QUESTIONNAIRE: Czech Republic

1. Assessment of behavioural disorders

1.1 Please specify the different kinds of behavioural disorders which in your opinion need to be assessed:

Irritability, agitation, apathy/indifference, aggression, disinhibition, pacing, aberrant motor behaviour, appetite/eating behaviour,

Depression/dysphoria, anxiety, delusions, hallucinations,
Self sufficiency disorders

1.2 Describe the most appropriate approach for this assessment:

We use scales of activities of daily living to assess the self sufficiency.

The BEHAVE AD scale or NPI (Neuropsychiatric inventory) when appropriate (mostly for research purposes).

In practice we simply describe individual symptoms and discuss them with caregivers and in the multidisciplinary team.

1.3 Describe the most used measurement / assessment tools for these symptoms:

Different departments use different tools according to our experience.

2. Types of home care provision provided by professional carers

2.1 Please describe different approaches to supporting and caring for people with dementia who live at home related to behavioural disorders:

Situation in the Czech Republic:
People who live at home have their general practitioners, some of them visit their patients at home (when necessary) regularly, some do not.

They are gate-keepers of home care (nursing services) and prescribe visits of home care nurses. The system of home help provide meals on wheels, shopping and some help in the household. However this home help is not available in all communities.

There are few specialised services for persons with dementia, day care centres are relatively rare.

Situation in Prague 8 (and Centre of Gerontology, Czech Alzheimer Society)
Centre of Gerontology has one small department (12 beds) for persons with dementia where also persons with behavioural problems can be admitted to change medications, care attitudes, advice caregivers etc. One of 2 day care units is specialised in the care for persons with dementia. Home care services are prescribed by our physicians (2 weeks after hospitalisation) and then by general practitioners. Where appropriate (difficult care including behavioural problems) geriatric team (geriatrician, nurse, social worker etc) visits patients and their families at home to consult care. We organise also education for family caregivers, self support groups. Czech Alzheimer Society provides caring families with respite care at home “granny sitting” (up to 10 hours per week).

2.2 Describe the appropriate non-drug treatment or measures used:

It is necessary to proceed according to individual needs of patients and to find the most appropriate solution according to the reason of the behavioural change (which may be discomfort, pain, anxiety, a simple change etc.).

2.3 In what circumstances is residential / institutional (including hospital) care required?

When care at home is not feasible and family caregivers do not manage to care. When behaviour is not manageable by all measures adopted in the home environment. When the behaviour of a person with dementia is a danger for herself-himself or other persons.

3. Training programmes/information

3.1 Which kind of information, training and education do exist for people with dementia and their carers?

Generally: there is very little information on this topic in the Czech Republic.

Both the Czech Alzheimer Society and the Centre of Gerontology are very active in this field. Our publications are targeted both on professionals and family caregivers and general public. We have published a book “Care for patients with cognitive disorders” which is a practical guide how to care for persons with dementia. Different methods and psychological attitudes are described both in this book and in different articles.

We have performed randomised controlled trials on dance and reminiscence therapy for persons in residential homes (half of them with cognitive disorder).

We have also frequent communication with media including broadcast, tv etc. where information on dementia including behavioural problems are disseminated.

3.2 Which are the most efficient dissemination tools for sharing information (for targeting the patients / the carers) and why?

We have no evidence but we think that all above mentioned ways are important.

3.3 What training and education programmes do exist for professionals?

Different systems of education are in health and social care in the Czech Republic. Some programmes focus on care for persons with dementia. Czech Society of Gerontology and Geriatrics and Czech Alzheimer Society organise many meeting and conferences with this topic.

Lately we formulated a strategy P-PA-IA of care for persons with dementia (which reflects the specific situation of the health and social care in our country) and a methodology of reflective support for persons that includes different non-pharmacological attitudes has been developed.

We have adopted also a strategy of palliative care of Alzheimer Europe (Iva Holmerova participated in the working group of Alzheimer Europe).

