

## Course module summary

Course development lead	<b>Dr. Anamarija Kejžar</b>			
Semester/Term	>>to be added later<<			
Course Unit/Module Code:	>>to be added later<<			
Course Unit/Module Name:	<b>Family &amp; Societal Perspectives</b>			
Credit Value:	01			
Core/Optional	Core			
Pre-requisites	None			
Hourly Breakdown	Theory	Practical	Other	Independent learning
	<b>14</b>	<b>02</b>	-	<b>34</b>
<b><i>Intended Learning Outcomes:</i></b>				
At the completion of this course student will be able to;				
<ul style="list-style-type: none"> <li>➤ identify the process of ageing in the family/society</li> <li>➤ describe the coping strategies with family</li> <li>➤ describe the concept of personal planning with shared decision making</li> <li>➤ identify the support systems available for the family in care of NDDs</li> <li>➤ explain the concept of the stimulating environment in NDDs</li> <li>➤ describe palliative care in NDDs</li> </ul>				
<b><i>Course Content:</i></b>				
<ol style="list-style-type: none"> <li>1. Introduction to ageing societies general</li> <li>2. Diagnosis/Coping with the disease</li> <li>3. Living with NDD</li> <li>4. Support systems for the family</li> <li>5. Families and the ageing society</li> <li>6. Stimulating environment</li> <li>7. Palliative care in NDDs</li> </ol>				

### ***Teaching /Learning Methods:***

Better to use the blended approaches (since it is asked in the application as a %). Give the approaches in %.

<b>Lectures</b>	<b>28%</b>
<b>Practical work</b>	<b>04%</b>
<b>Independent learning</b>	<b>68%</b>

***Assessment Strategy:*** >>provisional as is, to be finalized after course content is finalized<<

(Details: quizzes 0%, mid-term 0%, end course unit 0%, end term/year 80%, other 20% (2x 5% homework assignment, 1x 10% practical work assesment); Theory (90%), Practical (10%), Thesis (0%), Viva (0%) , Other (0%) (Homework and practical assesment graded as a project; End-of-course exam 5-10 MCQs per lecture, ??? Nr. Of SEQ)

Marks allocated for the evaluation of continuous assessment shall be within 20-40% and end semester examinations shall be within 60%-80%.

Formative Assessment (if necessary only)	Summative Assessment	
	Continuous assessments <b>20%</b>	End course assessment <b>80%</b>

### ***Mandatory Reading:***

○ **Lecture 1:**

- Sanderson, W. C., & Scherbov, S. (2010). Remeasuring aging. *Science*, 329(5997), 1287-1288. Available from: [https://demographic-challenge.com/files/downloads/9ed31aa1067a5d6a50c644c46812c0fa/dc\\_remeasuring\\_aging\\_sanderson\\_scherbov\\_science\\_2010.pdf](https://demographic-challenge.com/files/downloads/9ed31aa1067a5d6a50c644c46812c0fa/dc_remeasuring_aging_sanderson_scherbov_science_2010.pdf)
- *An Aging World: 2020*. (n.d.). Retrieved 1 September 2022, from <https://mtgis-portal.geo.census.gov/arcgis/apps/MapSeries/index.html?appid=3d832796999042daae7982ff36835e2e>
- *Age Structure - Our World in Data*. (n.d.). Retrieved 1 September 2022, from <https://ourworldindata.org/age-structure#the-global-population-pyramid>
- Harper, S. (2019). Living Longer within Ageing Societies. *Journal of Population Ageing* 2019 12:2, 12(2), 133–136. <https://doi.org/10.1007/S12062-019-09248-4>

○ **Lecture 2:**

- Adamson, K., Bains, J., Pantea, L., Tyrhwitt, J., Tolomiczenko, G., & Mitchell, T. (2012). Understanding the patients' perspective of emotional support to significantly improve overall patient satisfaction. *Healthc Q*, 15(4), 63-9.
- Gille, S., Griese, L., & Schaeffer, D. (2021). Preferences and Experiences of People with Chronic Illness in Using Different Sources of Health Information: Results of a Mixed-Methods Study. *International Journal of Environmental Research and Public Health*, 18(24), 13185.
- Krupat, E., Rosenkranz, S. L., Yeager, C. M., Barnard, K., Putnam, S. M., & Inui, T. S. (2000). The practice orientations of physicians and patients: the effect of doctor-patient congruence on satisfaction. *Patient education and counseling*, 39(1), 49-59.

