

Spominčica Alzheimer – Slovenija –
Nacionalno strokovno združenje za pomoč pri demenci

Zbornik povzetkov konference ASK 2026

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KONFERENCA O DEMENCI

**»DEMENCA DANES:
IZZIVI
IN REŠITVE«**

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Uvodni nagovor

Demenca je eden največjih izzivov sodobne družbe, na zdravstvenem, socialnem in finančnem področju. Osebo z demenco je potrebno obravnavati celostno, saj ta kronična napredujoča bolezen zmanjša kognitivne funkcije in povzroči težave s spominom, z motoriko, čustvovanjem ... Spreminja medosebne odnose, osebno dostojanstvo ter socialno vključenost. Bolezen ne prizadene samo osebo z demenco, ampak tudi njeno družino.

Prav zato je 13. mednarodna konferenca ASK 2026 »Demenca danes: izzivi in rešitve« pomembno stičišče različnih strok, izkušenj in pogledov, ki prispevajo k boljšemu razumevanju te bolezni, njenemu prepoznavanju in zmanjševanju stigme. Prvo konferenco je leta 1998 organiziral dr. Aleš Kogoj, specialist psihiatrije, ustanovitelj Združenja Spominčica, ki njegovo pionirsko delo na tem področju nadaljuje. Leta 2015 je tako v Cankarjevem domu soorganizirala jubilejno 25. letno konferenco organizacije Alzheimer Europe, ki se je je udeležilo več kot 600 delegatov iz 45 držav. Tudi konferenca ASK 2026 je nadaljevanje njegovega dela, ki ga Spominčica širi v domačem in mednarodnem prostoru.

Nova spoznanja vse jasneje kažejo, da je potrebno osebe z demenco obravnavati celostno, z upoštevanjem vseh vidikov njihovega zdravljenja, življenja in vključenosti v družbo. Program konference odpira širok nabor tem, ki skupaj tvorijo mozaik sodobne obravnave demence.

Strokovnjaki bodo osvetlili najnovejša dognanja o zgodnji diagnostiki in biomarkerjih, ki omogočajo prepoznavanje demence v fazah, ko so možnosti ukrepanja največje. Poseben poudarek bo namenjen tudi razpoloženskim in vedenjskim spremembam, ki spremljajo kognitivni upad, ter njihovem pomenu za zgodnje prepoznavanje demence in načrtovanje obravnave.

Pomemben del razprav bo posvečen kakovosti življenja oseb z demenco. Bolečina, intimnost, gibanje, stik z naravo in ustvarjalne dejavnosti niso

obrobne teme, temveč bistveni elementi celostne oskrbe. Prav tako bodo predstavljeni inovativni nefarmakološki pristopi, kot so glasbena terapija, terapevtsko pletenje in prilagojene aktivnosti v naravi, ki so dokaz, kako lahko s preprostimi in vsakdanjimi dejavnostmi vplivamo na dobrobit in ohranjanje sposobnosti oseb z demenco.

Konferenca odpira tudi vprašanja sistemske ureditve oskrbe, etike in družbene odgovornosti. Predstavljeni bodo modeli skupnostne oskrbe, izzivi dolgotrajne oskrbe, vloga paliativne podpore ter pomen vključevanja lokalnih skupnosti v ustvarjanje demenci prijaznega okolja. Posebno vrednost predstavljajo mednarodne izkušnje, ki kažejo, kako različni sistemi iščejo poti do bolj vključujoče in dostopne oskrbe.

