Intensive Course Workbook

Edited by Anitta Juntunen

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AMMATTIKORKEAKOULU
UNIVERSITY OF APPLIED SCIENCES

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Kajaani University of Applied Sciences

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Kajaani University of Applied Sciences publication series C

Educational Resources 2

The project was funded by:

Lifelong Learning Programme

Kajaani University of Applied Sciences

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Kajaani University of Applied Sciences publication series C 2 / 2014

ISBN 978-952-9853-64-9

ISSN 1458-6168

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1 ORIENTATION

This workbook contains students' learning assignments for the intensive course 'People First – Interventions Supporting Life Quality of People with Dementia' (5 ects). The course was planned and implemented by Kajaani University of Applied Sciences, School of Health and Sports (Finland), the University of Debrecen, Nyiregyháza Medical and Health Science Centre, Carinthia University of Applied Sciences, School of Health and Care (Austria), and Ondukuz Mayis University, School of Health, Nursing Department (Turkey) The course was held at Nyiregyháza, Hungary, 30th March - 12th April, 2014. Each participating higher educational institute sent 10 students and 1-2 teachers for the course; they represented different fields of health and social care: nursing, public health nursing, home care nursing, health care management, social work, sport and leisure management, and disability and diversity studies.

Dementia is a challenge for current and future health and social care service systems in EU countries. It is one of the most significant causes of disability in the elderly, and the prevalence of diseases causing dementia rises with age and doubles every five years after the age of 65. It is estimated that 9.9 million people suffer from dementia in Europa. (Batch & Mittelman 2012, WHO 2012). Although the growing amount of people with dementia is increasingly given attention at global, EU and national levels, related issues are not explicitly discussed in the classroom. Health and social care education providers have a responsibility to ensure that education responds proactively to global and national health issues and prepares students for health challenges within society (Baillie et al, 2012).

The assignments were planned according to the following aims of the course:

1. To enable a cross-cultural and interdisciplinary learning experience for future health and social care professionals and teachers
2. To broaden the limited focus of students and widen their perspective on maintaining the physical and mental capacities of people with dementia and their caregivers
3. To challenge discriminatory practices related to people with dementia
4. To develop a dementia prevention knowledge base, future skills and work with people with dementia and their caregivers in integrated caregiving systems
5. To analyse national memory action programs and health and social care services focusing on dementia in comparison with the EU context and beyond
6. To extend the knowledge and awareness of the participants leading to possible future cooperation across disciplines and between countries

2 CONTENT OF THE COURSE

Dementia is a decline in mental ability that usually progresses slowly, in which memory, thinking, and judgment are impaired, and personality may deteriorate. It is not a disease itself but rather a group of symptoms that may accompany neurodegenerative diseases or conditions. One of the most common causes of dementia in the EU is Alzheimer's disease (about 50-70% of cases). Dementia affects individuals and families. Beside most individuals with dementia stands an informal caregiver, usually a spouse or other relative managing everyday life. It is estimated that in Europe the number of caregivers of people with dementia is approximately 20 million. The caregiver may have given up leisure activities and a normal daily life to look after a relative afflicted with dementia. Although the impact of dementia on caregivers' lives is enormous, it is often not recognized in health and social services. In this IP-course our focus was to exchange knowledge about interventions improving the quality of life of people with dementia and their carers.

The life quality of a person afflicted with dementia relates to her/his health status, physical, mental and social resources, environmental factors and the quality of care. The life quality of people afflicted with dementia is important in reducing disabilities and dependency and delaying the progress of the disease from the mild to severe stage. Autonomy, self-determination and participation are the key concepts of life quality of people with dementia. (Vaarama et al., 2008). Encountering a person afflicted with dementia with dignity and utilizing his/her personal resources in managing everyday life are valuable in maintaining autonomy. On the other hand, life quality can be enhanced through early diagnosis and applying people-centred interventions, such as cognitive stimulation, maintenance of physical condition and safe environments. The period between the onset of dementia and disability may be extended by disease prevention measures, a healthier life style, improving social and economic

conditions and better care. Intervention studies have shown that interventions can reduce disabilities. (Van Mierlo et al., 2010).