○ **Lecture 3:**

- Mali, J., & Kejžar, A. (2019). A model of integrated care of residents with dementia – a case of innovation in long-term care with accommodation in Slovenia. *Ljetopis Socijalnog Rada*, 26(3), 447–469. <https://doi.org/10.3935/LJSR.V26I3.282>
- Hay, H. (2009). Lifestyle and Future Wishes. In H. May, P. Edwards, & D. Brooker (Eds.), *Enriched Care Planning for People with Dementia* (pp. 38–55). Jessica Kingsley Publishers.
- Salvatore R., Cianciulli A., Calvello R. and Panaro MA. Family Caregivers of Patients with Neurodegenerative Diseases: Life Challenge. *J Fam Med*. 2015;2(4): 1032.

○ **Lecture 4:**

- Mielniczek, K., Kowalska, A., Jóźwik, K., Lipiec, M., & Dolomisiewicz, D. (2022). Impact of neurological disorders occurring in neurodegenerative diseases on the conversation process and patients' quality of life. *Journal of Education, Health and Sport*, 12(7), 957-967.
- Schindler, J. S., & Kelly, J. H. (2002). Swallowing disorders in the elderly. *The Laryngoscope*, 112(4), 589-602.

○ **Lecture 5:**

- *Helpage Sri Lanka*. (n.d.). Retrieved September 7, 2022, from <https://www.helpagesl.org/>
- *Sabanaya Resource and Information Center - SRIC*. (n.d.). Retrieved September 7, 2022, from <https://sric.lk/page/services-for-elders/16>
- *The Government Information Center*. (n.d.). Retrieved September 7, 2022, from <https://gic.gov.lk/gic/index.php/en/component/info/?id=1336&catid=30&task=in f>

- *Services for the Elders - The Department Of Social Welfare, Probation and Child Care Service Affairs.* (n.d.). Retrieved September 7, 2022, from <http://www.socialproba.cp.gov.lk/en/social-welfare-services/services-for-the-elders.html>
- Rathnayake, S., & Siop, S. (2015). Quality of Life and Its Determinants among Older People Living in the Rural Community in Sri Lanka. *Indian Journal of Gerontology*, 29(2).

○ **Lecture 6:**

- Waller S, Masterson A, Evans SC. The development of environmental assessment tools to support the creation of dementia friendly care environments: Innovative practice. *Dementia*. 2017;16(2):226-232. doi:10.1177/1471301216635829
- Lin SY. 'Dementia-friendly communities' and being dementia friendly in healthcare settings. *Curr Opin Psychiatry*. 2017 Mar;30(2):145-150. doi: 10.1097/YCO.0000000000000304. PMID: 27997454; PMCID: PMC5287032.
- Vinick, D. (2019). Dementia-friendly design: Hogeweyk and beyond. *British Journal of General Practice*, 69(683), 300-300.
- *The LAHAIO definitions for animal assisted interventions and guidelines for wellness of animals involved in AAI.* (2018).
- Camic, P. M., Crutch, S. J., Murphy, C., Firth, N. C., Harding, E., Harrison, C. R., ... & Zeilig, H. (2018). Conceptualising and understanding artistic creativity in the dementias: Interdisciplinary approaches to research and practise. *Frontiers in Psychology*, 9, 1842.
- Kristensen, H. K., & Peoples, H. (2020). Experiences related to quality of life in people with dementia living in institutional settings—A meta-aggregation. *British Journal of Occupational Therapy*, 83(3), 145-161.

○ **Lecture 7:**

- *Palliative care manual for health care professionals in Sri Lanka* (2nd ed.). (2021). Palliative Care and End of Life Care Taskforce, Sri Lanka Medical Association.
- van der Steen JT, Lennaerts H, Hommel D, Augustijn B, Groot M, Hasselaar J, Bloem BR and Koopmans RTCM (2019) Dementia and Parkinson's Disease: Similar and Divergent Challenges in Providing Palliative Care. *Front. Neurol.* 10:54 am. doi: 10.3389/fneur.2019.00054

***Additional:***

○ **Lecture 1:**

- *World Population Maps - Graphs and maps - Ined - Institut national d'études démographiques.* (n.d.). Retrieved 1 September 2022, from [https://www.ined.fr/en/everything\\_about\\_population/graphs-maps/world-maps-interactive/](https://www.ined.fr/en/everything_about_population/graphs-maps/world-maps-interactive/)

- *Population of WORLD 2022 - PopulationPyramid.net.* (n.d.). Retrieved 1 September 2022, from <https://www.populationpyramid.net/world/2022/>
- *World Population Prospects - Population Division - United Nations.* (n.d.). Retrieved 1 September 2022, from <https://population.un.org/wpp/>

○ **Lecture 2:**

- Saranjit, S., & Lennard, L. (2004). *Health literacy: being able to make the most of health.* National Consumer Council.
- Cartwright, J., & Magee, H. (2006). *Information for People Living with Conditions that Affect their Appearance.* Picker Institute Europe.