Spominčica s svojim delovanjem že vrsto let dokazuje, da demenca ni le medicinsko vprašanje, temveč izziv celotne skupnosti. Njena prizadevanja so tesno povezana z uspešno implementacijo 2. nacionalne Strategije obvladovanja demence v Sloveniji do leta 2030, ki jo je Vlada RS sprejela leta 2023, pri kateri je Spominčica aktivno sodelovala. S povezovanjem strokovnjakov, svojcev, prostovoljcev, lokalnih skupnosti in odločevalcev ustvarja trdno mrežo podpore, ki omogoča, da osebe z demenco ostajajo čim dlje vključene v družbo, razumljene in spoštovane. K temu od leta 2017 Spominčica prispeva tudi s širjenjem mreže Demenci prijaznih točk v lokalnem okolju, ki pripomorejo k destigmatizaciji demence ter zagotavljajo varno in razumevajoče okolje.

Zbornik je stičišče dognanj domačih in tujih strokovnjakov ter odseva izkušnje in različne poglede. Konferenca naj bo vzpodbuda za ukrepanje in iskanje rešitev na področju demence. Odpira nujna vprašanja in išče rešitve na socialno zdravstvenem področju ob sodelovanju in podpori države. Naše poslanstvo pri tem ostaja zgraditi prihodnost, ki bo osebam z demenco in njihovim bližnjim svojcem omogočila boljšo diagnostiko, zdravljenje in podporo v domačem okolju.



GIB IN MISEL: DEMENCA IN PARKINSONOVA BOLEZEN

Prof. dr. Zvezdan Pirtošek, dr. med., spec. neurolog

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Medicinska fakulteta za nevrologijo, Slovenija

Parkinsonovo bolezen tradicionalno razumemo kot motorično bolezen, zaznamovano s tremorjem, upočasnjenostjo in togostjo. Vendar sodobna klinična izkušnja in nevroznanost jasno kažeta, da Parkinsonova bolezen že od zgodnjih faz naprej presega zgolj motorični okvir. V njenem jedru je preplet motenj gibanja in širokega spektra kognitivnih ter vedenjskih sprememb — od subtilnih diseksekutivnih težav in motenj pozornosti do Parkinsonove demence, demence z Lewyjevim telesci ter pogostih kombinacij z Alzheimerjevo patologijo.

Takšen pogled spreminja razumevanje bolezni: gib in misel nista ločeni domeni, temveč dva neločljivo povezana izraza delovanja možganskih omrežij, nekakšen jin in jang notranjega življenja. Zato tudi zdravljenje Parkinsonove bolezni ne more biti usmerjeno zgolj v lajšanje motoričnih simptomov. Potrebna je celostna obravnava, ki vključuje prepoznavanje in zdravljenje

je kognitivnih motenj, nevropsihiatričnih simptomov (apatija, depresija, halucinacije), motenj spanja ter avtonomnih disfunkcij.

V tem kontekstu predavanje odpira tudi obratno perspektivo: pri Alzheimerjevi bolezni, ki jo običajno razumemo kot kognitivno motnjo, se v poznejših fazah vse pogosteje pojavljajo tudi motnje gibanja, kot so apraksija, upočasnjenost, togost in motnje hoje. Meja med »motoričnimi« in »kognitivnimi« boleznimi se tako postopoma zabrisuje.

Ključno sporočilo predavanja je, da bolnika ne smemo obravnavati skozi posamezne simptome, temveč kot celoto. Uspešna obravnava zahteva sodelovanje nevrologa, psihiatra, nevropsihologa, fizioterapevta, delovnega terapevta, medicinskih sester ter svojcev. Le takšen celostni pristop lahko ohranja funkcionalnost, dostojanstvo in kakovost življenja bolnika v vseh fazah bolezni.

Prof. dr. Zvezdan Pirtošek je specialist nevrologije in predstojnik Katedre za nevrologijo Medicinske fakultete Univerze v Ljubljani. Njegovo strokovno in raziskovalno delo je usmerjeno v področje neurodegenerativnih bolezni, zlasti demenc in Parkinsonove bolezni. Je redni profesor nevrologije in aktiven raziskovalec na področju klinične nevroznanosti.

