

# **Existential health** and person-centered dementia care

How can existential health contribute to person-centered care for people with dementia?

The purpose of the conference is to

- provide an overview of the status regarding dementia and person-centred care
- present updated knowledge about existential, meaning-related and spiritual perspectives on health in general and related to dementia care in particular

The conference is organized in collaboration between the Research Center for Existential Health (FEH) and the Research Center for Age-Related Functional Impairment and Disease (AFS), both at Sykehuset Innlandet, Norway.

The conference targets researchers and practicionaires in the field.

#### Main contributors:

Peter Kevern, Tatjana Schnell, Sverre Bergh, Anne Marie Rokstad, Sidsel Hammer, Panagiotis Pavlos.













**PROGRAM** (Simultaneous translation of contributions in Norwegian into English)

**MONDAY 23 OCTOBER** 

10.00 Opening, Lars Danbolt

10.15-11.00 Hva er demens? Status, oversikt over feltet. (What is dementia? Status and overview) **Sverre Bergh** 

11.15-12.00 Hva er personsentrert omsorg for personer med demnes? (What is person-centered care for persons with dementia?) Anne Marie Mork Rokstad

# 12.00-13.15 Lunch

13.15-14.45 *An existential perspective on health:* meaning in life and suffering. Tatjana Schnell

15.00-15.45 Meaning and identity in dementia care, multi-cultural perspectives. Peter Kevern

15.45-16.15 Coffee break

16.15-17.00 Panel with speakers. Knut Hestad moderator

17.00-17.30 Poster introductions

19.00 Dinner

20.30 Cultural evening: Dylan and Dementia



# **Oddgeir Synnes**

Poems from creative writing with persons with dementia linked with Bob Dylan's music

# **TUESDAY 24 OCTOBER**

09.00-09.45 Existential themes and spirituality of people with late-stage dementia. Peter Kevern

10.00-11.00 Å være skapt av Gud: hva skal vi gjøre med det? Eksistensielle perspektiver på å leve med demens i lys av kristen antropologi og pårørendes erfaringer. (Being created by God: So what? Existential perspectives on living with dementia in the light of Christian anthropology and relatives' experiences).

**Panagiotis Pavlos og Sidsel Hammer** 

11.15-12.00 How comunicate about existential themes with persons with dementia? Three examples

- > Examples from research in specialist health care, severe dementia. Tor-Arne Isene
- Examples from nursing homes. Silje Nylund og **Ingvild H Feiring**
- > CFI (Cultural Formulation Interview, DSM-5) as a clinical tool. Sigrid Helene Kjørven Haug

### 12.00-13.00 Lunch

13.00-13.45 Workshops: Existential health in person centered dementia care. How can we contribute?

14.00-14.45 Outlook from the conference: How can existential health contribute to person-centred care for people with dementia? Irene Røen and Sverre Bergh

14.45-15.00 Closing. Lars Danbolt

### **WORKSHOPS, TUESDAY 13.00:**

- How can existential health be important for care-givers in dementia care? Peter Kevern and Hans Stifoss-Hanssen (in English)
- Hvordan kan eksistensiell helse bidra til personsentrert omsorg i sykehjem? (How can existential health contribute to person-centered care in nursing homes?) Bjørn Lichtwarck and Anne Marie Mork Rokstad (In Norwegian)
- ➤ Har eksistensiell helse betydning for tilretteleggelse av god demensomsorg i multikulturelle sammenhenger? / Does existential health matter for the provision of good dementia care in multicultural contexts? Önver Cetrez and Sigrid Helene K Haug (In Svandinavian languages)
- Eksistensielle samtaler med personer med demens ved hjelp av Kortmetoden basert på Kilder til mening. / Existential conversations with persons with dementia by means of the Card Method. The methood has been used in a nursing home and applies 7 cards based on Schnell's research on meaning in life. Peter la Cour og Bendik Sparre Hovet

#### **POSTER-PRESENTATIONS**

You are invited to submit an abstract for the poster session. The abstracts will be peer-reviewed.