○ **Lecture 3:**

- Kejžar, A., Rihter, L., Sajovic, J., & Drevenšek, G. (2022). Nutrition and congruent care improve wellbeing of residents with dementia in Slovenian care homes. *Frontiers in Nutrition, 0*, 277. <https://doi.org/10.3389/FNUT.2022.796031>

○ **Lecture 4:**

- Kaakinen J R, Coehlo D P, Steele R, *Family Health Care Nursing: Theory, Practice, and Research* – 2014, Publisher: A Davis Company
- Schulz R, O'Brien A, Czaja S, Ory M, Norris R, Martire L M,, Belle S H, Burgio L, Gitlin L, Coon D, Burns R, Gallagher-Thompson D, Stevens A: *Dementia caregiver intervention research: in search of clinical significance.* Published in final edited form as: *Gerontologist.* 2002 October ; 42(5): 589–602. (NIH Public Access)
- <https://www.alzheimers.org.uk/dementia-professionals/resources-professionals/dementia-knowledge-centre>
- <https://www.forwardwithdementia.org/en/article/communicating-a-dementia-diagnosis/#>
- [https://solidaritessante.gouv.fr/IMG/pdf/french\\_neurodegenerativediseasesplan2014\\_2019-2.pdf](https://solidaritessante.gouv.fr/IMG/pdf/french_neurodegenerativediseasesplan2014_2019-2.pdf)

○ **Lecture 5:**

- Siddhisena, K.A.P., 2005. Socio-economic implications of ageing in Sri Lanka: an overview. Oxford Institute of Ageing Working Papers. Oxford: Oxford Institute of Ageing, 1, p.27.

- Perera, B., 2011. Social support and social security issues of elders in Sri Lanka. *Galle Medical Journal*, 16(2).
- Holmes, W.R. and Joseph, J., 2011. *Social participation and healthy ageing: a neglected, significant protective factor for chronic non communicable conditions*. *Globalization and health*, 7(1), pp.1-8.

○ **Lecture 6:**

- *Hierarchy of Dog Needs | Dog Psychologist On Call*. (n.d.). Retrieved September 7, 2022, from <http://www.dogpsychologistoncall.com/hierarchy-of-dog-needs-tm/>
- Bilal Ahmed, S., Obieta, A., Santos, T., Ahmad, S., & Elliot Ibrahim, J. (2022). Effects of Nonpharmacological Interventions on Disruptive Vocalisation in Nursing Home Patients With Dementia—A Systematic Review. *Frontiers in Rehabilitation Sciences*, 0, 106. <https://doi.org/10.3389/FRESC.2021.718302>
- De Boer, B., Beerens, H. C., Katterbach, M. A., Viduka, M., Willemse, B. M., & Verbeek, H. (2018, November). The physical environment of nursing homes for people with dementia: Traditional nursing homes, small-scale living facilities, and green care farms. In *Healthcare* (Vol. 6, No. 4, p. 137). MDPI.
- Lai NM, Chang SMW, Ng SS, Tan SL, Chaiyakunapruk N, Stanaway F. Animal-assisted therapy for dementia. *Cochrane Database Syst Rev*. 2019 Nov 25;2019(11):CD013243. doi: 10.1002/14651858.CD013243.pub2. PMID: 31763689; PMCID: PMC6953240

○ **Lecture 7:**

- Kristjanson, L. J., Toye, C., & Dawson, S. (2003). New dimensions in palliative care: a palliative approach to neurodegenerative diseases and final illness in older people. *Medical Journal of Australia*, 179, S41-S43.
- Kristjanson, L. J., Aoun, S. M., & Oldham, L. (2006). Palliative care and support for people with neurodegenerative conditions and their carers. *International journal of palliative nursing*, 12(8), 368-377.
- Low, J. A., Pang, W. S., Chan, D. K., & Chye, R. (2003). A palliative care approach to end-stage neurodegenerative conditions. *Annals of the Academy of Medicine, Singapore*, 32(6), 778-784.

