in food;*
- *periodic monitoring of body mass and muscle strength;*
- *regularity and order in food intake, separation of meals into the main and secondary meals;*

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[67] NAVRÁTILOVÁ, Miroslava. Sledování nutričního a psychického stavu u nemocných s Alzheimerovou chorobou – vliv nutriční intervence v longitudinální studii. (Influence of nutritional support on nutritional and mental status in dementia patients with Alzheimer's disease: comparative and intervention study.) Doctoral thesis [on-line]. Psychiatric Clinic of the Faculty of Medicine of Masaryk University and the Brno University Hospital, 2009 [retrieved on: 5 June 2014]. Available at: http://is.muni.cz/th/71307/lf_d/pro_tisk_Navratilova_2-117_1_.pdf.

[68] PIDRMAN, Vladimír. Demence (Dementia), p. 160. Prague: Grada, 2007. 183 p. ISBN 978-80-247-1490-5.

- *maintenance of decorum and style of dining;*
- *respect for the patients' tastes where possible (be careful about fatty and sweet foods);*
- *ensuring good nutritional balance of foods;*
- *ensuring sufficient and uninterrupted availability of drinks;*
- *objective information on the real consumption of food;*
- *motivation and involvement of the patient in the preparation of the food and dining."*

Considering the importance of correct nutritional care and the risks associated with neglecting it, a nutritional therapist should be present, in an ideal situation, as a member of the multi-disciplinary team that ensures comprehensive care for the client; the therapist would determine the client's nutritional needs, the state of his or her nutrition, select suitable nutritional complements and prepare a meals plan.

The Defender released basic information concerning malnutrition prevention to the broader public in the accessible form of a leaflet.[69]

i) Nutritional screening

Good practice

Nutritional screening is a quick and simple process that can be carried out by an employee (carer) with proper training, using standardised tests. It can result in finding that a client is not at risk of malnutrition, but may require regular check-ups in specific intervals; or the client may be at risk and should receive a nutritional plan and specialised care, either in the facility or in by a provider of health care services, depending on the seriousness of the condition.

The facility should record data on the body weight, height, BMI and food intake upon admission of a new client. In clients who cannot stand up, the circumference of the arm should be measured instead of body weight. Based on these input data, it should be determined whether the client is at risk of malnutrition. Such procedure and assessment of the possible risks should be performed by the facility in regular intervals.

Findings from the visits

The Defender often criticised the fact that the facilities failed to systematically monitor the clients' body weight. In one of the facilities a nurse stated that clients were weighed two times a year (which would still have been insufficient), but the last record of weight in the documents was over one year old in most cases.

In another facility, the staff members claimed that nobody was at risk of malnutrition, despite the fact that some of their clients weighed less than 40 kg at the time of the last measurement (one even weighed mere 32 kg). An external consultant working for the Office concluded on site that most of the permanently bedridden clients were at risk of malnutrition.

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[69] PUBLIC DEFENDER OF RIGHTS. Malnutrice – riziko a možnosti ochrany v zařízeních sociálních a zdravotních služeb (Malnutrition – Risks and Possibilities of Protection in Social and Health-care Facilities) [on-line]. Brno: Office of the Public Defender of Rights, 2014 [retrieved on: 30 March 2015]. Available at: http://www.ochrance.cz/stiznosti-na-urady/chcete-si-stezovat/zivotni-situace-problemy-a-jejich-reseni/malnutrice/.

There has also been a case where the body weight had been monitored, but the data were certainly not used for the purpose of monitoring of the risk of malnutrition. One client's records showed obvious weight loss of five kilograms over three months. Despite that, the causes had not been addressed and no further measures had been adopted.

In another case, the body weight was recorded, but there were no data on the body height, making a BMI calculation impossible, despite it being one of the quickest ways of determining that a person is underweight and possibly undernourished. Responding to the question why there were no data on the body height, the nurse said that the "clients are not growing up any more".

Recommendations

- Consistently monitor the clients' weight and systematically evaluate any weight loss.
- Use alternative methods in case of clients who cannot stand up on the scales.
- Consult any clients' weight loss with a physician and determine further procedure.
- Keep sufficient documentation on the care provided in the area of nutrition and malnutrition prevention.

ii) Monitoring of food and liquids intake

Good practice

A facility should devote adequate attention to a systematic monitoring of food and drinks intake. This applies especially to those clients who cannot, due to their medical condition, ensure adequate drinks or are at risk of malnutrition. Such records may be a part of the client's **nutritional report**.

Primarily, it is necessary to **determine who needs food and drinks monitoring**; the fact whether a client is properly hydrated and not at risk of malnutrition should not be left to the intuitive assessment and attention of the employees in direct care.

It is necessary that **the records be objective**. Diligent keeping of records does not necessarily have to be burdensome. There is a possibility of using standardised forms, where food intake is monitored by crossing the appropriate fields (e.g. quarter/half/full portion eaten).

Records based on the staff member's intuitive assessment (e.g. "ate enough", "ate little") do not represent a sufficient basis for proper assessment of the potential risk. While one carer may use this indication if the client cannot eat two successive full portions, another carer may record this if the client does not finish his or her lunches and dinners for a week. The follow-up intervention thus may not arrive in time, in a stage where it could still be of a preventive nature.

Similar procedure should be **applied to monitoring of drinks**. A social services carer does not have to write a record of each drink. A drink may be served in a suitable cup, enabling objective measurement of how much the client has drunk at the end of the shift.

A good provider should not rely solely on intuitive assessment. It should set up criteria for determining the clients in whom drinks intake will be monitored and instruct the staff on how to accomplish this. In case of the selected clients, the carers should have access to data on how much should a particular client drink in a day.

Findings from the visits

Many of the facilities visited did not pay sufficient attention to monitoring and assessment of the clients’ foods and drinks intake. There often was **no rule as to which clients should be subject to food and drinks monitoring**, and the staff in direct care lacked clear instructions in this regard. When asked whether the clients’ food and drinks intake was monitored, the staff often responded in the affirmative, but noted that all clients always finished their meals. In other cases they stated that food intake monitoring was useless because the clients ate food brought by their relatives.

In cases where the intake of food was monitored, the senior employees often had **not set up any requirements as to the form of the records** and the carers passed these information by word of mouth or they had subjectively determined whether, what, where and in what form would be recorded. Moreover, the **records often lacked objective information**. Carers made records in one of the documentation tools on the basis of their intuitive assessment, such as “the client did not finish his lunch” or “the client did not eat enough”. Such records were usually not processed any further.

Commonly, a **unified procedure as to the form of drinks monitoring was lacking**. The form thus included disparate information, such as when one carer wrote that the client had drunk a cup of tea whereas another carer wrote that the client had drunk 250 ml of fluids. It is equally insufficient if the staff record the individual sips in the documents, but only estimates how much fluid did the client actually drink. The records may then not reflect the real intake of liquids. In some places, records were only made in the following form: “Drinks little / does not drink / drank twice today /sufficiently hydrated.” Such data have zero information value and cannot serve as a basis for further work.