APPENDIX: Strategy of the Czech Alzheimer Society of care for persons with dementia P PA-IA

P-PA-IA: Strategy for care and support of persons with dementia

This strategy has been a result of many discussions in the Czech Alzheimer Society, workshops and meetings of our contact points during the recent two years. I would like to thank especially to Mgr. Martina Rokosová, PhDr. Hana Janečková, Ph.D., Pavla Hýblová, PhDr. Eva Jarolímová and MUDr. Helena Nováková. The strategy is also based on our experience from the Centre of Gerontology, especially from the day care unit for persons with dementia, were Mgr. Jitka Suchá and Mgr. Iva Jindrová, have been creating programmes and activities for persons with dementia. Also staff from our geriatric ward and the palliative care department, especially both chief nurses Jiřina Jirásková and Eva Bašná have provided me with important opinions and remarks. I have consulted also staff members in different institutions and organisations in our country and abroad (in Austria, Germany, Norway, Switzerland etc). I have tried to put together all this knowledge and experience in a brief recommendation on care for persons with dementia. I hope that this recommendation, the strategy of care for persons with dementia that was adopted by the board of the Czech Alzheimer Society in 2008, will help all of us to understand better what persons with dementia need and how we can better provide the care.

What does it mean P-PA-IA?

P – many words in the Czech language start with this letter, including words
Support (podpora), counselling (poradenství), help (pomoc), legal issues (právní aspekty) – these terms are relevant for the initial phase of the disease.
Also support of caregivers (podpora pečujících) starts with „p“ in Czech – and finally also palliative care (paliativní péče).

PA – programmed activities (programované aktivity)
IA – individualized assistance or individualized activities (individualizovaná asistence, individualizované aktivity)

Dementia is a long-term chronic and progressive condition (syndrome) usually caused by neurodegenerative diseases, vascular causes or other disturbances of the central neural system.

Dementia progresses subsequently according to the causing disease. We can describe three main phases of dementia according to the severity of the disease, and the need of care. Despite the above mentioned characteristic of this syndrome and despite its unfavourable prognosis it is possible to improve or preserve the quality of life and comfort of persons suffering from dementia (and their family caregivers) by adequate support, therapy and care. Therefore we focus in our care for persons with dementia on their dignity, alleviation of symptoms that may cause discomfort and on the quality of life of persons with dementia and their family caregivers.

Modern pharmacotherapy may limit and delay the progression of most cases of dementia for a certain period of time. It enables to preserve the self-sufficiency and good quality of life and to moderate further symptomatology of dementia, especially behavioural disturbances and other psychic symptoms.

Non-pharmacological methods are an integral component of comprehensive care for persons with dementia. They help to maintain good quality of life and to moderate behavioural disturbances. Also safe and adequate environment is integral part of non-pharmacological management of dementia.

Necessary condition of care for persons in any phase of dementia is a proper and complete diagnosis and assessment (and adequate therapy when appropriate).

Most of the care for persons with dementia is provided at home by family caregivers. They need both financial support (care allowance according to our new legislation on social services) and also other services and support, so that they would be able to act in this important role as long as possible.

When it is not possible to provide the care at home, it is necessary to assure professional services according to needs of persons with dementia and according to the phase and progression of the syndrome.

Most of diseases that cause dementia (e.g. Alzheimer´s disease) are terminal diseases. They are shortening human life and terminate it preliminarily. Therefore we should keep in mind that also palliative care is necessary and that palliative care (in its different modifications according to needs of persons with dementia) is the only optimal solution for persons in terminal stages of dementia and dying from dementia.

Environment for care, equipment and staff: it is important to stress following principles.
When the care is provided in an institution, it is necessary that the environment is adapted according to needs of persons with dementia. The care must by provided by professionals who are qualified and have training in dementia care. Staffing and equipment are to a certain extent complementary – when the environment does not comply with needs of persons with dementia, we should add more staff members.

Cooperation with family and support of family caregivers are also very important when a person with dementia lives in an institution (on a temporary or long-term basis) or when the care is provided in a day care unit. Family caregivers must be respected by professional staff as important partners in care. Communication with family caregivers has the same importance as a communication with persons with dementia. Proper and smooth communication and mutual exchange of information (as well as advice and counselling in care) are necessary and important conditions for continuity and quality of care.

The characteristics of phases of dementia P-PA-IA is based on needs of people with dementia (and does not necessarily reflect other severity classifications). Care provision, therefore should reflect these needs.

Phase P-PA-IA 1:

What is characteristic for this phase: people are relatively self-sufficient, they need some assistance, support and supervision which should be provided regularly. But they do not need permanent care and/or supervision.