3 LEARNING METHODS

The pedagogical approach of the course was based on experiential and socio-constructive learning. Experiential learning means learning through reflection upon what is being done and experienced, and socio-constructive learning means that knowledge is built jointly by international and inter-professional discussion between the participating students and lecturers. This pedagogical approach enabled the students to engage themselves actively in the learning process. The didactical framework was flexible in order to link reflection, dialogue and collaboration. Thus the focus was on methods that would enable students to be active partners in learning.

The students prepared themselves for learning in an international environment by working on two pre-course assignments: memory impairment in the European context and social services for people afflicted with dementia and their informal carers. The assignments of the first week focused primarily on general concepts related to perspectives of dementia and identifying the cognitive, physical and socio-economic resources and capabilities of a person with dementia, while assignments in the second week enabled students to extend their knowledge of specific issues e.g. social and cultural support systems, preventive interventions, therapeutic living environment, maintaining independence. A post course assignment, in which the students were requested to reflect upon their learning experiences, was set on the last day of the course. The students were permitted to write the essay (1500-2000 words) in their mother tongue and it was assessed by their own teachers.

Interactive reflection regarding the knowledge base and perception of the group was conducted using lifelong-learning methods such as: ice-breakers and getting to know each other, collaboration, demonstrations, learning cafes and presentations. Experts delivered key note lectures that were logically sequenced to ensure integration and progression. These lectures provided students with content-related orientation, which was collated with the personal and shared perspectives of the participants. In the workshops, students had the opportunity to gain hands-on experiences (e.g. testing functional capacity, practicing person-centred interventions, instructing physical exercise etc.) and to learn through application-oriented methodologies (such as focus groups, seminar discussions, learning cafes, etc.).

An open learning environment was available for all participants; other students from the partner institutions as well as the public (see https://sites.google.com/site/14peoplefirst/). ICT usage was encouraged during the course for information seeking, screening, testing and dissemination.

4 THEME: MEMORY IMPAIRMENT IN A EUROPEAN CONTEXT

The participants' experience of dementia in their own country

Find information and make notes before the course starts

- demographic data of the population in your country, statistics about the number and age of people suffering from dementia and their caregivers, regional differences
- structure of elderly care service system, services available for the people suffering from dementia (private, public)
- main principles of health and social care policy in your country
- main principles of elderly care policy related to dementia in your country
- main programs and pilot projects related to improving life quality of people with dementia and their carers in your country

The students are divided into five groups, two students from each country. In pairs, the students present the data of their own country. During the presentations, the similarities and differences between countries are observed. Each group draws a poster or prepares a power point presentation about the similarities and differences between countries and presents their conclusions to the other groups. The presentations are followed by discussion, during which similarities and differences between countries are summarized.

5 THEME: SOCIAL SERVICES FOR PEOPLE AFFLICTED WITH DEMENTIA AND THEIR INFORMAL CARERS

Social services for people with dementia and their carers in participating countries

Find information and make notes before the course starts:

- social security services for people with dementia in your country
- voluntary organizations working with people suffering from dementia and their carers in your country
- importance and organization of informal care in your country
- support informal carers receive in your country
- position of young/ work aged people with memory impairment/dementia in your country
- service guidance for people with memory impairment/dementia in your country

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6 THEME: ACTIVATING THE PERSONAL RESOURCES OF PEOPLE WITH DEMENTIA

Students work in groups to make a plan with sustainable solutions in order to meet the following challenge: What can management do for people with dementia to increase their life quality in social and nursing care services of the future? Social and nursing care environments are: out-patient, in-patient/elderly care homes, hospital and community care. One group makes one plan only, for one environment. The plan must include three levels: vision, strategy and implementation (see figure 1). The plans will then be discussed with the whole group.