Clients can then very easily become dehydrated. In objective terms, this may be reflected in a client who was transferred to a medical bed because of deteriorating medical condition. The cause stated in the nursing records was dehydration.

Recommendations

- Identify persons whose intake of food and drinks should be preventively monitored.
- Make objective records that will clearly show if the client ate the whole portion, or half or quarter portion.
- Regularly evaluate the records and, in co-operation with a physician, set a follow-up procedure in case the client repeatedly does not finish his or her meals.
- Determine which clients should be subject to drinks intake monitoring.
- Determine the amount of liquids these clients should consume each day.
- Monitor drinks intake using objective indicators.

iii) Nutritional value of food

Good practice

Provision of **suitable daily meals** represents one of the basic activities in provision of a social service. The meals must correspond to the age, the principles of proper nourishment and specific dietary needs. The Decree sets the minimum of three main meals a day. However, if a facility provides care to people with dementia, the meals have to be adjusted to the needs of these clients. Patients with Alzheimer’s disease have increased energy needs and they should thus be provided with nutritionally and energetically adequate foods reflecting the current stage of their illness, the nutritional condition and any potential concurrence with another illness. Clients suffering from dementia should also have uninterrupted access to food. The facility must respect the statutory limit to the maximum amount of payment for the meals provided, which is CZK 170.[70]

Findings from the visits

Nutritional values of foods were often ignored in the facilities, or the meals were not suitable to the client’s medical condition.

One of the visited facilities used only seven alternating menus. The menus were subsequently assessed by an external consultant of the Office, a nutritional therapist, who found serious errors in them and concluded they were inadequate, unsuitable and absolutely disproportionate to the price of CZK 160 (the amount of payment for meals). The menus contained a large amount of foods which often cause intolerance (legumes, sweet foods and offal). The amount of fruits and vegetables, but also of milk products, was insufficient. Conversely, there were too many sweet foods, 9 in total (i.a. sweet dinner – “cinnamon pasta”). The meat content was insufficient and the share of smoked meats

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[70] The amount of payment for basic activities provided by a specific social service are defined in the Implementing Decree to the Social Services Act.

and sausages was excessive. There was a lack of variety – goulash soup for lunch and potato goulash for dinner.

Meals in one of the facilities were supplied from a factory canteen, without any regard to the special needs of the clients and their medical conditions. In another facility, dinner usually consisted of soup and bread. Clients have thrown the bread away as they were unable to chew such large slices or break it down into smaller pieces. Dinner was served already at 4:30 p.m. The next meal was served only at 7:30 a.m.; there was no food available during the night. No client received special nutritional attention, with the exception of clients with diabetes.

Recommendations

- Prepare menus with regard to the nutritional values of the meals and the needs of the clients.
- Make sure clients with dementia have food available throughout the whole day.

iv) Consistency of food

Good practice

Clients who have trouble swallowing should receive food in suitable consistency. **The decision on adjusting the consistency of food should be recorded in the client's documents** with sufficient information on who made it, when and for what reason. A transition to a modified consistency diet represents a major change for the clients as they perceive the loss of their abilities and self-sufficiency, as well as lose the full experience of eating a meal.

Blending food should be considered an extreme in modified consistency diet. Chopping and mincing should take precedence as these methods enable the client to experience the food's texture. **The individual components of a meal** should always be separate. This makes it possible ensure, amongst other things, that the client consumes the nutritionally more valuable component if he or she does not finish the whole portion. When all the components are blended together, the resulting mixture is usually unsightly and tasteless. Serving such a food to the clients is not dignified.

Findings from the visits

Unfortunately, the Defender encountered the practice of **blending foods together (i.e. meat with the side-dish)** in 4 of the visited facilities. In some facilities, soup was even included in the blend.

Recommendations

- Record the decision to start with modified consistency diet in the clients’ documents (including who made the decision, when and for what reasons).
- If the consistency of the food needs to be modified, the individual components should be modified separately.

v) Serving of meals

Good practice

During the systematic visits, the Office’s employees observed serving of meals to clients who were unable to eat on their own. Assistance with eating should be based primarily on the determination which clients require the staff’s help in this respect. The decision should be recorded in the documents. It is also necessary for the facility to assign sufficient staff for serving of meals or ensure help from volunteers.

Findings from the visits

In several cases, the Defender criticised the **excessively short time of serving of meals**. The carer was standing over the client and did not observe whether the client had enough time to properly chew and taste the food; she moved the spoon with the food to the client’s mouth too quickly. She even used the spoon to wipe the leftovers from the client’s lips and served them back to the client. In another case, the carer started serving dinner to one client, but moved to another client in the middle of the serving. The first client was not able to eat on her own and was left watching the food get colder in front of her.

Recommendations

- Ensure sufficient staff and time for assistance with eating.

vi) Availability of communal dining, decorum of dining

Good practice

Communal dining is a **major force in socialisation**. Clients are able to meet others in the dining room, build social connections and change their environment. Facilities should take care to ensure proper quality and decorum of dining.

Findings from the visits

Several of the visited facilities **lacked a dining room or a common room** that could have served this function. The clients were thus eating in their rooms; often they ate while sitting on the bed with the plate on the bedside table, or even in their lap.

The Defender criticised the **unsuitable manner of serving meals**, where meals were served to the clients in plastic bowls, drinks were served in plastic cups, yoghurt cups or baby bottles. In one of the facilities, drinks were even poured into cups from plastic garden watering cans. The Defender also objected to the practice of forcing clients to eat with spoons only.

Eating foods while sitting on a portable toilet chair, which in some facilities was used instead of a standard chair, is completely inappropriate and undignified.

Recommendations

- **Create proper conditions for communal dining.**
- **Use dishes for serving meals and drinks that are appropriate with respect to the needs of the clients.**

b) Decubitus ulcers

Good practice

Some clients in the facilities visited had limited mobility and were bedridden for most of the time. The provided care must include addressing the risk of decubitus ulcers (bedsores) and their prevention.[71]

Findings from the visits

In the visited facilities, the issue of bedsores prevention was often addressed in an intuitive fashion. The risk of bedsores had not been systematically evaluated, there were no data on the number of clients at risk of bedsores. Social services employees usually informed the nurses only when the clients' skin was affected and it was thus too late to take preventive steps.

The Defender repeatedly criticised the facilities for their failure to maintain proper documentation on prevention and treatment of bedsores. The documentation often did not include information on the time intervals for repositioning of bedridden clients. In one facility, records consisted in a single tick per day in a box titled "repositioning" in a printed form containing information on the care provided. In clients suffering from skin perforation, there was no information on the condition of the wound, its size, the course of healing and the rebandaging.

External consultants also pointed out the **unsuitable mattresses** on the beds with permanently bedridden clients. The mattresses were often very thin and lacked anti-decubitus overlays.