Diagnosis of dementia and of the disease causing dementia is based on the personal history, tests of cognitive functions, clinical examination (including necessary laboratory screening) and on the brain imaging. Diseases causing dementia afflict predominantly memory (Alzheimer´s) and other cognitive functions, and they cause also some other symptoms including psychic and behavioural (changed behaviour, depression etc.)

Persons in this phase of dementia are still relatively self-sufficient (with some help or services) and they are often active. They can stay alone in their households for a distinct period of day or week. Usually it is sufficient when they have regular supervision by their families, phone consultation are also useful as well as home help services. It is useful when these persons with dementia help their memory by different tools and advices, leaflets, reminders etc. They also understand what has happened inside them and what does the disease mean, therefore they often have feelings of uncertainty, sometimes also depression.

(this phase corresponds roughly to the 2-4 grade of the Reisberg´s scale)

What do people with dementia in P-PA-IA 1 phase need?

Persons with dementia in P-PA-IA 1 phase need early and correct diagnosis, adequate pharmacotherapy (when appropriate) and they need to know their diagnosis (if they want to): the proces of the disclosure of diagnosis of dementia is important. It is necessary that the relevant physician provides person with dementia with enough information and also support, answer his/her questions. Enough time for this process is also essential.

Planning of the future process of care together with a physician (advance directives): People with dementia are able to decide in this time about their future and also about important things that would happen in time when they will not be able to decide about them. It refers also to the care and cure process. Therefore persons with dementia should be informed by their physicians to be able to decide important decisions in advance.

Legal issues. Information provided by a physician and the early disclosure of diagnosis should help a person with dementia to decide about important legal issues that he/she considers to be relevant (and he/she will not be able to decide about them when the disease progresses).[1]

Psychological support, counselling: persons with dementia need support that can be provided by the Czech Alzheimer Society (contact points in all regions of our country). Sometimes it is feasible to find professional psychological support.

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Phase P-PA-IA 2

It reflects the possibility of the care provision in social institutions when the stay in institution becomes the chosen option

This phase of dementia lasts e.g. in Alzheimer´s disease 2-10 years. Persons with dementia are gradually losing their self-sufficiency, they become disoriented and need permanent supervision and assistance. Despite this fact it is necessary to keep in mind that people in this phase of dementia are able to perform different activities (under supervision and in the protected environment) and their quality of life is good, even very good in many aspects. They enjoy some activities and some events,that they are able to perceive and understand and also their communication is (more or less) sufficient. These people are able to participate in different programmes and they profit from gentle programming of their activities. They do not suffer from (severe) behavioural disturbances (agitation, aggressivity), severe psychic symptoms (hallucinations). Less serious behavioural problems are easily manageable by non-pharmacological and restraint-free methods.

This phase of dementia corresponds roughly to 4-5 stage of Reisberg´s scale.

People in this stage of dementia must not be admitted to an institution (social type of institution) without their consent (this consent must be expressed in writing and by patient´s behaviour during the admission procedure). If a person with dementia does not agree with admission to the institution, and if the admission is the only possible solution of his/her situation, the relevant court has to be informed and decides it.

Persons in this phase of dementia profit from regular programme and from programming of their activities (or programmed activities – PA), they mostly enjoy being involved in them according to their individual needs and preferences. Implementation of this regular programme of day brings about regularity, rhythm and thus the feeling of safety and predictiveness. People with dementia enjoy activities that support their self-sufficiency, which are meaningful and support their dignity. These activities also support the normal diurnal rhythm, because active people do not sleep during the day (and they sleep better at nights).

Programmed activities are useful also for family caregivers. They are able to care longer, especially because the diurnal rhythm is preserved and they may have rest and sleep at nights.

Programmed activities have similar positive effect also in institutions. They create a framework for care for persons with dementia. Activities might be organized for small groups of persons with dementia and therefore they contribute to more effective care. They also contribute to relaxed (and not disturbed) nights both for persons with dementia themselves and other residents.

We can describe programmed activities as activities that fill in days of persons with dementia and they support their autonomy, dignity and self-sufficiency. Therefore we promote self sufficiency of persons with dementia in a regular regime of hygiene (in the morning and in the evening) and also at mealtimes, when people with dementia help to prepare and arrange table and to serve their meals, prepare a cup of coffee or tea and etc. These activities are meaningful, they are important for the support of self-sufficiency, they are regular and repeated, pleasant and they divide days into smaller periods that can be filled in by other activities and non-pharmacological therapies etc.