Guidelines for abstracts:

- Please provide the project/study with a clear title.
- State the name and affiliation of (all) the author(s).
- Mark the corresponding author with an asterisk (\*) and include contact information.
- Please order your abstract with the sections: Background, Methods, Results and Conclusion (if you don't have any results yet, you can use the heading "Perspectives" instead of Results/Conclusion).
- You do not need to provide keywords.
- Max 400 words.

Submit your poster proposal (topic and content) for assessment by 15 September to Önver Cetrez, <a href="mailto:onver.cetrez@teol.uu.se">onver.cetrez@teol.uu.se</a>. We will get back to you within a week. Note that you must print your own poster and take it with you to the Honne conference.

#### FEE

Conference fee (includes participation and lunch): NOK 3,600 / student and pensioners NOK 2,000

PArticipation one day: NOK 2,200 / students / pensioners NOK 1,300

Accommodation is not included in the conference fee and is paid to the hotel. Price for half pension per person in single room NOK 1,150 and double room NOK 1,000. This is paid to the hotel upon check-out.

For those not staying at the hotel: Dinner on Monday evening NOK. 445 (paid to the hotel).

### **REGISTRATION**

Electronic registration: Fag- og forskningskonferanse i eksistensiell helse (deltager.no)

Registration deadline: 20 September 2023.

Registration is binding. If you cancel after 20 September, the full amount will be charged.

**Updated information** about the conference and about approvals can be found at www.religionspsykologi.no.

### **APPROVALS**

Approvals for **doctors' specialisation**, further and continuing education:

- Psychiatry: approved with 14 hours for the specialists' continuing education.
- > Geriatrics: approved with 12 hours as an optional course for doctors in specialization and the specialists' continuing education.
- ➤ General medicine: approved with 12 optional course credits for further and continuing education (extension of the right to additional rates).

Approved by the **Norwegian Clergy Association** as part of the specialist training for priests in the health and social sector, counting for 14 hours.

It has also been applied for approval by the Nurses' Association and the Psychologists' association (14 hours).

#### **PLACE**

Honne hotel and conference centre, Biri (Gjøvik). 160 km north of Oslo

Hjem 2022 - Honne Hotell og Konferansesenter

#### **CONFERENCE COMMITTEE:**

Lars Danbolt, Sverre Bergh, Sigrid Helene Kjørven Haug, Bjørn Lichtwarck, Tatjana Schnell, Önver Cetrez, Sidsel Hammer, Hans Stifoss-Hanssen, Liv S. Ødbehr, Knut Hestad, Silje Nylund, Tor-Arne Isene, Ingvild Hjorth Feiring.

#### MORE ABOUT THE THEME OF THE CONFERENCE

*Person-centered care* has for several decades been an important standard for work in the health and care services. Not least, this is a central perspective in the care of people with dementia, where we also see an increasing focus on existential health.

Existential health relates to the *I*-perspective, and focuses on patients as subjects even when we are objects of diagnostics, treatment and care. Central to this is who we are as persons with our cultural affiliations, beliefs and worldviews, ways of orienting ourselves in different life situations, and how we experience meaning in life. Existential health seeks to integrate the whole of what it means to be *me* or *us* with the bodily, mental, social and ecological prerequisites we have in the face of the challenges we meet. To a large extent, the *I*-perspective will be connected with *we*-perspectives, not least when we are in a situation of dependence on others, such as in the case of dementia or other serious illness or disorders.

Meaning in life is a central theme in existential health. Here a distinction is made between meaning of life, which refers to a universal perspective and is mainly reflected upon cognitively, and meaning in life, which concerns experiences of life as meaningful, as well as which sources we draw on for meaning. Meaning in life is an often unconscious appraisal of life as worth living, when I perceive myself as coherent, significant, oriented, and belonging, and seeing hope when facing difficult situations and challenges.

With regard to cognitive impairment, research on meaning in life is interesting, since the emphasis is not primarily on cognitive reasoning, but on experiencing. This means that also bodily and sensory experiences are emphasized.