The Defender was repeatedly told by the staff that the clients had not developed bedsores in the facility, but already in the hospital from where they had been moved. If a client of a residential social

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[71] For more information, see e.g. MIKULA, Jan, MÜLLEROVÁ, Nina. Prevence dekubitů (Prevention of Decubitus Ulcers). Prague: Grada Publishing, a. s., 2008. ISBN 978-80-247-2043-2.

services facility is temporarily hospitalised, such facility should remain interested in the client's medical condition and, if necessary, defend the client's rights (e.g. through assistance with filing a complaint against the health care service that resulted in bedsores).

Recommendations

- **Assess the risk of developing bedsores in each individual.**
- **Prevent development of ulcers through preventive steps (positioning, suitable foods).**
- **Keep proper documentation with respect to this area and ensure it contains sufficient information.**

c) Permanently bedridden client

Good practice

Becoming permanently bedridden represents a fundamental change in a person's life. The person becomes dependent on the carers in all areas of care. Therefore, it represents a fundamental and permanent worsening of the client's quality of life. For this reason, the decision on keeping a particular client in bed permanently must be neither intuitive nor arbitrary. It should likewise not be premature. The decision should always be made by the team of carers after a consultation with a physician. The documentation should indicate the time when the patient became permanently bedridden, who made the relevant decision and what prompted it. It is necessary to ensure that the care for the client compensates his or her permanent stay in the bed to the greatest degree possible.

Findings from the visits

In most of the facilities visited, there were completely immobile and permanently bedridden clients. Some of those clients were not put on a chair or put into a sitting position for eating. In some cases, the clients were not put into a vertical position at all. It was often unclear from the (nursing) documents kept in respect of the particular client who made the relevant decision and for how long had the situation lasted.

Recommendations

- The decision to stop putting a client in a sitting position should always be consulted with a physician.
- The client's documents should include information on who made the decision, why and since when has the situation lasted.

d) Pain monitoring

Good practice

Identifying pain in patients with progressive dementia is not always an easy task. Unfortunately, undetected and untreated pain significantly reduces the clients' quality of life,[72] may indicate an overlooked serious illness, and may potentially lead to behavioural disorders (manifesting as restlessness or aggression) with the subsequent needless use of psychoactive drugs.

In provision of care, it is thus necessary to devote special attention to pain and its treatment. It is necessary for the staff to be able to detect pain on their own especially in progressive stages of dementia when clients are no longer able to verbalise their feelings.[73] It is equally important for the facility's management to set up a standardised system of pain monitoring, which sets out clear procedures and responsibilities of the individual staff members.

Findings from the visits

In practically **none of the facilities visited was there a standardised system for regular testing and recording data on the clients' pain**. If the staff knew that a client suffered from pains, this was a result of everyday intuitive observation. The carers could often very empathically describe the ways the clients let know they were in pain. However, relying on intuition and helpful interest on the part of the staff is neither systematic nor dependable.

When the carers noticed a client was potentially in pain, they usually informed the nurse. However, there were no rules as to how this information was to be presented nor what the subsequent procedure should be like. The documents also did not record any information on the nurse's response to the information, whether she forwarded the information to a physician, with what result, and to what degree this was reflected in the care for the client.

Recommendations

- Implement standardised monitoring and evaluation of pain, especially in clients with reduced communication abilities.

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[72] P-PA-IA Strategy.

[73] There are multiple pain classification scales intended for patients with progressive dementia, e.g. DOLOPLUS-2, ECPA, PACSLAC and PAINAD.

e) Depression

Good practice

Depression accompanies most forms of dementia, especially vascular dementia,[74] but it is often neglected and confused with the initial symptoms of dementia, which can be similar to depression. The initial symptoms of depression may thus go unnoticed and untreated, which may significantly impact the clients' quality of life. It is therefore necessary for the facility to be aware of these risks and establish a standardised system for monitoring of signs of depression, which will set out procedures and responsibilities of the individual staff members.

Findings from the visits

Over the course of the systematic visits, the Defender reached the conclusion that **most of the facilities did not devote sufficient attention to monitoring and establishing whether their clients suffered from dementia**. The staff were insufficiently educated on the possible manifestations of depression such as restless or aggressive behaviour, loss of appetite, apathy and tearfulness, and the options for addressing them. If the staff noticed symptoms of depression, this resulted from intuitive and coincidental observation.

Recommendations

- Devote special attention to finding out whether clients with dementia suffer from depression. Set up clear instructions and responsibilities for the staff in this regard.

f) Personal hygiene

Good practice

The facility staff should assist the clients in their personal hygiene [see Section 50 (2)(c) of the Social Services Act]. This means ensuring personal hygiene according to the individual's need; however, the clients should receive a full bath at least once a week. Naturally, the clients' privacy must always be respected [for more on privacy in hygiene, consult chapter "Privacy in personal hygiene, toilet and ursing", p. 26]. Pursuant to Section 88 (f) of the Social Services Act, a social services provider also has the duty to keep records of the tasks performed with respect to clients who require assistance with personal hygiene. This is the only way of documenting that the client receives proper care in this area.

Findings from the visits

In one case, the Defender noted that the clients did not have adequate conditions for personal hygiene. Most clients did not have their own toothbrush and cosmetics. Soap and shampoo were shared by clients in the whole ward, which does not meet the requirement of individualised care (the same product may not be suitable for all clients).

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[74] HOLMEROVÁ, JAROLÍMOVÁ and SUCHÁ, p. 72.

The Defender also criticised the practice where bathing did not take place according to the clients' individual needs and wishes. The Defender also encountered long intervals between bathing, where some clients had not received a bath for 10 or even 15 days. In one of the facilities visited, bathing was subject to a strict schedule that everybody had to adhere to. This meant a client could not bathe according to his or her need. In other places, there were doubts as to whether personal hygiene was even being carried out in the evenings, as the clients slept in their usual day-clothes instead of night-clothes.

Insufficient records of personal hygiene, especially of full baths, was a related problem. While the staff had various informal schedules for bathing, it could not be verified whether full baths really took place.

The Defender also encountered a completely unacceptable practice where the carers wiped the mouths of immobile clients with a cloth dipped in a bucket with dirty water that had been used to clean tables just before that.

Recommendations

- Keep objective and up-to-date records on completed baths.
- Make sure all the clients have personal hygiene products available.
- Ensure suitable bathing according to the needs of the individual clients.

g) Bladder voiding regime

Good practice

Incontinence is one of the symptoms of dementia. Care in this area should aim to delay the onset of incontinence for as long as possible using proper routines, especially the bladder voiding regime. A client should have the option to urinate at least in approx. 2-hour intervals, or even more frequently. Such a regime may reduce the consumption of incontinence aids, which could then be used "just in case".[75]

Carers (social services workers) should receive clear instruction which clients should use (portable) toilets and how often, and who should be accompanied to the lavatory and how often. A communication barrier on the part of the client (where the client will not ask for being accompanied to the toilet) should not be a reason for stopping the assistance with using the toilet. The bladder voiding regime should be based on the individual needs of each client and should be reflected in his or her documents, including records on the course of care in this area.