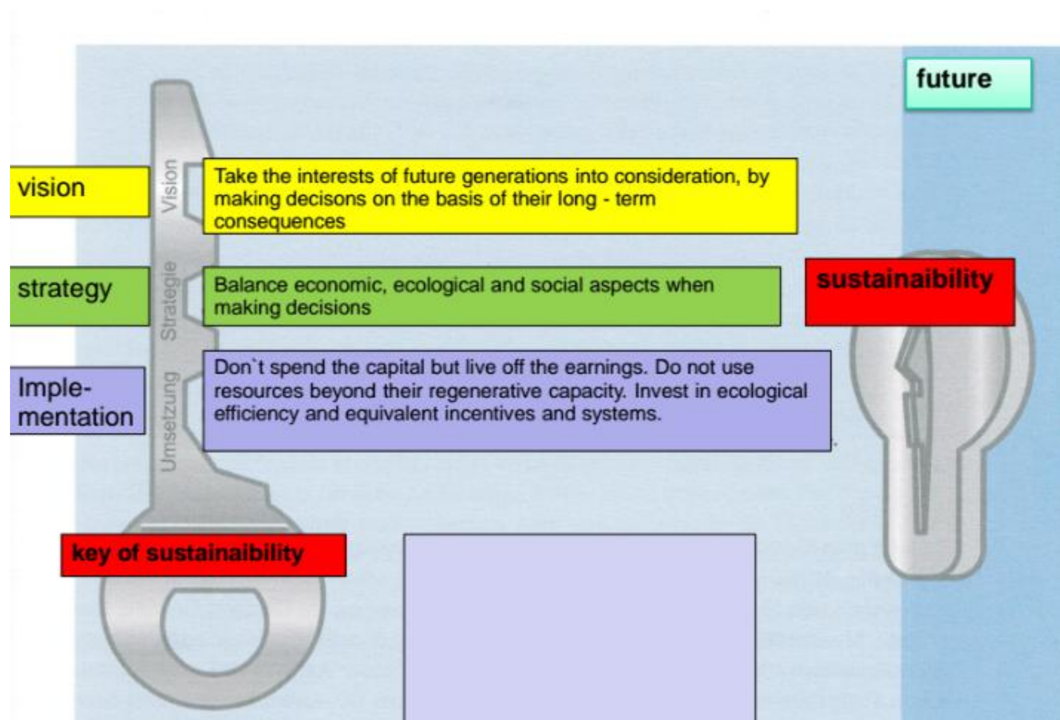


Figure 1. A framework for planning sustainable services to increase the life quality of people with dementia.

7 THEME: LIVING WITH DEMENTIA AT HOME

The participants work in groups, with four people from different countries in each group. Each group defines the problems described in a case and discusses the solutions to the problems from a multi-professional perspective.

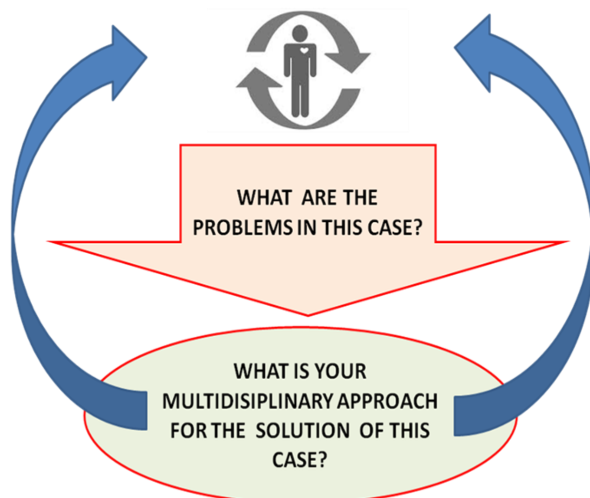


Figure 2. Questions for case-study problem solving

CASE 1

A successful 65 year-old male photographer who lives alone, began to have trouble finding names for people and objects. He continued to take photos for small businesses but had trouble filling in paper orders, making frequent spelling mistakes. He was found unexpectedly very far away from his home and could not remember his address. He was becoming socially withdrawn but was aware of his situation. Soon afterwards he began to comb the beach, spending many hours looking for seashells. While at home, he began to repeat actions such as going up and down the stairs. He developed new habits such as not having a shower for a month. There was no family history of dementia and he was not in receipt of social benefits.