Sodeluje v številnih mednarodnih raziskovalnih projektih in je avtor številnih znanstvenih publikacij. Aktiven je tudi v strokovni in javni razpravi o staranju, kognitivnem zdravju in dostojanstvu starejših. Leta 2026 je nastopil mandat neodvisnega izvedenca Združenih narodov za uveljavljanje vseh človekovih pravic starejših.

V svojem delu povezuje klinično nevrologijo, nevroznanost in — kot predsednik Slovenske matice — tudi humanistični pogled na človeka.

MOVEMENT AND MIND: DEMENTIA AND PARKINSON'S DISEASE

Prof. dr. Zvezdan Pirtošek, MD, Specialist in Neurology

University Medical Centre Ljubljana, Neurology Clinic and Chair of Neurology,
Faculty of Medicine, Slovenia

Parkinson's disease has traditionally been understood as a motor disorder, characterized by tremor, slowness, and rigidity. However, modern clinical experience and neuroscience clearly show that Parkinson's disease, even from its earliest stages, extends beyond a purely motor framework. At its core lies an interplay between movement disorders and a broad spectrum of cognitive and behavioral changes — from subtle dysexecutive difficulties and attention deficits to Parkinson's disease dementia, dementia with Lewy bodies, and frequent overlaps with Alzheimer's pathology.

This perspective reshapes our understanding of the disease: movement and thought are not separate domains, but rather two inseparably connected expressions of brain network function — something like the yin and yang of inner life. Consequently, the treatment of Parkinson's disease cannot focus solely on alleviating motor symptoms. A comprehensive

approach is required, including the recognition and treatment of cognitive impairment, neuropsychiatric symptoms (apathy, depression, hallucinations), sleep disturbances, and autonomic dysfunction.

In this context, the lecture also introduces a reverse perspective: in Alzheimer's disease, which is usually understood as a cognitive disorder, movement disturbances increasingly emerge in later stages, such as apraxia, slowness, rigidity, and gait impairment. The boundary between »motor« and »cognitive« diseases thus gradually becomes blurred.

The key message of the lecture is that patients should not be treated through isolated symptoms, but as whole persons. Effective care requires collaboration among neurologists, psychiatrists, neuropsychologists, physiotherapists, occupational therapists, nurses, and family members. Only such a comprehensive approach can preserve functionality, dignity, and quality of life at all stages of the disease.

Prof. dr. Zvezdan Pirtošek is a specialist in neurology and Head of the Chair of Neurology at the Faculty of Medicine, University of Ljubljana. His professional and research work focuses on neurodegenerative diseases, particularly dementias and Parkinson's disease. He is a full professor of neurology and an active researcher in clinical neuroscience. He participates in numerous international research projects and is the author of many scientific publications. He is also active in professional and public discussions on aging, cognitive health, and the dignity of older adults. In 2026, he began his mandate as an independent United Nations expert on the promotion of all human rights of older persons.

In his work, he integrates clinical neurology, neuroscience, and — also as President of Slovenska matica — a humanistic perspective on the individual.



UPANJE NA OBZORJU: ZGODNJA DIAGNOZA IN SODOBNO ZDRAVLJENJE DEMENCE

Izr. prof. dr. Milica Gregorič Kramberger, dr. med., spec. nevrologije

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Zaradi staranja prebivalstva se število oseb z demenco povečuje, kar še dodatno poudarja pomen pravočasnega prepoznavanja prvih znakov bolezni.

Poseben poudarek predavanja bo namenjen izboljšanju ozaveščenosti o zgodnjih fazah Alzheimerjeve bolezni, ki so pogosto spregledane ali napačno pripisane normalnemu staranju. Blage motnje spomina, težave pri orientaciji ali spremembe v razpoloženju so lahko prvi opozorilni znaki, ki zahtevajo pozornost. Prav zgodnje prepoznavanje teh simptomov in hitra napotitev k zdravniku sta ključna za postavitev diagnoze v začetni fazi, ko so možnosti za učinkovito ukrepanje največje.