Findings from the visits

Practically none of the facilities visited provided the clients with a bladder voiding regime with clear instructions for the staff as to who should be taken to a portable toilet, who should be accompanied to the lavatory, or which of the clients should be reminded to urinate and how often. If this was carried out, it was a result of the staff's intuitive approach, which was not reflected in the individual plans or in the care documentation.

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[75] HOLMEROVÁ, JAROLÍMOVÁ and SUCHÁ, p. 109.

Very often, clients were either able to use a toilet completely on their own, or they exclusively urinated into diapers. In one of the facilities, the employees of the Office witnessed a situation where a client told the staff she wanted to go to the toilet. A carer replied that she had diapers, so she should urinate into them.

The Defender encountered **artificial inducing or acceleration of the onset of incontinence** in several facilities. The staff "trained" the clients to urinate into diapers by forcing them to use incontinence aids throughout the whole day, even though the clients were not incontinent at that time. In one facility, all clients with dementia were using diapers, including the clients who were mobile and, had a proper bladder voiding regime been put in place, they could have remained continent for much longer.

In another facility, there was a suspicion that night gowns were being tied between the legs of clients with dementia in order to prevent them from going to the toilet. Such a practices are **damaging to the clients' health**. They prematurely and completely uselessly increase their dependence on care.

Another example of unsuitable **practice rested in using several incontinence aids simultaneously**, especially during the night in order to make work easier for the staff, who did not have to change them so often.

In some places, proper bladder voiding regimen was hindered by a **lack of toilets and absolutely insufficient staff in direct care**. This was reflected also in the fact that incontinence aids were not being replaced as needed and the clients had to wait in wet clothes. The stench in the facilities was often overwhelming.

Recommendations

- Establish a proper bladder voiding regime for the clients which will address issues of which clients should use incontinence aids (diapers and pads) during the night, which clients should use these also during the day and which clients should be helped to the toilet and how often.

- Use incontinence aid with regard to the needs of individual clients, not to compensate for insufficient staff.

h) Disposal of drugs

During the visits, the Defender observed the way drugs were prepared and administered to the clients and by which members of staff, and the safety of storage of the drugs. Incorrect administration of drugs and unsafe storage could represent a significant risk to the clients' health or even life.

Preparation of drugs – medication cards

Individual facilities use specific procedures for preparing drugs. Usually, drugs are put into vials in accordance with a certain document (drugs schedule put on a bulletin board, the client's medication cards, medication sheets, etc.). The Defender encountered cases where these documents contained strikethroughs, overwritten text and lack of information on the time of the record and its author. **Altered and overwritten medication sheets** were confusing and illegible. If any of the staff members had made an incorrect change in the records, such an error would have been practically untraceable. It was not clear who was authorised to make changes, i.e. whose task it was to make changes in case the physician modified the prescribed drugs. A senior employee (the head nurse) was often not involved in authorising the medication schedule.

The records were often incomplete. The name of the drug lacked information on the active substance content (identification of the drug) or the form (drops, pills, etc.). There were also several cases where repeated rewriting caused **an error in dosage and in indication of the drug's potency**. In a number of cases, the Defender saw that a document used as a basis for **preparation of drugs did not correspond to the up-to-date medication indicated in the client's medical records**. There were also cases where a facility used several informal drugs schedules, which were not consistent. The staff was then unable to answer the question which of two differing pieces of information was correct at that moment.

In a vast majority of cases, this situation did nor result from an individual failure on the part of the staff, but from the fact there were no rules on how to safely dispose of the drugs. Senior employees are responsible for putting such rules in place.

Recommendations

- Establish rules for safe handling of drugs.
- Prepare drugs in such a way as to minimise the risk of error.
- Ensure that the records in the medication sheet correspond to the exact prescription as given by the physician and that changes are recorded immediately.
- Identify the person responsible for the records in the medication sheet and prepare medication sheets in such a way as to make clear who made them.
- Have the head nurse or a physician verify the correctness of the medication sheets.
- Changes in the medication sheets should be carried out by means of a new record (also authorised) instead of rewriting or deletion.

Storage of drugs

In some facilities, **safe storage of drugs** was not ensured. The clients' drugs, either in original packages or prepared in vials, were left in places accessible by all members of the staff (including those not authorised to dispose of the drugs) and even the clients.

For example, drugs were kept in an unlocked storage locker at the nurses station; they keys to the lockers were available to the nurses, carers and even technical staff who used the station as their smoking room. A nurse commented on this by saying they were "like a family and have to trust each other".

Recommendations

- Safely store drugs so that only authorised personnel can access it.

Pursuant to Decree No. 55/2011 Coll., on activities of healthcare workers and other professionals, as amended, only general registered nurses and emergency medical rescuers can administer drugs without professional supervision, but only based on a physician’s order.

In a number of cases, the Defender criticised the practice where **drugs were administered to the clients by an unauthorised member of the staff**, usually a carer (social services worker). In one of the facilities, drugs were being prepared by an unregistered nurse.

Recommendations

- Ensure that drugs are prepared and administered to clients only by authorised employees with the necessary competence.

Concerning preparation of drugs into vials in advance (usually for a one-week period), the Defender warned that if **drugs are administered by employees who did not prepare them**, there is no way of making sure the prepared drug is correct and the employees are thus exposed to the risk of an error they did not cause themselves.

In some facilities, the medical staff **ground pills** without consulting a physician. However, it is primarily a physician’s responsibility to decide if a client should take drugs in a non-standard way. The staff explained that the clients in question had trouble swallowing. However, the fact that the clients had trouble swallowing was not recorded in their documents. In some facilities, the employees were not even aware of the fact that some drugs’ effects could be altered by grinding.

In one facility, the staff had ground pills for more than one client. However, it was found that the mortar and pestle was not cleaned after each grinding. This resulted in unacceptable mixing of various drugs.

Recommendations

- Inform a physician if a client has trouble swallowing a particular drug and ask for prescribing the drug in another form.
- Consult the physician for information on which drugs may be ground; obtain a written opinion for the documents of the relevant clients.
- Make the list of these clients available to the nurses who prepare the drugs.
- If grinding is carried out for multiple clients, clean the mortar and pestle to prevent mixing of drugs.

To conclude, two especially cautionary cases of exceptionally neglectful and hazardous disposal of drugs should be noted.

One concerns the manner of administering the drugs to the clients. A nurse had vials inscribed with the ames of the clients in a trolley and she made a round of the clients in the dining room. There were approximately 180 clients. When asked if she knew all these clients by name, she replied that she did. However, employees of the Office witnessed her asking other staff members for names of certain clients, where not even these staff members were completely sure. There was thus a relatively significant risk of accidental mix up of drugs. Although this was an extreme and rare exception, it should serve as a warning and a cautionary example of bad practice.