CASE 2

A 70-year-old female retired executive began having difficulty finding words. She lives in her own house. One of her children is a doctor; the other is a police officer and works 24 hour- shifts. She slowly began to lose her ability to express ideas. She became quieter and somewhat socially withdrawn. She also started to have trouble writing. When talking, she took a long time to express her ideas and communicated ungrammatically with nouns. Others told her that she had trouble "spitting out her words." Social graces remained preserved, although she expressed a profound frustration regarding her speech problems, and developed major depression. There was no family history of dementia.

CASE 3

Mrs S is 81 years old and has dementia. She lives with her daughter and grandsons. Her family loves her and she is valued by her family. She has become aware of her failing memory, disorientation and her failure to recognise and understand risks and hazards. These problems caused her to neglect herself and frequently leave her own home, becoming lost, often in the middle of the night. One of the things that made her particularly vulnerable was her tendency to talk to complete strangers, telling them where she lived. She was suspicious of everyone believing that those around her were all in some way to blame for what was happening to her. One night she woke up to go to the toilet but she went out. While going down the stairs she tripped. After this when the family asked her why she had gone out, she said that she had gone to the toilet.

CASE 4

Mr M is married and is 86 years old. Although he lives at home, his family have been unable to manage his level of night time wakefulness and his desire to walk about for sometimes several hours at a time and problems with falling back to sleep. However his disorientation increased. Mr M's wife was highly anxious about how to cope with his wakefulness at night. Mr M's mobility was quite poor. Mr M's memory is very poor and he relies heavily on emotional memories to make sense of the situation, disorientated by time. He often finds it difficult to remember nouns and loses the thread of his thoughts. Due to sleeplessness he wants to eat his meals at unsuitable times. One night he wanted to cook a meal and put the saucepan on the cooker but then forgot about it and went back to sleep. His wife then woke up to the smell of smoke.

CASE 5

Mr C. came to a nursing home when the home he had been living in was sold. Mr C had complex health problems; his dementia seemed to have been seen as part of his overall 'frailty'. Mr C was doubly incontinent and although he could bear his own weight, he was unable to walk more than one step or two at a time, when being transferred by two members of staff. Mr C had lost a considerable amount of weight and was prescribed liquid dietary supplements to increase his calorie intake. Mr C. spoke only a few words and would often sit for long periods humming to himself, or singing the same line of a song over and over again. As staff approached Mr C to offer him help or bring food or drinks he would often appear startled; not appearing to see them until they were right in front of him. Sometimes Mr C would eat and drink independently but more often than not he needed staff to assist him.

8 THEME: ENVIRONMENT SUPPORTING ACTIVE LIVING OF A PERSON SUFFERING FROM DEMENTIA

Assess on the basis of the check list the accessibility and safety of the following public buildings and outdoor environments. Take photos of good / poor examples. Present the results in class (6-7 minutes). In conclusion, the characteristics of outdoor environments supporting the active life of people with dementia will be discussed as a group.

Checklist of characteristics of dementia-friendly neighbourhoods

A familiar environment

- Places and buildings are long established with any change being small-scale and incremental
- The functions of places and buildings are obvious
- Architectural features and street furniture are in designs familiar to or easily understood by
- older people

A legible environment

- There is a hierarchy of street types, such as main streets, side streets, alleyways and passages
- Blocks are small and laid out on an irregular grid based on an adapted perimeter block pattern
- Streets are short and fairly narrow
- Streets are well connected and gently winding with open ended bends to enable visual continuity

- Forked and t-junctions are more common than crossroads
- Latent cues are positioned where visual access ends, especially at decision points, such as
- junctions and turnings
- Entrances to places and buildings are clearly visible and obvious
- Signs are minimal, giving simple, essential information at decision points
- Signs have large graphics with realistic symbols in clear colour contrast to the background,
- preferably dark lettering on a light background
- Directional signs are on single pointers
- Signs locating important places and buildings are perpendicular to the wall
- Signs have non-glare lighting and non-reflective coverings

A distinctive environment

- Urban and building form is varied
- There is a variety of landmarks including historic and civic buildings, distinctive structures and
- places of activity
- There is a variety of welcoming open spaces, including squares, parks and playgrounds
- Architectural features are in a variety of styles, colours and materials