Udeleženci bodo spoznali sodobne diagnostične pristope, vključno z naprednimi slikovnimi metodami, biomarkerji ter nevropsihološkimi testi, ki omogočajo od-

krivanje bolezni že v zelo zgodnjih fazah. Predavanje bo osvetlilo tudi pomen razlikovanja med različnimi oblikami demence ter razumevanje dejavnikov tveganja, kot so genetika, življenjski slog in pridružene bolezni. Predstavljeni bodo ključni premiki na področju prepoznavanja in obravnave demence in najnovejše terapijske možnosti – tako farmakološke kot nefarmakološke, vključno s kognitivnim treningom, telesno aktivnostjo in prilagoditvami življenjskega okolja. Poudarjena bo tudi vloga svojcev ter multidisciplinarnega pristopa pri obravnavi bolnikov.

Zaključek bo usmerjen v prihodnost: razvoj novih terapij, pomen ozaveščanja ter zmanjševanje stigme. Ključno sporočilo predavanja je, da pravočasno ukrepanje prinaša več možnosti – in več upanja.

Izr. prof. dr. Milica Gregorič Kramberger, dr. med., je specialistka nevrologije z bogatimi kliničnimi in raziskovalnimi izkušnjami na področju kognitivnih motenj in neurodegenerativnih bolezni. Zaposlena je na Nevrološki kliniki Univerzitetnega kliničnega centra Ljubljana, kjer vodi Center za kognitivne motnje. V svojem delu se posveča diagnostiki, zdravljenju in celostni obravnavi bolnikov z demenco ter drugimi kognitivnimi motnjami.

Je izredna profesorica nevrologije na Medicinski fakulteti Univerze v Ljubljani, kjer sodeluje pri pedagoškem procesu in izobraževanju študentov medicine ter specializantov. Aktivno sodeluje v domačih in mednarodnih raziskovalnih projektih ter je avtorica številnih znanstvenih in strokovnih publikacij. Je članica strokovnega odbora Spominčice-Alzheimer Slovenija. Odlikujejo jo strokovnost, predanost bolnikom ter sposobnost povezovanja kliničnega dela z raziskovanjem in izobraževanjem.

HOPE ON THE HORIZON EARLY DIAGNOSIS AND MODERN TREATMENT OF DEMENTIA

Milica Gregorič Kramberger, MD, PhD, Specialist in neurology

Center for Cognitive Disorders, Neurology Clinic, University Medical Centre Ljubljana, Slovenia

Due to population ageing, the number of people affected by dementia is increasing, further highlighting the importance of early recognition of the first signs of the disease.

A special focus of the lecture will be on improving awareness of the early stages of Alzheimer's disease, which are often overlooked or mistakenly attributed to normal ageing. Mild memory problems, difficulties with orientation, or changes in mood can be early warning signs that require attention. Early recognition of these symptoms and prompt referral to a physician are crucial for establishing a diagnosis at an early stage, when the possibilities for effective intervention are greatest.

Participants will become familiar with modern diagnostic approaches, including advanced imaging techniques, biomarkers, and neuropsychological tests, which enable detection of the disease at very early stages. The lecture

will also highlight the importance of distinguishing between the various types of dementia and understanding risk factors such as genetics, lifestyle, and comorbid conditions.

The presentation will shed light on key advances in the recognition and management of dementia and will introduce the latest therapeutic options—both pharmacological and non-pharmacological—including cognitive training, physical activity, and adaptations of the living environment. The role of family members and the importance of a multidisciplinary approach in patient care will also be emphasized.

The conclusion will focus to the future: the development of new therapies, the importance of awareness, and the reduction of stigma. The key message of the lecture is that timely action brings more opportunities—and more hope.