The second example of bad practice demonstrates what happens when clear rules for preparation and administration of drugs are lacking. The records book in one of the facilities contained the following records:

- Record of 12th March 2013 concerning Ms N. reads: "Dentist, Ibalgin 1 pill." A note below reads: "Do not administer more Ibalgin today, she has already had 3 pills!!!"
- Record of 29 July 2013 in the day report reads: "Do not administer Ibalgin to Mr S. – he's on Warfarin – it's been contraindicated."

Medication cards analysis

During inquiries, the employees of the Office made copies of the medication cards (documents used by the staff to prepare medicines) of clients with dementia. A total of 307 of these cards (omitting the names) were provided by the Defender to a clinical pharmacologist for analysis. The analysis forms and annex to this report. The analysis yielded i.a. the following information:

In certain cases where generic substitution was possible, this was carried out improperly and the recommended maximum dosage was exceeded in some cases. Information on the manner of administering was often missing. For example, the instruction to administer the drug before a meal was omitted. The clinical pharmacologist's findings concerning formal errors that could lead to incorrect administering of drugs do partially correspond to the Defender's overall findings [see the chapter "Handling of sedatives", p. 36].

More than two thirds of the clients included in the sample were using antipsychotics. Over one third were using benzodiazepines. A total of 4 clients with Parkinson's disease were using older antipsychotics, whose effects further aggravated the symptoms of Parkinson's. Modern cognitive drugs were administered only to 55 clients. The clinical pharmacologist explained that under geriatric recommendations, antipsychotics and benzodiazepines count as hazardous drugs. In clients with dementia, general usage of antipsychotics in reaction to restlessness or aggression can result from insufficient treatment of pain. Their use requires regular evaluation of the necessity of further therapy.

7) Safety

Care necessarily entails providing for the clients’ safety. During the visits, the Defender focused on prevention of falls, whether rules had been put in place for the use of bed rails and whether the clients had available a functional signalling equipment to call in the staff in case of need.

a) Bed rails

Good practice

Firstly, it should be briefly explained when bed rails represent a restraint. Bed rails are a tool that has the potential to restrict a person’s movement and the degree of such restriction depends on the person’s mobility.[76] Permanently bedridden clients are not restricted in movement by the bed rails and, therefore, they do not constitute a restraint. Bed rails do restrict movement in persons who can get up and leave the bed on their own. This means that if a client is able to get up on his or her own but is prevented from doing so by raised bed rails, this constitutes a restriction of movement.

Not even this situation is necessarily unlawful. Bed rails or barriers represent a standard means for the provision of nursing care and for preventing clients’ falls from the bed. However, their use must adhere to certain conditions.

The use of **bed rails must always be adequate with regard to the risk**. Therefore, it is necessary to map the **risk of falls in the given client**. Bed rails cannot be correctly used as a tool of prevention of falls unless the risk of falls is properly assessed.

If it is assessed that a certain preventive measure has to be used to prevent a client’s fall from the bed, the **least restrictive measure should be used**. Subsequently, the team of carers must decide whether a different, less restricting form of a restraint than bed rails could be used to protect the client from falls. These include e.g. lowering the bed or placing a mattress next to the bed. [77]

When using bed rails with mobile clients only for the purpose of preventing falls (e.g. while turning over in sleep), it is necessary to make sure the clients have the **possibility to leave the bed on their own** (e.g. by using shorter bed rails or other technical modifications).

The purpose of using bed rails must always only be the prevention of falls, i.e. providing for clients’ safety. Bed rails must not be used to make the staff’s work easier. It is likewise impermissible to use bed rails during the day because a mobile client is restless and the staff needs to keep the client in bed.

Finally, the circumstances of using bed rails need to be determined on an **individual basis with each client** (e.g. whether bed rails should be used at night, the whole day or a part of the day, e.g. during afternoon rest). Such an information should be indicated in the client’s documentation. The record should show who made the decision to use bed rails and why. The staff should have available a list

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[76] Unlike the restraints listed in Section 89 of the Social Services Act, which restrict movement under all circumstances.

[77] For more information on the alternatives to bed rails, see JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS. Prevence pádů ve zdravotnickém zařízení (Prevention of Falls in a Medical Facility). Prague: Grada Publishing, a. s., 2007, p. 55 et seq. ISBN 978-80-247-1715-9.

of clients with whom bed rails are to be used, and this list should be authorised by a senior employee. This list should then serve as a guideline for the staff in direct care as well as an instrument of review for the senior employees. Using bed rails should never result from an intuitive decision on the part of the staff.

If these conditions are satisfied, using bed rails does not require a physician's consent or approval by a family member or a curator. Giving such consent is legally irrelevant; however, it can help to build trust between the team of carers and the client's family members. On the other hand, if the above conditions are not satisfied, the legitimacy of using bed rails (barriers) is doubtful even if this is approved by a physician, family member or curator.

While using bed rails or other physical restraints, care must be taken to prevent **development of the immobilisation syndrome** and other consequences of long-term stay in bed.

Findings from the visits

In most of the facilities visited, the staff was not informed of the principles governing the use of bed rails. In some facilities, bed rails were not considered to be a form of restraint. Sometimes, staff members said bed rails were a part of the bed, at other times that bed rails were used **based on the client's wish**, which, nevertheless, had not been documented. The bed rails were thus used in a completely uncoordinated fashion and on the basis of intuitive decisions by each staff member (social care worker).

In other places, bed rails were considered a measure restricting movement, but their use was **subject to consent from the client, a family member or a physician**. If such consent had been given, no further consideration was given to whether the bed rails should be used at night or during the day, or for how long.

The Defender advised that it was problematic to rely on the wish or consent given by a client with dementia whose ability to make decisions was limited due to his or her medical condition. In case of these persons, the decision on using bed rails must be made by a team of carers in the facility and this fact, together with the justification, must be recorded in the client's documents.

Often, the documents **did not indicate the reason for using bed rails**, i.e. whether they were used to counter a certain risk to the client's safety. There were no records on with whom bed rails were actually used and when.

The Defender noted a major shortcoming consisting in the practice where staff in direct care **did not have an authorised list of clients eligible for using bed rails**. This information was spread by word of mouth among the staff, or staff members made ad hoc decisions based on their momentary subjective evaluation. When asked which clients were eligible for using bed rails, individual staff members were giving different answers. In such a situation, the risk of miscommunication between the staff members is high, and the facility management unnecessarily leaves room for the staff to misuse bed rails as a restraint, which is especially dangerous in facilities insufficiently staffed by employees in direct care.

The most serious cases included situations where **bed rails were used to obstruct a client from walking or getting up from bed**; in those cases, bed rails were used as an unlawful restraint. Where the staff's reports included records such as "tried to climb over the bed rails" or "constantly put down the bed rails", the Defender concluded that bed rails were used not to protect clients against falls, but to prevent them from getting out of bed. If a client attempted to climb over the bed rails, the client was at a risk of a fall from a much greater height and of more serious injury.