These non-pharmacological methods and therapies have (according to the increasing evidence) beneficial effect on self-sufficiency, condition and they are important as a prevention of behavioural disturbances (kinesiotherapy, walks, cognitive rehabilitation, sensoric stimulation, reminiscence etc.)[2]

Programmed activities are useful in the day care units and centres and also in residential care, where persons with dementia live (on temporary or long-term basis)

In the care for persons with dementia it is necessary to assure adequate home-like environment, adequate tools and also adequately skilled staff (see in more details in recommendation of the Czech Alzheimer Society)[3].

Technical and environmental aspects:

The space (room) for programmed activities should be equipped so that it would look home-like (kitchen, dining room)

- small kitchen tools and devices are here to enable coffee cooking, arranging of the table,
- accessible and visible toilets
- calmer spaces („corners“) for having a rest (with armchairs, not with beds)
- common „social“ space for activities that may include light training and movement, dance, activities on chairs that are arranged in a circle etc.

It is necessary to have appropriate equipment for activities, e.g. a „set for cognitive training“ (good example gives the Czech Alzheimer Society in cooperation with Lundbeck), paper and pencils for drawing, colours for painting, flowers and leaves for arranging, simple „music instruments“, tools for preparing different paper objects, simple cooking and baking, „gardening“ etc. It is not necessary to name all methods and tools, because they usually depend on preferences of persons with dementia (but also on preferences of therapists who work with them).

It is not important which activities are used, but it is important that they are appropriate for persons with dementia, who enjoy them. Activities must also support dignity of persons with dementia and it is optimal to combine psychic and physical activities.

It is not necessary to perform complicated and costly activities. Sometimes activities that are simple and „common“ (in the sense of common daily life) are even more appropriate, because

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[2] Holmerová I, Jarolímová E, Suchá J et al: *Péče o pacienty s kognitivní poruchou.* Praha: EV Verlag, 2007.

[3] Holmerová I, Jarolímová E, Suchá J et al: *Péče o pacienty s kognitivní poruchou.* Praha: EV Verlag, 2007.

they are part of normal life and they support self-sufficiency. Therefore we recommend these activities of daily life as hygiene, including the regime support of continence, proper dressing, self-sufficiency at the table, help during the preparing table, making coffee, washing small dishes etc.

Staff

All staff members should be informed about dementia in all appropriate theoretical and practical aspects, they should have practical training in care for persons with dementia including prevention of problem behaviour. Number of staff should respond to needs of persons with dementia.

Care is provided (and activities organized) individually or in groups. Groups should have maximum 15 persons with dementia. In case of bigger groups, departments or institutions, it is necessary to create smaller activity groups.

One group of patients should be taken care of by 2 staff members (with education of carers in social services or carers in health services). If patients have specific needs (e.g. need to be fed etc.) it is necessary that the number of staff is higher at least for instance at the time of regular meals. If the group is bigger than 15 persons, we should divide the group and to add 1 additional staff member for each 5-8 persons. If people with dementia stay in institution over nights it is necessary to assure permanent supervision (details on staff in these departments are included in the recommendation of ČALS).

Qualification of staff: The care for patients in the P-PA-IA 2 stage might be provided by staff with the basic education for health or social care provision (in Czech language: pracovník v sociálních službách a sanitář). However it is necessary that they have additional training and education in dementia (both practical and theoretical).

A skilled nurse is available on demand of the staff in all cases when it is necessary (drug dispensation, qualified nursing acts etc). It might be a nurse from other department of a residential facility or (in case of a community centre or day care unit) a home care nurse.

The scope of skills and knowledge:

Professional caregivers (defined above) are acquainted with the syndrome of dementia, its causes, symptoms of dementia and also (both theoretically and practically) with non-pharmacological methods and attitudes. They can perform and organise activities, they are aware (and can use in practice) the validation, they are able to communicate properly with persons with dementia.

Institutions and departments providing care to persons with dementia in the phase P-PA-IA 2
It is necessary, especially in long-term stay facilities, to provide enough privacy to persons with dementia, therefore we recommend single rooms for them as the most appropriate.