Milica Gregorič Kramberger, MD, PhD, is a specialist in neurology with extensive clinical and research experience in the field of cognitive disorders and neurodegenerative diseases. She is employed at the Neurology Clinic of the University Medical Centre Ljubljana, where she heads the Centre for Cognitive Disorders. Her work focuses on the diagnosis, treatment, and comprehensive care of patients with dementia and other cognitive impairments.

She is an Associate Professor of Neurology at the Faculty of Medicine, University of Ljubljana, where she is involved in teaching medical students and medical residents. She actively participates in national and international research projects and is the author of numerous scientific and professional publications. She is also a member of the expert board of Spominčica – Alzheimer Slovenia. She is distinguished by her professionalism, dedication to patients, and her ability to integrate clinical work with research and education.



DEMENCA IN RAZPOLOŽENJE

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Depresija v poznejšem življenjskem obdobju je tesno povezana s kognitivnim upadom in demenco. Številne epidemiološke in klinične študije kažejo, da prispeva k povečanemu tveganju za razvoj blage kognitivne motnje in različnih oblik demence. Razpoloženske spremembe v starosti vse pogostejše razumemo kot del širšega nevropsihiatričnega spektra, ki zajema tako klasično depresijo v poznejšem življenjskem obdobju do blage vedenjske motnje in kasneje vedenjske in psihološke simptome demence.

Koncept blage vedenjske motnje opisuje trajne, na novo nastale vedenjske in psihične spremembe v starosti pri osebah brez demence, ki vključujejo predvsem afektivno disforijo, apatijo, impulzivnost, motnje nadzora impulzov ter spremembe socialne kognicije. Podatki iz longitudinalnih raziskav kažejo, da so posamezne domene blage vedenjske motnje, zlasti afektiv-

na in motivacijska, povezane z višjim tveganjem za kasnejši razvoj kognitivnega upada in demence ter s specifičnimi vzorci možganskih sprememb. S tem ta koncept dopolnjuje tradicionalni pogled na depresijo v poznejšem življenjskem obdobju kot dejavnik tveganja, prodromalno fazo ali komorbidni sindrom v okviru nevrodegenerativnih bolezni.

V prispevku bo predstavljen kontinuum razpoloženskih in vedenjskih sprememb v starosti, od blagih sprememb do izražene demence, s poudarkom na diagnostičnih kriterijih, tipičnih kliničnih profilih in prognostičnem pomenu ter obravnavi, ki vključuje nefarmakološke in farmakološke pristope. Poseben poudarek bo namenjen razlikovanju med depresijo, blago vedenjsko motnjo in zgodnjo demenco ter posledicam za načrtovanje obravnave bolnikov in podporo svojcem.

Doc. dr. Polona Rus Prelog, dr. med., je specialistka psihiatrije, zaposlena v Centru za klinično psihiatrijo Univerzitetne psihiatrične klinike Ljubljana, kjer dela na intenzivnem geriatričnem oddelku, od leta 2018 tudi vodi Enoto za gerontopsihiatrijo. Njeno klinično delo je usmerjeno predvsem v diagnostiko in zdravljenje demence ter duševnih motenj v starosti, tudi pri kompleksnih in vedenjsko zahtevnih bolnikih. Po doktoratu s področja peripartalnih duševnih motenj je raziskovalno dejavnost razširila na področje demence, nevropsihiatričnih simptomov in samomora v vseh starostnih obdobjih. Je docentka za področje psihiatrije na Medicinski fakulteti Univerze v Ljubljani, kjer sodeluje v dodiplomskem in podiplomskem izobraževanju ter pri usposabljanju specializantov psihiatrije, nevrologije in družinske medicine. Je avtorica številnih znanstvenih in strokovnih člankov in publikacij, sodeluje v kliničnih, multidisciplinarnih in multicentričnih raziskavah, redno predava na domačih in mednarodnih srečanjih ter se posveča tudi izobraževanju strokovne in laične javnosti o demenci. Je članica Strokovnega sveta Spominčice – Alzheimer Slovenija in delovne skupine pri Ministrstvu za zdravje za pripravo Nacionalne strategije obvladovanja demence do leta 2030.