On one occasion, the bed rails raised at a time when the client was not in bed and thus could not return. The staff explained that the bed rails were raised on purpose, in order to prevent the clients from wetting their beds over the day.

Recommendations

- Assess the risk of falls in each individual client.
- Use bed rails only after exhausting all other ways of protecting the client against falling from the bed.
- Ensure that independently mobile clients can leave their beds even when bed rails are raised.
- Determine on an individual basis with each client when bed rails should be used (whether at night, over the whole day or during afternoon rest, etc.).
- Record the decision on using bed rails and the reason for this in the client's documents, including information on who made the decision, when and why.
- Provide the staff in direct care with a clear and visible authorised written list of clients eligible for using bed rails.

b) Falls

Good practice

Falling can have very serious consequences for an older person (e.g. broken bones, head injuries, anxiety and depression).[78] Therefore, it is necessary to devote sufficient attention to prevention of falls and to evaluate the **risk of falls in each client**, record this and keep the record up to date. In the event a fall occurs, causes need to be found and the **circumstances of the fall need to be recorded** (the client's condition, location, time, etc.). The causes should be **analysed and ways should be found to prevent further falls**. The whole team of carers should be involved in this process.

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[78] JOINT COMMISSION ON ACCREDITATION OF HEALTHCARE ORGANIZATIONS. Prevence pádů ve zdravotnickém zařízení (Prevention of Falls in a Medical Facility). Prague: Grada Publishing, a. s., 2007, p. 29 et seq. ISBN 978-80-247-1715-9.

In clients with a risk of falls, **preventive measures** need to be put in place, e.g. stable furniture, lowered bed, firm footwear, sufficient number of hand rails, monitoring adverse effects of drugs, mattresses under the beds, hip guards, etc. Individualised preventive measures will enable the facility to clearly delimitate the extent of its liability and, if necessary, prove that proper supervision was not neglected.

It is further necessary to put in place **comprehensive records on falls** to find out the most usual causes, places and times of falls. Regular evaluation will allow to identify risk factors and locations where falls occur most frequently.

Findings from the visits

The Defender often noticed that the risk of falls was not being evaluated at all, which should have been the first step in a system of preventive measures. An external expert consultant often noted when inspecting the sites that there was a number of risk factors present in the facilities which needlessly increased the risk of falls. For instance, there were the following problems:

- unsuitable footwear not offering sufficient support to the feet (Crocs shoes) or shoes of unsuitable size;
- long corridors with no hand rails, rest areas or points of reference;
- unsecured pieces of furniture with wheels;
- missing compensation aids (walking sticks, wheelchairs, etc.).

In one facility, the risk of falls was evaluated in a token fashion only, by the local social worker. The other employees did not use the evaluation at all.

In two facilities, the Defender criticised the practice where despite the fact that the risk of falls had been evaluated (during admission screening and in the individual records of falls), the evaluation did not result in any adjustment and individualised care for the particular client, or at least it was not clear that there was any difference in care given to clients with the risk of falls and those with no such risk.

Records of the falls were made in all of the facilities visited. However, the documentation tools differed, as well as the scope of the recorded information.

In one of the homes, a client’s fall was recorded either in the nurses’ records book or in the carers’ record book, where the facility management had not put in place any rules as to which information should be recorded; the records did not serve as a basis for any further action. They were not even included in the nursing documentation.

In a number of the facilities visited, a printed form was filled in after a fall. Even if the form contained information on the cause, location and circumstances of the fall, this information lead to no further action, there was no prevention of further falls, not even in case of clients who were falling frequently. When asked why the records were kept at all, the staff in one facility said the records were used as a proof for the clients’ family members that the clients were not falling as often as they thought.

In one case, forms were used to record the clients’ falls, but the forms were not properly chronologically numbered. Moreover, the forms concerning a single clients were, in a number of cases, filed in two different rooms on different floors. The staff said that forms were filled in to be archived later.

If a facility makes records of falls but the records do not serve as a basis for further action, filling in forms merely constitutes a useless administrative burden.

The Defender also addressed the **preventive measures** adopted to prevent clients’ falls. In several facilities, clients were physically restrained in a chair or a wheelchair; bed rails were often used. In one facility, the “measures adopted” section of the form contained information that “the client was warned”, which definitely cannot be considered an effective form of prevention in clients with dementia.

Finally, the Defender criticised the practice where the **records did not clearly show** how often a certain client had fallen in a given period of time and where it was not possible to systematically evaluate the seriousness of the falls and look for preventive measures.

In a majority of cases, insufficient prevention of further falls did not result from faults on the part of staff in direct care. This was a fault of the managements of the facilities, which had failed to put in place proper procedures and instructions on evaluating the risk of falls and on further procedure in response to a particular situation. An especially serious error consisted in the failure to take action after filing a record form on the fall, i.e. there was no evaluation of the causes and no search for preventive measures by the team. Staff members in direct care then understandably saw filling in the forms as useless paperwork.

Recommendations

- Regularly update the evaluation of risk of falls in each client.
- If there is a fall, record the relevant circumstances of the fall (time, place, persons present, cause of the fall, injuries, treatment, etc.) and adopt well-considered and adequate individualised preventive measures.
- Regularly evaluate records on clients’ falls, address their causes and circumstances (time of the fall, location, injuries etc.) and adopt preventive measures.

c) Signalling

Good practice

The option to call in the staff in case of emergency (rapidly worsening medical condition, acute restlessness of a roommate, etc.) is a critical precondition for safety of the clients. Signalling equipment should further allow (not only) immobile clients to call in a carer if he or she needs to go to the toilet or change an incontinence aid. If a client cannot reach a functional signalling tool, he or she has to rely on the help of a roommate or has to call in the staff by shouting. Both can be a significant nuisance to other clients, especially at night. Clients disturbing each other may negatively affect the relations between them and represents a potential sources of tension and conflicts. **Signalling equipment reachable from the bed and from the bathroom/lavatory must be a standard.**

Obviously, certain clients are prevented from effectively **using the equipment by their cognitive impairment**. In case of such clients, the information should be recorded in their individual documents. If a client cannot call in the staff on his or her own, availability of assistance must be ensured in another way, e.g. by more frequent contact with the carers.

Findings from the visits

In facilities where signalling equipment was not available to all the clients, the staff claimed this was because they had good overview of each client and regularly visited the individual rooms. This argument must be rejected. Regular check-ups by the staff cannot substitute for a functioning signalling equipment. The staff can never be present in all the rooms all the time; moreover, more frequent check-ups during the night can be nuisance for the clients.

In a number of the visited facilities, **signalling equipment was completely missing in the rooms or it was placed out of reach of clients lying in beds** (too high above the bed, on the other side of the room, etc.) or it was **not set up at all beds**. The latter two situations represent a problem especially in case of permanently bedridden clients. In one of the homes, the way to call in the staff was to use a phone placed near the door to the room. A client had to dial a 4-digit number in order to reach the nurses station. Many clients were physically unable to get from the bed to the phone, while others could not dial the 4-digit number due to their cognitive impairment. Moreover, staff were not present at the nurses station all the time.