The common practice in most of institutions does not enable this and therefore we stress at least preserving of privacy in performing hygiene, toilet, physical examination etc.

However it is necessary that at least new services are designed and built to assure privacy adequately.

Departments and spaces for persons with dementia should be simple and easy for orientation. People with dementia should see where the staff is and the staff should be aware and see (without disturbing them) where persons with dementia are (more details in the further recommendation of the Czech Alzheimer Society).

Respect of rights and dignity, acceptable restraints.

These aspects are very important for persons with dementia.

Address:

It is very important to address persons with dementia properly, according to their preferences. Therefore we address them „Sir, Madam“ with the surname or academic title. If some people wish to be addressed by their first name, it is advisable to add „Sir, Madam“ to that. Any childish addresses are not acceptable.

Clothes:

It is necessary that persons with dementia are dressed properly, daily dress for the day and the night one for the night. The dress should be adapted to activities that people with dementia do. It is also very important when they stay in institutions. It is not acceptable that persons with dementia stay all-the-day-round in pyjamas etc.

Protected environment:

The understanding that persons with dementia are disoriented, they may wander, lose their way and thus threaten themselves when they are without supervision, is very important for the care for them. According to our opinion it is necessary to protect them, to assure them the permanent supervision. Therefore it is necessary that they stay in a protected environment together with staff members. This environment is safe for them and they are not able to leave it without assured supervision.

According to our meaning this above mentioned principle is a primary one. Technical ways how we create this „protected environment“ are only secondary. It is the same case, for a person with dementia, when there is a person who prevents him or her from leaving the department – or if it is a technical device, digital code (that is seen sometimes as the „softest“ and „most acceptable“ measure, however it is very obvious that it is a simply locked door for persons with dementia, that do not understand the digital system), or whether it is a locked door. However we stress that in the protected space there are both patients and staff together (with a very similar chance to leave it).

All cases of locking or closing persons with dementia in separate spaces without staff are not acceptable.

Use of restraints – with the exception of the above mentioned safe environment where persons with dementia stay together with staff – no restraints are acceptable in these departments (P-PA-IA 2). No mechanical or pharmacological restraints can be used (we consider as unacceptable: any forms of locking alone, fixation in bed or chair, pharmacological sedation etc.- see Alzheimer Europe and CALS recommendations).

However it is necessary to add that the „safe environment“ (defined above) and the use of bedrails when patient wish them as well as activity programming, we do not consider as restraints.

Behavioural problems: When behavioural problems occur, it is necessary to manage them by non-pharmacological methods and attitudes. When behavioural problems occur repeatedly or they persist despite applied non-pharmacological methods, a skilled health care worker (registered skilled nurse) must be called. She/he analyses problems and the health status of a person with dementia (regarding to possible somatic reasons of behavioural problems), takes appropriate measures according to her/his competence and in the case of need she/he calls a physician. When behavioural problems are difficult to manage by non-pharmacological methods available to the staff of the department P-PA-IA 2 and this situation occurs repeatedly, it is necessary to consider that dementia has progressed into the phase P-PA-IA 3, and the care must be assured according to needs of persons in P-PA-IA 3 phase.

Phase P-PA-IA 3

Persons in this phase of dementia need skilled nursing care and social care (combined in a comprehensive long-term care)

This phase roughly corresponds to stages 6 and 7 of the Reisberg´s scale and also to any type of dementia that is complicated by repeated (and not easily manageable, see above) behavioural problems or by severe somatic problems.

Persons in this phase of dementia profit from the individualized assistance and from different activities that are adapted to their needs. It is necessary to consider that in this phase dementia has progressed and persons with dementia are not any more able participate in all programmed activities, or they do not profit from participation in them. Programming of activities does not improve quality of life and comfort of these people, on the contrary it may cause discomfort. These people profit from an individualized regime and care (including some meaningful activities).