*In institutionalized care,* the framework for life unfolding can change significantly, and patients in hospitals or residents in nursing homes can lose access to sources of meaning that were important to them earlier in life.

We ask: How can existential health contribute to person-centered care for people with dementia?

#### **ABOUT THE CONTRIBUTORS:**

**Sverre Bergh**, psychiatrist, Ph.D., is research leader at the Research Center for Age-Related Functional Impairment and Disease (AFS) and senior researcher at the National Center for Aging and Health. His research areas within dementia and geriatric psychiatry are particularly linked to depression, anxiety and substance abuse. Ansatte – AFS-SI

Anne Marie Mork Rokstad, Nurse, Ph.D. is a professor at Molde University College, Department of Health and Social Sciences and senior researcher at the National Center for Aging and Health. She has 25 years of clinical experience as a nurse, specialist consultant and leader in geriatric psychiatry and has a doctorate from the University of Oslo on the development of personcentred dementia care in nursing homes. She has also focused on needs and user involvement, the effect of day services designed for people with dementia and on the possibility of preventing dementia through health-promoting lifestyles. Ansatte - Aldring og helse

Tatjana Schnell is professor of Existential Psychology at MF Specialized University, Oslo and professor II at the University of Innsbruck, Austria, where she established the Existential Psychology Lab. She studied Psychology, Theology and Philosophy in Göttingen, London, Heidelberg and Cambridge/UK, earned her doctorate at Trier University and her habilitation at Innsbruck University. Tatjana works on existential issues such as meaning in life, suffering, mortality and religious/spiritual/secular worldviews and their practical significance for individuals, organisations, society and the environment. Numerous international publications, collaborations, functions, and lectures. Latest book: *The Psychology of Meaning in Life* (Routledge, 2021) <u>Tatjana Schnell | MF</u>

**Peter Kevern** is Professor of Values in Health and Social Care and Head of the Graduate School at Staffordshire University. His academic background is as a theologian, but he has written widely on subjects ranging from Primary Care Chaplaincy to Policy in Adult Social Care. Peter's experience of his mother's dementia led him to

his focus of the last 14 years, which has been a consideration of dementia's religious, spiritual and philosophical dimensions. Further details can be found at <a href="https://www.staffs.ac.uk/people/peter-kevern">https://www.staffs.ac.uk/people/peter-kevern</a>

**Oddgeir Synnes** is professor at VID University of Applied Sciences (Diakonhjemmet). Through research and teaching, he is involved in dementia care, elderly care and palliative treatment. He works with narrative approaches and is concerned with practice stories and illness stories. Synnes holds writing courses for various patient groups in creative writing. He is also a skilled interpreter of Bob Dylan's music.

Knut Hestad, neuropsychologist, is a professor at Innlandet University College and a researcher at Innlandet Hospital. For a number of years, he has been professor of neuropsychology at NTNU, and has researched and taught, among other things, dementiarelated topics. He has an extensive research network and is currently concerned with holistic approaches to health and treatment where both biology and psychology can contribute together with social and existential perspectives.

Panagiotis Pavlos is a researcher in philosophy at the University of Oslo and a research partner in the Center for the Study of Platonism, Cambridge University. His research interests include the relationship between Platonism and Christian thought in Late Antiquity philosophy. He is also a musician, playing the violin and singing Byzantine music. Latest book: *Platonism and Christian Thought in Late Antiquity* (Main Ed. Routledge, 2019). Panagiotis is son in law of Sidsel Hammer, and they will lecture trogether.

Sidsel Hammer is relative of persons with dementia in her close family. She is a member of the User Forum of the Research Center for Age-Related Functional Impairment and Disease (AFS), has been a peer person in the National Association for Public Health, sat on the board of the Indre Østfold Dementia Association, as well as of the Hamar and surroundings Dementia Association. By profession, Sidsel is a pharmacy and chemistry technician. She is mother in law of Panagiotis Pavlos, and they will lecture trogether.