- There is a variety of aesthetic and practical features, such as trees and street furniture

An accessible environment

- Land uses are mixed
- Services and facilities are within 5-10 minutes walking distance of housing
- Footpaths are wide and flat
- Pedestrian crossings and public toilets are at ground level
- Unavoidable level changes have gentle slopes with a maximum gradient of 1 in 20
- Entrances to places and buildings are obvious and easy to use
- Gates/doors have no more than 2 kg of pressure to open and have lever handles

A comfortable environment

- The outdoor environment is welcoming and unintimidating
- Urban areas have small, well-defined open spaces with toilets, seating, shelter and lighting
- There are quiet side roads as alternative routes away from crowds/traffic
- Some footpaths are tree-lined or pedestrianised to offer protection from heavy traffic

- Acoustic barriers, such as planting and fencing, reduce background noise
- Street clutter, such as a plethora of signs, advertising hoardings and bollards is minimal
- Telephone boxes are enclosed
- Bus shelters are enclosed and have seating
- Seating is sturdy with arm and back rests and in materials that do not conduct heat or cold

A safe environment

- Footways are wide, well maintained and clean
- Bicycle lanes are separate from footways
- Pedestrian crossings have audible cues at a pitch and timing suitable for older people
- Paving is plain and non-reflective in clear colour and textural contrast to walls
- Paving is flat, smooth and non-slip
- Trees close to footways have narrow leaves that do not stick to paving when wet
- Spaces and buildings are oriented to avoid creating areas of dark shadow or bright glare
- Street lighting is adequate for people with visual impairments
- Level changes are clearly marked and well lit with handrails and non-slip, non-glare surfaces

(http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/Neighbourhoods_for_Life_Findings_Leaflet.pdf)

Dementia Friendly Physical Environments Checklist

Checklist

There are some quite small changes that can have a major impact on improving accessibility for people with dementia. Some such as clear signs and lighting can be done at minimal cost, others will involve some investment, and should be considered as budgets allow, and when replacing fittings.

Use this check list to have a good look round the public areas in your building. Remember to check corridors for example leading to the toilet – people can go in following the signs – but not remember which door they came in by. A simple way 'out sign' on that internal door will help.

For further information on the impact of design on people with dementia, you can visit the International Dementia Design Network website (http://www.international-dementia-design.org/page/getting-out-and-about) and search for information and resources. Alternatively if you have a specific question on the topic, you can contact Natalie Yates-Bolton at the International Dementia Design Network on n.yates-bolton@salford.ac.uk.

Quiet Space:

- Do you have a quiet space for someone who might be feeling anxious or confused? A few minutes with a supportive person might be all that's needed to continue the transaction.

Signage:

- Are your signs clear, in bold face with good contrast between text and background?
- Is there a contrast between the sign and the surface it is mounted on? This will allow the person to recognise it as a sign
- Are the signs fixed to the doors they refer to? – They should not be on adjacent surfaces if at all possible.
- Are signs at eye level and well-lit?
- Are signs highly stylized or use abstract images or icons as representations? (These should be avoided).
- Are signs placed at key decision points for someone who is trying to navigate your premises for the first time? – People with dementia may need such signs every time they come to your building
- Are signs for toilets and exits clear? – These are particularly important.
- Are glass doors clearly marked?

Lighting:

- Are entrances well-lit and make as much use of natural light as possible?
- Are there pools of bright light or deep shadows (these should be avoided)?
- Are there any highly reflective or slippery floor surfaces? – Reflections can cause confusion.

- Do you have bold patterned carpets? – Plain or mottled surfaces are easier; patterns can cause problems to people with perceptual problems.

- Are changes in floor finish flush rather than stepped – changes in floor surfaces can cause some confusion due to perceptual problems. If there is a step at the same time you also introduce a trip hazard.

Changing rooms and toilets:

- Do you have a changing room (where applicable) where an opposite sex carer or partner can help out if the person needs help with their clothes? If not are staff briefed in how to meet this need sensitively.

- Do you have a unisex toilet or other facility which would allow someone to have assistance without causing them or other user's embarrassment?