In this phase of dementia people have severe problems also in communication, their ability to communicate verbally is limited. Therefore staff members should be aware how to communicate with persons with dementia non-verbally and how to understand them. Also behavioural disturbances are more frequent in this phase. Staff members should analyze reasons of problem behaviour. They must keep in mind that reasons of problematic behaviour may be often somatic (pain, discomfort, dehydration, constipation, urine retention etc.) Also mobility is limited in this phase, therefore it is necessary to perform adequate rehabilitation, both active and passive, aiming at comfort of patients. It is also necessary to care for nutrition, manage swallowing problems, prevent aspiration etc. Above mentioned problems and needs have illustrated in a sufficient way that these persons with dementia need skilled nursing care.

Individualized assistance (or activities) do not mean that we do not involve persons with dementia in activities. On the contrary: when people profit from any meaningful activity, participate in it, enjoy it, it is very important to involve them. However, the difference from P-PA-IA 2 is important: persons with dementia in P-PA-IA 3 phase are invited to activities, they are offered to them, but we have to respect that they need more individual care, more comfort, calm environment, more sleep, more time for care etc. Therefore the „programming of activities“ (as in P-PA-IA 2) might be already disturbing for them.

According to the above mentioned description of needs of persons with dementia in this phase it is obvious that the care in institution must be provided in the close cooperation with skilled health care staff (registered skilled nurse), who is present during the day time and available during the night time. It is also necessary to assure that physician is available.

The stay in these departments should be voluntary (usually expressed by person´ with dementia behaviour, and by independent witnesses). If a person with dementia does not agree with the stay in an institution (which is obvious from the behaviour) or if the dementia has progressed so that it is not possible to detect the consent event from patient´s behaviour – it is necessary to inform immediately the court that decides.

Staff competencies for care P-PA-IA 3

Staff members are aware of the syndrome of dementia, its reasons, symptoms, complications, possibilities of non-pharmacological methods and communication with persons with dementia. They have necessary knowledge and experience and they are able to work with persons with severe dementia, to perform activities with them. Nurses are able to identify and solve health problems and worsening within their competence, and also to call a physician when necessary.

Respect for rights and dignity, acceptable measure of restraints

Respect for right and dignity must be a key-point in the care for persons with dementia.

Address:

It is very important to address persons with dementia properly, according to their preferences. Therefore we address them „Sir, Madam“ with the surname or academic title. If some persons with dementia wish to be addressed by their first names, it is advisable to add „Sir, Madam“ to that. Any childish addresses are unacceptable.

Clothes:

It is necessary that persons with dementia are dressed properly, daily dress for the day and the night one for the night is preferable also for persons in P-PA-IA 3 stage. Clothes should support dignity of a person with dementia. It is also very important when they are in institutions. However we recommend more comfortable (than normal civil) clothe, that is similar to home or training clothes. It is unacceptable that persons with severe dementia stay all-the-day-round in night linnen which is easy for care but it does not support dignity of a patient.

Protected environment:

The understanding that persons with dementia are disoriented, sometimes agitated, they may wander, lose their way and thus threaten themselves when they are without supervision, it is very important for the care for them. According to our opinion it is necessary to protect them, to assure them the permanent supervision. Therefore it is necessary that they stay in a protected environment together with staff members. This environment is safe for them and they are not able to leave it without assured supervision.

All cases or locking or somehow closing persons with dementia in separate spaces without staff are not acceptable.

The use of restraints: restraints are used only exceptionally, any use of restraints must be individual, based on medical examination (each use of every restraint in all patient). Each use of restraints must be documented.

When restraints are used, it is necessary to observe persons with dementia carefully, individually and in case that it is necessary to increase the number of staff. Observation must continue as long as problem behaviour continues and restraints are applied (see recommendations of Alzheimer Europe and CALS on use of restraints[4]).

What we do not consider as restraints: Bedrails during sleeping time of persons who fall from bed during their sleeping. Also in these cases it is necessary to supervise persons with dementia when they are waking up and remove bedrails, because people who fall over bedrails fall from increased height.

Also the above mentioned protected environment (see above) where patients stay together with staff members we do not consider as a restraint.

Problem behaviour: Problem behaviour should be prevented by non-pharmacological methods.

Behavioural problems that are severe or persist despite applied non-pharmacological methods must solved by skilled health care staff (nurse), who would analyze the cause of problem bahaviour and according to its nature calls a physician. Medication can be applied only on the basis of physician´s decision.