**Tor-Arne Isene** is a hospital chaplain in mental health care at Innlandet Hospital (Sanderud). He is currently also a Ph-D.-studemt at the Research Center for Existential Health, doing research on existential and spiritual themes among people with dementia in hospital.

**Silje Nylund** is a psychologist and currently a PhD student at the Research Center for Existential Health (FEH) on a study on meaning in life among residents with dementia in nursing homes.

**Ingvild H. Feiring** is a nurse with a master's degree in mental health and a project employee at the Research

Center for Age-Related Disease and Functional Impairment and Disease (AFS). She is co-researcher in a study on meaning in life among residents with dementia in nursing homes.

Bjørn Lichtwarck, is a specialist in the geriatric psychiatry department and a researcher (postdoctoral fellow) at the Research Center for Age-Related Functional Impairment and Disease (AFS), Sykehuset Innlandet. He has previously worked for many years as a nursing home doctor. In his PhD, he explored neuropsychiatric symptoms in people with dementia in nursing homes, the use of medication and environmental measures with a view to quality of life, the best possible person-centred care and reduction of neuropsychiatric symptoms.

Hans Stifoss-Hanssen is professor emeritus at VID University of Applied Sciences. He researches and publishes on topics related to health, diaconia, spiritual care and ritual use. He has been head of the PHD program in diaconia, values and professional practice at VID, and previously worked at the Practical Theological Seminary, University of Oslo, and at Østmarka Hospital (psychiatry). His book on "Livssyn og helse" (Gyldendal, 1998, together with K. Kallenberg) has become a classic.

Önver Cetrez, professor of Psychology of Religion and Cultural Psychology, is recognised for his work on psychosocial health with regard to migrants and refugees in the context of ethnic and religious identities, resilience, coping, existential health, and acculturation. He has led numerous EU and national grants within the wider fields of immigration and refugee studies, most recently as the coordinator of the Horizon Europe project GAPs on return migration and an earlier project RESPOND (www.respondmigration.com).

Sigrid Helene Kjørven Haug is a researcher at the Research Center for Existential Health and associate professor at Innlandet University College. She is a trained psychiatric nurse and deacon. Her research areas are within clinical psychology of religion and medical anthropology with particular focus on existential themes in different patient populations, and implementation and evaluation of the Cultural Formulation Interview from DSM-5 in clinical contexts.

Irene Røen, nurse, PhD, is the general manager at the Research Center for Age-Related Functional Impairment and Disease (AFS) and manager of the Development Center for Nursing Homes and Home Services in Innlandet (Hedmark). Røen has researched the quality of life in patients with dementia and the degree of person-centred care in nursing homes, and seen this in the context of how staff at nursing homes experience their work situation.

Øystein Wang is the conference's regular pianist. He is currently a parish priest in Søndre Land, and he is an active jazz pianist with a number of releases together

with his band Pastor Wang quintet. In addition to theology and music, he also is educatied in philosophy, and he has researched and published on the Gospel of John as drama and narrative. Latest book: *Begynnelser. Johannesevangeliet som fortelling, dialog og drama* drama.

Lars Danbolt is head of research at the Research Center for Existential Health (FEH) and adj. professor at the MF Norwegian school of theology, religion and society. He researches existential themes related to health challenges, illness and treatment, as well as practical-theological themes such as pastoral care and ritualization after disasters.

# **THE ORGANIZERS**

The Research Center for Existential Health (FEH) (formerly the Center for Psychology of Religion) at Innlandet Hospital Trust was established in 2008 and is a leading research environment for existential themes and psychology of religion related to health and treatment.

The Research Center for Age-Related Disease and Functional Impairment (AFS) was established in 2004 and is a center of gravity within Norwegian geriatric psychiatry research and a driver of development projects within geriatric psychiatry and in the municipalities.

Welcome to the Nordic conference on existential health and person-centered dementia care at Honne Conference Hotel, 23-24 October 2023!