- Toilet seats that are of a contrasting colour to the walls and rest of the toilet are easier to see if someone has visual problems.

Seating:

- In larger premises – do you have seating area, especially in areas where people are waiting? This can be a big help.

- Does any seating look like seating? People with dementia will find this easier - so for example a wooden bench would be preferable to an abstract metal Z-shaped bench.

Navigation:

- Research shows that people with dementia use “landmarks” to navigate their way around, both inside and outside. The more attractive and interesting the landmark (which could be a painting, or a plant) the easier it is to use it as a landmark. Have you had a good look round and thought about these landmarks?

Other issues:

- This list is not exhaustive – if possible speak to people living with dementia and ask them how they find your premises. Other unexpected things can cause problems –for example reflections can be confusing.

We would like to acknowledge Innovations in Dementia, a Community Interest Company, whose original check list formed the basis of this checklist and the Bradford Alzheimer’s Society; who further developed this checklist to include all of the points above. The original Innovations in Dementia checklist can be found in the guide 'Developing dementia friendly communities' which was written on behalf of the Local Government Association. The full guide can be found at http://www.local.gov.uk/ageing-well following the links to resources

(http://www.dementiaaction.org.uk/assets/0000/4336/dementia_friendly_environments_checklist.pdf)

9 THEME: PREVENTION OF DEMENTIA

This assignment is to study national memory programmes in groups, with one group assessing one national memory program on the basis of the questions below. After assessing the programmes, the group will present its findings to the other groups. Finally, conclusions from the comparison between differences and similarities of the programmes will be drawn together.

- What are the challenges related to dementia in Norway, Finland, Scotland, England and the USA?
- What are the objectives defined in the plans?
- What is the key strategy of each country?
- How will each country implement the strategy in future?

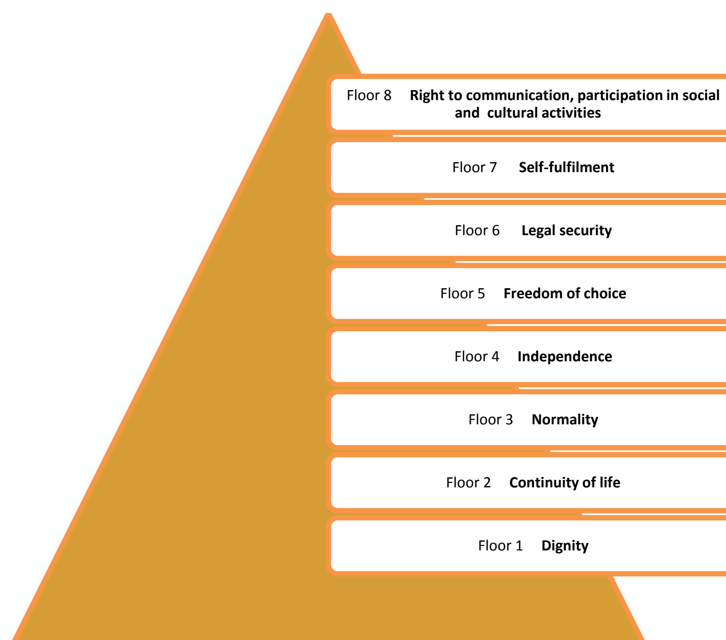
The programmes are found from the link:

http://www.alz.co.uk/alzheimer-plans

10 THEME: DEVELOPMENT OF FUTURE SCENARIOS TO IMPROVE LIFE QUALITY OF PEOPLE WITH DEMENTIA

Dementia-friendly care in the year 2030

A Dementia-friendly society in 2030 is decribed as an 8-floor house; the vision guided care provided for clients on each floor is based on values, as shown below.



Assignment:

- Give a general overview of each floor
- Make a care and service plan for people with dementia on your floor
- Define the vision, strategy and implementation of the care and service plan
- Describe the environment, services, interventions used, funding etc.
- Describe the life quality of the clients on the floor. How do you measure it?

Present your outcomes verbally using creative methods:

- dance
- films/video
- photos
- mime/pantomime
- still pictures
- drama
- story-telling photos
- painting
- written story
- music
- treasure map
- booklet/ brochure

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