Activities: we offer to persons in P-PA-IA 3 different activities, from which patients profit. We respect their wish to participate or not to participate in them. Persons in severe condition sleep longer in the morning (or sleep most of the day), this need of sleeping should be respected in case that they sleep also during night. We also adapt the rhythm of necessary activities to need of persons with dementia (morning and evening hygiene etc.). Despite that we try to promote

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[4] *Doporučení Alzheimer Europe k používání omezovacích prostředků*, Praha: ČALS 2006. Accessed: www.alzheimer.cz, 12.4.2007

daily regime during the day, including daily clothing, getting out of bed and participation in activities when possible.

Despite the above mentioned principles, also in the department for patients with dementia with P-PA-IA 3 we organise different activities for people who profit from them. Persons with dementia in these departments should not under any circumstances stay all in beds or in armchairs at bedside or on the contrary all in the common room for activities etc. This department should respect their individual needs which are various in different individuals and therefore usually some people stay in common spaces, some in armchairs and some in beds.

Terminal phase of dementia

Dementia shortens human life and diseases causing dementia are mostly terminal diseases. The terminal phase of dementia lasts usually several weeks. It can be characterized as a phase when a persons with dementia has subsequently lost the ability to communicate, communication is reduced to some nonverbal signs, the mobility is severely impaired, also the reduction of muscle mass progressed, the food intake is reduced, including the fluid intake, swallowing disturbances are present, people are totally incontinent and also some other somatic symptoms are present. Pain is a frequent consequence of muscle contractures, dyscomfortable position and of other somatic problems.

Department for palliative care for people with terminal dementia and other persons with dementia who have special nursing needs:

This department differs from the above mentioned one by increased number of skilled health care staff (nurses).

Palliative care is a skilled health care, it focuses on comfort and symptom management especially pain management.

Critical criteria – information for the audit of the Czech Alzheimer Society (CALS)

The list of main indicators of quality of care (non-compliance considered as exclusion criteria for audit)

Organisational and technical criteria

The institution or organization is registered under health or social care legislation.

The CALS require the registration as a social care provider or health care provider.

Documentation

Documentation must depict care for persons with dementia (vision, strategy, individual plans of care, informed consent etc.)

Environment

General cleanness and cosines of the environment. Absence of „institutional“ smell.

Technical conditions

Rooms for 3 persons maximum, appropriate equipment and furniture of rooms (beds for care, other furniture, rehabilitation aids, storing space…)

Attitudes to persons with dementia, care

Clothes of patients

Inadequate hospital clothes or other clothing that does not support dignity is not acceptable.

Abuse

Dehydration, pressure ulcers, malnutrition and other signs of abuse and bad care are not acceptable

Care with dignity

Dignity must be promoted also by communication and relationship with persons with dementia, address. Address by first name and „thee“ and other forms that harm dignity are not acceptable.

Activities for persons with dementia

No form of deprivation is acceptable (letting persons with dementia without meaningful activities, attention and care). Big groups (more than 15) for activities are not acceptable.

Restraints

Recommendation of CALS and Alzheimer Europe should be respected

Staffing

- availability of health care personnel is a necessary condition
- permanent presence of care staff is a necessary condition

Types of services and explanation of structural criteria:

These abbreviations are used for staff according to the qualification:
CS - care staff – qualification of carer in the social care or in the health care
N - skilled nurses – skilled health care staff, competence to work without supervision
SS – specialised staff – staff members with special qualification, usually high school, University: therapists, managers, physiotherapists, occupational therapist, social workers, nurse specialist

P-PA-IA 2

Day care unit, department of long-term or temporary stays for persons with dementia in P-PA-IA 2 phase

Technical dispositions:

Spaces: rooms and spaces for programmed activities should be arranged so that they remind home environment. Following principles are recommended:

- kitchen-like furniture or corner with simple kitchen equipment (for preparing coffee, tea, arranging table)
- accessibility and visibility of toilets (suitable for persons with dementia)
- calm corner or room for having a rest (preferably with armchairs, not beds)
- appropriately equipped common room or space for activities and programmes including movement activities (dance, training, arranging chairs in a circle for different activities)

Activity groups of persons with dementia should not exceed 15 persons (if they do, it is necessary to divide them and add additional staff).