The Defender also criticised cases where **signalling equipment was present in the rooms, but did not function (was broken)**. In some other cases signalling was technically operational, but the signal was not reaching the facility's staff. The reason usually was that the signal was not being sent to a portable pager but to a room (typically the nurses stations), where permanent presence of the staff was not ensured. During one of the visits, the employees of the Office tried using the signalling to call in staff to help a client who had got stuck in bed rails and was moaning. The signalling button was pushed a few times, but no member of the staff arrived to help.

In a number of facilities, signalling was also missing from bathrooms and toilet cabins. This is a problem especially in case of a fall, where help could not reach the client fast enough.

Recommendations

- Make signalling equipment available to all clients who are in a sufficiently good cognitive condition to be able to use it; the clients should be able to reach the equipment from their beds.

- Make organisational provisions to ensure that staff will always respond to a client's signal.

8) Staff

Sufficient staffing is a prerequisite of individualised care. Staff levels should correspond to the difficulty of addressing the clients' needs. Insufficient staff leads to care being organised according to the capacities of the staff and not according to the individual needs of the clients.

It is equally important to note that the present trends in this area focus not only on the needs of the clients but also on the carers. It is especially important to **support employees in direct care**. This does not entail supervision only, albeit it should be noted that supervision was entirely absent in many facilities. It is important to monitor the needs and problems faced by the employees and provide them with the support they need in a suitable form. Supervision or the person of the supervisor may not be suitable for all employees.

Recommendations

- **Ensure sufficient staffing corresponding to the needs of the clients.**
- **Pay attention to the needs of the employees and provide them with assistance, e.g. in the form of supervision.**

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Convention on the Rights of Persons with Disabilities, promulgated under No. 10/2010 Coll. of International Treaties.

Decree No. 55/2011 Coll., on the activities of medical workers and other professional workers.

Decree No. 505/2006 Coll., implementing certain provisions of the Social Services Act.

Act No. 101/2000 Coll., on personal data protection and on amendment to certain laws.

Act No. 108/2006 Coll., on social services.

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V) Annex – Medication cards analysis

Administering medication to clients with dementia in social services facilities[79]

The analysis of 307 medication cards aimed to provide general information on administration of medication to clients with dementia placed in social services facilities. **The analysis was carried out by an external consultant working for the Office – clinical pharmacologist Mgr. Pavla Lerchová**. Aside from the list of medication used, she had information on the sex and sometimes the age and previous diagnoses. On the basis of comparison with professional literature, she evaluated whether or not the medication was administered correctly and whether the individual therapeutic groups were distributed normally.

Treatment of pain

According to the available data, 40–80 % of residents in nursing facilities suffer from pain in general;[80] according to the observations in the Czech Republic, 75–80 % suffered of permanent or frequent pain.[81]

In the observed group of 307 clients, **only 20% were prescribed some form of analgesic therapy**. This was even though some studies[82] indicate that administration of paracetamol (also known as acetaminophen) to relieve pain leads to a favourable change of the behaviour of residents in these types of facilities.

Therefore, it is likely that better treatment of pain enables to decrease the frequency and dosage of the antipsychotics used, which entails a lower sedation of the clients and reduction in occurrence of other adverse effects of antipsychotics, such as further deterioration of cognitive functions and adverse effects on the heart and the blood vessels. And of course, the clients will be relieved of pain.

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[79] The analysis is also available on the Defender's website at: PUBLIC DEFENDER OF RIGHTS. Podávání léčiv klientům s demencí v zařízeních sociálních služeb (Administering Medication to Clients with Dementia in Social Services Facilities). Analýza medikačních karet z navštívených zařízení pro seniory (Analysis of Medication Cards from Visited Retirement Homes) [on-line]. Brno: Public Defender of Rights, 2014 [retrieved on: 18 January 2014]. Available at: http://www.ochrance.cz/fileadmin/user_upload/ochrana_osob/ZARIZENI/Socialni_sluzby/analyza-farmaceutka.pdf.

[80] HOLMEROVÁ, Iva, BAUMANOVÁ, Michaela, JURAŠKOVÁ, Božena, VAŇKOVÁ, Hana. MOBID-2 – Praktická škála bolesti vhodná nejen u lidí s demencí (MOBID-2: Useful Pain Scale Suitable Not Only for People with Dementia). Česká geriatrická revue (Czech Geriatric Revue) [on-line]. 2009, 7(2), pp. 79–81. Available at: http://www.geriatrickarevue.cz/pdf/gr_09_02_06.pdf.

[81] Ibid; KERNOVÁ, Alena. Prevalence bolesti a spokojenost s léčbou mezi klienty domova pro seniory (Prevalence of Pain and Satisfaction with Pain Management in a Residential Home for Elderly) [on-line]. 2008. Diploma thesis. Masaryk University, Faculty of Medicine. Supervisor: Ondřej Sláma. Available at: http://is.muni.cz/th/59971/lf_m/.

[82] CHIBNALL, John T. et al. Effect of Acetaminophen on Behavior, Well-being and Psychotropic Medication Use in Nursing Home Residents with Moderate-to-severe Dementia. Journal of American Geriatrics Society 2005, 53(11), pp. 1921–9. HUSEBO, BS, BALLARD C, SANDVIK R, NILSEN OB, AARSLAND D. Efficacy of Treating Pain to Reduce Behavioural Disturbances in Residents of Nursing Homes with Dementia: Cluster Randomised Clinical Rrial. British Medical Journal [on-line]. 2011, 343. Available at: http://www.bmj.com/content/bmj/343/bmj.d4065.full.pdf.

On the other hand, the lesser prevalence of use of nonsteroidal anti-inflammatory drugs (used by 25% of clients who receive some analgesic therapy) in comparison to other analgesics is a positive sign. Nevertheless, it should be noted that nonsteroidal anti-inflammatory drugs are medication less suitable for older persons due to their serious adverse effects on the digestive system and kidneys.

Antidepressants

Generally speaking, depression affects up to 50% of patients with dementia,[83] which is reflected in the use of antidepressants in this group (44 % of the clients). Tricyclic antidepressants used by 8 % of the clients are known for their more pronounced adverse effects as compared to the more modern selective serotonin reuptake inhibitors (SSRIs), including adverse effects on cognitive functions.[84] The combination of antidepressants usually appeared rational, with the exception of one 83-year-old woman who was simultaneously using citalopram and escitalopram, where the dosage of escitalopram (20 mg/day) exceeded the limit of 10 mg/day for people over 65 years set by State Institute for Drug Control. Interestingly, the drugs have practically identical desired and adverse effects.

Antipsychotics and their combinations

More than two thirds of the clients were using antipsychotics. According to geriatric guidelines,[85] antipsychotics are high risk medicines with an increased risk of cerebrovascular accidents and anticholinergic effects, which impair cognitive functions and may lead to parkinsonism. Their use is sometimes unavoidable, but it should be time-limited where possible.