Course module code and name – **Family & Societal Perspectives**

**Credits – 1**

**Total time allocation – 50 hours**

Unit no. and name	Unit objectives <i>(The objectives of this lesson are for the students to be able to ;)</i>	Lesson plan in brief	Allocated time	Teaching learning methods	Method of assessment
<p><b>I.</b> The introduction to ageing societies</p>	<ul style="list-style-type: none"> <li>– Define what an ageing society is,</li> <li>– Describe the causes and the process which leads to the aging of a society,</li> <li>– Describe and predict the socioeconomic consequences of societal aging,</li> <li>– Define healthy aging and its importance in an aging society.</li> </ul>	<ol style="list-style-type: none"> <li>1. Ageing society; definition, causes, 5-stage model introduction</li> <li>2. Ageing society; population pyramids of example countries by stage</li> <li>3. Consequences; dependence, socioeconomics of dependence, healthy ageing model introduction</li> <li>4. Brief presentation of the data for Sri Lanka in the year 2022</li> <li>5. Homework assignment to create the population pyramids and dependency graphs for Sri Lanka 2022-2100, explain issues with the trends and propose realistic solutions</li> </ol>	<ul style="list-style-type: none"> <li>– 1h (Lecture)</li> <li>– 2h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>– Lecture</li> <li>– Discussion during the lecture</li> <li>– Homework</li> <li>– Independent learning</li> </ul>	<ul style="list-style-type: none"> <li>– <b>Homework assignment</b> (5% of the final module grade)</li> <li>– <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>
<p><b>II.</b> Coping with the disease</p>	<ul style="list-style-type: none"> <li>– Explain the tenets of good communication with family members</li> <li>– Interpret the reactions of the family towards the diagnosis</li> </ul>	<ol style="list-style-type: none"> <li>1. Breaking bad news – first things to say to family after diagnosis</li> <li>2. Assessing reaction to diagnosis</li> <li>3. What NDD means for patients</li> <li>4. What NDD means for families</li> <li>5. Empathizing with patients with NDD and their families</li> <li>6. Communication with family delivered with positivity</li> </ol>	<ul style="list-style-type: none"> <li>– 2h (Lecture)</li> <li>– 4h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>– Lecture</li> <li>– Facilitated discussion</li> <li>– Independent study</li> </ul>	<ul style="list-style-type: none"> <li>– <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>

	<ul style="list-style-type: none"> <li>- Recognize the importance of 'balanced education' about the disease</li> <li>- Explain strategies of planning an effective living environment for a person with NDD</li> <li>- Outline the partnership in own care model</li> <li>- Discuss the impact of early onset dementia on children</li> </ul>	<ol style="list-style-type: none"> <li>7. Strategies for caregivers: communicating with NDD patients</li> <li>8. Strategies for caregivers: communicating with family</li> <li>9. Helping family members communicate with loved ones</li> <li>10. What are the information needs and how best to deliver this information?</li> <li>11. Balanced education about the disease (not too much too early)</li> <li>12. Planning the living conditions/environment (overview)</li> <li>13. Partnership in own care model (overview)</li> <li>14. Understand the impact of young onset dementia on children</li> </ol>			
<b>III. Living with NDD</b>	<ul style="list-style-type: none"> <li>- Outline the important aspects of educating caregivers on NDDs</li> <li>- Describe different aspects of care and well-being for individuals with NDDs,</li> <li>- Outline the role of the caregiver in the shared decision making process,</li> <li>- Explain the need for institutional help in</li> </ul>	<ol style="list-style-type: none"> <li>1. Step by step education for parent and care-giver</li> <li>2. Personal plan of care with shared decision making</li> <li>3. Dynamic adaptation of plan – living document , new family roles</li> <li>4. Teaching relatives/informal care givers, how to deal with aspects of care</li> <li>5. When to seek institutionalized help</li> <li>6. Caring for the caregivers – respite care, prevention of burn out</li> </ol>	<ul style="list-style-type: none"> <li>- 3h (Lecture)</li> <li>- 1h (Case studies)</li> <li>- 6.5h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture</li> <li>- Facilitated discussion</li> <li>- Independent study</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>