Staff (per one group of max 15 persons with dementia)
2 CS – permanently
3 hours of SS per day (specialised staff, occupational therapist is recommended)

It is necessary that 2 care workers are permanently taking care of one group of persons with dementia (carers should have basic training in social care or in health care and also in the care for persons with dementia). However additional staff is necessary if there are people with special needs in the group, for instance (during meals when patients need assistance). If the group exceeds the number of 15 persons, it is necessary to divide it or to add additional staff, so that there is 1 staff member for 5-8 persons with dementia. If patients stay overnight in the institution, it is necessary to assure permanent supervision by staff. In the care P-PA-IA 2 we stress the importance of programmed activities and also of the social work, communication and cooperation with families.

Qualification

Care for people in P-PA-IA 2 phase should (any may) be provided in social care institutions by staff without health care education. It is necessary that staff members have at least basic education for care in social services and skills and basic education in care for persons with dementia. Skilled nursing staff is available (it may be a home care nurse or part-time nurse in community centres or a nurse from another department of a residential facility).

Scope of knowledge and skills

Care staff members are acquainted with the syndrome of dementia, its most frequent causes, with symptoms of dementia and non-pharmacological methods. They are able to perform different simple activities with people with dementia, they are able to apply validation and other non-pharmacological methods, they are able to communicate properly with people with dementia.

In case that more than 30% of people with dementia have needs for P-PA-IA 3 (and if there is somebody in the terminal stage of dementia), it is necessary to apply the P-PA-IA 3 recommendations.

In case that more than 30% percent of people with dementia (in P-PA-IA 3 stage department) are in terminal phase it is necessary to increase numbers of skilled staff (according to the terminal phase recommendation)

P-PA-IA 2 and P-PA-IA 3

Residential care settings for persons with dementia P-PA-IA 2 and P-PA-IA 3
(long-term care stays or temporary stay for respite care)

Environment and equipment
Departments for care for persons with dementia should be relatively small (for max 15 persons). If the institution provides care for higher numbers of these persons it is necessary to create smaller care units for 15 persons maximum. Every unit should have recommended equipment and staff. Staff should be seen by persons with dementia (and they also should have the possibility to see them).

It is also important that the environment is cosy, tidy and home-like as far as possible.

Privacy: Privacy of persons with dementia should be protected as far as possible, therefore it is important that they have their own private space, a single room when possible is recommended especially in long-term care stays. However the common practice and disposition of present institutions does not enable single rooms for all inhabitants. Despite that the privacy of persons with dementia (as well as any others) should be protected especially during hygiene, toileting etc. New departments should be planned and constructed so that they provide enough privacy.

Rooms: As it is mentioned above. Single rooms are preferred. Maximum 3 persons in a room are considered as feasible.

Rooms are equipped with nursing-care beds (at least 2/3) for adequate nursing care provision when necessary, anti-decubital aids are available when necessary (at least 3 for 1 department), every patient has a comfortable chair or armchair and necessary storage space.

The department for care for persons with dementia has a sufficient space (room) for activities and also appropriate equipment for them.

Toilets
Toilets should be either at each room or separate toilets for men and women.

Personal hygiene: we recommend a possibility of a „small hygiene“ in the room (or at the room) where persons with dementia live. Then it is necessary to have properly equipped bathrooms in the department, so that the hygiene procedure could be accessible to and comfortable for persons with limited mobility.

Health care: It is important to assure skilled nursing care, at least by skilled nurse (skilled nursing health care staff- N), who is present during the day (and accessible at nights). Physician is called when necessary, minimum one consultation per week is recommended.

Permanent presence of care staff: Staff must be permanently present in the department, we recommend 2 care staff members (CS) during the day and 1 during the night in the department on the condition that there are other staff members in the institution. In case of smaller institutions with only 1 department it is necessary to assure the presence of at least 2 staff members permanently.

Flexibility of staffing according to care needs: This is an important principle. It is necessary to increase the number of staff in case that there are patients with special needs in the department (with behavioural problems, complex nursing needs, in terminal phases etc.). Extra staff numbers should also be in departments for short-term stays (because of adaptation demands of patients).

Needs for palliative care

Department of palliative care and care for people with complex nursing care needs:

This department differs from the above mentioned one by an increased number (and higher health care qualification) of the staff. Permanent presence of skilled nurse is necessary as well as the permanent availability of a physician. The palliative care is skilled health care focusing on comfort care, support, symptom management and especially pain management.