In some cases (8%), two kinds of antipsychotics were combined in a single client, where the two drugs had a very similar or identical effect: olanzapine + quetiapine, tiapridal + buronil.

In 11% of the clients using antipsychotics, the oldest types were also used (levomepromazine, chlorprothixen). Anticholinergic biperiden was administered to a number of clients, probably to reduce the adverse effects of antipsychotics. Biperiden is another drug considered unsuitable for patients with dementia. In clients with dementia, restlessness and agitation can result from insufficiently treated pain.

Benzodiazepines and hypnotics

Benzodiazepines (tranquilising drugs, e.g. Neurol) are also unsuitable for regular use in all age groups due to the risk of falls, addiction, etc. Benzodiazepines were prescribed to more than one third of the clients in the observed group, where three quarters of them used them regularly.

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[83] HOLMEROVÁ, Iva, MÁTLOVÁ, Martina, VAŇKOVÁ, Hana, JURAŠKOVÁ, Božena. Demence (Dementia). Medicína pro praxi (Practical Medicine) [on-line]. 2010(7)(3), pp. 139–144. Available at: http://solen.cz/pdfs/med/2010/03/11.pdf. PIDRMAN, Vladimír. Demence – 1. část: Diagnostika a diferenciální diagnostika (Dementia – Part 1: Diagnostics and Differential Diagnostics). Medicína pro praxi (Practical Medicine) [on-line]. 2007, 2, pp. 83–88. Available at: http://solen.cz/pdfs/med/2007/02/10.pdf.

[84] Czech Republic Experts' Consensus; HOLMEROVÁ at al. Demence (Dementia).

[85] CHIBNALL, John T. et al. Effect of Acetaminophen on Behavior, Well-being and Psychotropic Medication Use in Nursing Home Residents with Moderate-to-severe Dementia. Journal of American Geriatrics Society 2005, 53(11), pp. 1921–9. HUSEBO, BS, BALLARD C, SANDVIK R, NILSEN OB, AARSLAND D. Efficacy of Treating Pain to Reduce Behavioural Disturbances in Residents of Nursing Homes with Dementia: Cluster Randomised Clinical Rrial. British Medical Journal [on-line]. 2011, 343. Available at: http://www.bmj.com/content/bmj/343/bmj.d4065.full.pdf.

Of the observed group, 30% were using hypnotics. Of these, one third used benzodiazepine during the night (included in the previous paragraph); six clients were using Prothiaden, a sedative antihistamine drug with an anticholinergic effect, i.e. a drug that is not very suitable either.[86] When using antipsychotics and benzodiazepines, it is advisable to continue re-evaluating whether continuing the therapy is necessary.

Potentially unsuitable combinations of other drugs

In four patients with Parkinson's disease, older antipsychotics with a pronounced extrapyramidal effect (an attribute aggravating the symptoms of Parkinson's, which can even lead to parkinsonism itself).

The clients also used other drugs unsuitable for long-term therapies due to their extrapyramidal effects, such as cinarizine (cognitive enhancer with minimal desirable effects) and metoclopramide (a drug affecting motility of the digestive system), which can be substituted for a less aggressive drug.

In some cases, the drugs were administered to patients treated for Parkinson's. In four cases, long-term medication combined regularly administered nonsteroidal anti-inflammatory drugs with ACE inhibitors (antihypertensive drugs), which carries a risk of kidney damage.

In a patient using ibuprofen in the long term, aspirin and escitalopram (an antidepressant) were also used; in the absence of gastroprotection, such a combination significantly increases the risk of digestive tract bleeding. Professional associations have been warning against the use of these combinations and physicians should not prescribe them.

Cognitive enhancers

In five cases, the clients used cognitive enhancers that are considered insufficiently effective on the basis of the experts' consensus,[87] or they used them in an ineffective dosage. By contrast, modern cognitive drugs were only administered to 55 clients.

Formal shortcomings

In some cases, the medication sheets lacked information on the administered drug's potency, or the dosage of drugs administered ad hoc – for example, Tramal drops (analgesic) were to be used "in case of pain", without any specification of the number of drops to be administered. Drugs were often prescribed "in case of restlessness" or "in case of insomnia" or even "as needed" with an option to select from several prescribed drugs. Very often, there was no information on the maximum daily dosage. Such a prescription represents a potential hazard, especially with sedatives.

Medication sheets from different facilities differ greatly in terms of the information they provide. In some cases, it was clear that the same patient's medication sheet had been altered several times, without any clear indication of who had made the changes.

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[86] HOLMEROVÁ, Iva, MÁTLOVÁ, Martina, VAŇKOVÁ, Hana, JURAŠKOVÁ, Božena. Demence (Dementia). Medicína pro praxi (Practical Medicine) [on-line]. 2010; 7(3), p. 139-144. Available at: http://solen.cz/pdfs/med/2010/03/11.pdf. PIDRMAN, Vladimír. Demence – 1. část: Diagnostika a diferenciální diagnostika (Dementia – Part 1: Diagnostics and Differential Diagnostics). Medicína pro praxi (Practical Medicine) [on-line]. 2007, 2, pp. 83–88. Available at: http://solen.cz/pdfs/med/2007/02/10.pdf.

[87] Czech Republic Experts' Consensus; HOLMEROVÁ at al. Demence (Dementia).

Sometimes, medication sheets included information on the possibility of generic substitution – the sheet contained several registered drugs and the nurses were to administer the medication they had available. However, the substitution was carried out incorrectly in some cases and the medication sheet indicated drugs with different effects (e.g. the antidepressants citalopram and escitalopram, where the latter is almost twice as potent, and the drugs pantoprazol and omeprazol, which have very different potential interactions with other drugs – this means that if one drug is substituted for the other, this may negatively affect the other medication used by a client).

On the other hand, in a case of a young patient using a number of antipsychotics, two active substances were administered (the antipsychotic drug olanzapine and the antidepressant escitalopram) under four different trade names, which led to exceeding the recommended dosage of both these active substances.

A very usual shortcoming of the medication sheets **consisted in the omission of information on administering the drugs with food or on an empty stomach**; this was even true in case of drugs where proper administering is necessary for the drug to be absorbed, e.g. bisphosphonates (drugs used to treat osteoporosis and some types of cancerous pains), medicaments containing iron, omeprazole or thyroid hormones – information on the need to administer on an empty stomach was missing in 49 drugs (it was indicated in 11 cases). In these medicaments, lower absorption may result in a reduced effect; bisphosphonates cannot be absorbed at all if administered with food. Moreover, bisphosphonates are among the more expensive drugs and their use with food is thus also uneconomical. Conversely, some drugs (e.g. cognitive enhancers) should be administered with food in order to eliminate the usual adverse effect of nausea; nevertheless, this information was completely omitted. In drugs that should be administered with food or on an empty stomach, proper administration thus depended on the individual knowledge of the staff members.