	<p>care for individuals with NDDs</p> <ul style="list-style-type: none"> <li>- Discuss the importance of ‘caring for the caregiver’</li> <li>- Outline strategies to recognize and prevent abuse.</li> </ul>	7. Recognizing and preventing abuse			
<b>IV. Families and the ageing society</b>	<ul style="list-style-type: none"> <li>- Identify the impact of ageing on families</li> <li>- Describe the impact of caring for an elderly with NDD on the caregivers in the family</li> <li>- Discuss the burnout for all types of caregivers</li> </ul>	<ol style="list-style-type: none"> <li>1. Presentation of the impact of ageing on families, including the Sri Lankan context</li> <li>2. Discussion and presentation of effects that caring for an elder with an NDD has on the caregivers in the family, including some NDD specifics</li> <li>3. Impression of the importance of burnout of caregivers of all types on the students</li> </ol>	<ul style="list-style-type: none"> <li>- 1h (Lecture)</li> <li>- 2h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture</li> <li>- Independent study</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>
<b>V. Support systems for the family</b>	<ul style="list-style-type: none"> <li>- Identify the challenges faced by families and roles of the families towards caregiving</li> <li>- Identify the support systems available within the family of care for the individuals with NDs</li> <li>- Describe the different aspects of support rendered by each organization</li> </ul>	<ol style="list-style-type: none"> <li>1. Support systems within families</li> <li>2. Assessing who are the important other support options</li> <li>3. Family caregiving</li> <li>4. Role of the family members</li> <li>5. Care shifting from family to public and private facilities</li> <li>6. Government and non-government support options (NGOs)</li> </ol>	<ul style="list-style-type: none"> <li>- 2h (Lecture)</li> <li>- 1h (Case studies)</li> <li>- 4.5h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture</li> <li>- Facilitated discussion</li> <li>- Independent study</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>

	(government/non-government)				
<b>VI. A stimulating environment</b>	<ul style="list-style-type: none"> <li>- Describe the essential components of a stimulating environment for an individual with ND</li> <li>- 2. identify non-pharmacological approaches on caring for individuals with ND</li> <li>- 3. describe strategies on prevention of social isolation of individuals with NDDs</li> </ul>	<ol style="list-style-type: none"> <li>1. Introducing the concept of a stimulating environment for quality of living for person with a NDD</li> <li>2. Planning a stimulating environment (indoor and outdoor)</li> <li>3. Spatial adjustments - security and active life</li> <li>4. Non-pharmacological approaches (gardening, dancing, music, art, yoga, physical activities...)</li> <li>5. Use of ICT devices</li> <li>6. Preventing social isolation</li> <li>7. Introduction to animal-assisted interventions</li> </ol>	<ul style="list-style-type: none"> <li>- 2h (Lecture)</li> <li>- 1h (Case studies)</li> <li>- 4.5h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture</li> <li>- Facilitated discussion</li> <li>- Independent study</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Homework assignment</b> (5% of the final module grade)</li> <li>- <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>
<b>VII. Palliative care in NDDs</b>	<ul style="list-style-type: none"> <li>- Define the key terms 'palliative care', 'end-of-life care' and 'hospice'</li> <li>- Describe the ethical and legal aspects of end-of-life care/palliative care</li> <li>- Identify the role of the care giver in end-of-life care/palliative care</li> </ul>	<ol style="list-style-type: none"> <li>1. Definition of terms palliative care, end-of-life care and hospice</li> <li>2. What can be done in the late stages of a NDD</li> <li>3. Palliative care in ND (why is it so special for degenerative diseases - non communicative diseases)</li> <li>4. Assisting with daily living</li> </ol>	<ul style="list-style-type: none"> <li>- 1(Lecture)</li> <li>- 1(Case studies)</li> <li>- 2.5h (Independent learning)</li> </ul>	<ul style="list-style-type: none"> <li>- Lecture</li> <li>- Facilitated discussion</li> <li>- Independent study</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Final exam</b> (some questions, together with other lectures 80% of the final module grade)</li> </ul>

	<ul style="list-style-type: none"><li>- Recognize and address the main issue in palliative care from the perspective of medicine, patient and caregivers</li></ul>	<ol style="list-style-type: none"><li>5. Palliative care in home environment, help for relatives</li><li>6. Ethical - living will, Euthanasia (discussions)</li><li>7. Religion/prayers/chanting</li><li>8. Easing lives of patients as well of care givers</li><li>9. Recognizing the pain</li></ol>			
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