DEMENTIA AND MOOD

Assoc. prof. Polona Rus Prelog, MD, PhD, Specialist in Psychiatry

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Depression in later life is closely associated with cognitive decline and dementia. Numerous epidemiological and clinical studies show that it contributes to an increased risk of developing mild cognitive impairment and various forms of dementia. Mood changes in older age are increasingly understood as part of a broader neuropsychiatric spectrum, ranging from classical late-life depression to mild behavioural impairment and later behavioural and psychological symptoms of dementia.

The concept of mild behavioural impairment describes persistent, newly emerging behavioural and psychological changes in older adults without dementia, including mainly affective dysphoria, apathy, impulsivity, impaired impulse control, and changes in social cognition. Data from longitudinal studies show that certain domains of mild behavioural impairment—particularly

affective and motivational—are associated with a higher risk of subsequent cognitive decline and dementia, as well as with specific patterns of brain changes. This concept thus complements the traditional view of late-life depression as a risk factor, a prodromal phase, or a comorbid syndrome within neurodegenerative diseases.

The presentation will outline the continuum of mood and behavioural changes in older age, from mild changes to manifest dementia, with an emphasis on diagnostic criteria, typical clinical profiles, prognostic significance, and treatment approaches, including both non-pharmacological and pharmacological strategies. Special attention will be given to distinguishing between depression, mild behavioural impairment, and early dementia, as well as the implications for treatment planning and support for family members.

Assoc. Prof. Polona Rus Prelog, MD, PhD, is a specialist in psychiatry, employed at the Centre for Clinical Psychiatry of the University Psychiatric Clinic Ljubljana, where she works in the intensive geriatric ward and has headed the Geriatric Psychiatry Unit since 2018. Her clinical work is primarily focused on the diagnosis and treatment of dementia and mental disorders in older age, including complex and behaviourally demanding patients. After completing her PhD in peripartum mental disorders, she expanded her research to dementia, neuropsychiatric symptoms, and suicide across all age groups. She is an Associate Professor of Psychiatry at the Faculty of Medicine, University of Ljubljana, where she is involved in undergraduate and postgraduate teaching and in the training of residents in psychiatry, neurology, and family medicine. She is the author of numerous scientific and professional publications, participates in clinical, multidisciplinary, and multicentre research studies, regularly lectures at national and international meetings, and is also engaged in educating both professional and general audiences about dementia. She is a member of the Expert Council of Spominčica – Alzheimer Slovenia and a member of the working group at the Ministry of Health for the preparation of the National Dementia Strategy until 2030.



BOLEČINA PRI BOLNIKIHZ DEMENCO

Prim.izr. prof. dr. Martin Rakuša, dr. med., spec. neurologije
Klinika za nevrologijo, Univerzitetni klinični center Maribor, Slovenija

Bolečina je neprijeten občutek, ki je najpogosteje posledica okvare ali poškodbe tkiva. Pojavi se ob škodljivem dražljaju in praviloma preneha, ko se ponovno vzpostavi ravnovesje v organizmu. Ljudje iste bolečinske dražljaje doživljamo različno, zato enak dražljaj ne povzroči enake intenzivnosti bolečine pri različnih posameznikih. Na zaznavanje bolečine pomembno vplivajo tudi sociološki in psihološki dejavniki.

Bolečine ne moremo povsem objektivno oceniti. Pri kliničnem pregledu si pomagamo z anamnezo, vprašalniki in v redkih primerih z nevrofiziološkimi metodami. Najenostavnejši način ocenjevanja bolečine je vizualno-analogni lestvica z razponom od 0 do 10; vrednosti od 7 do 10 pomenijo zelo hudo bolečino.

Posebej zahtevno je prepoznati in oceniti bolečino pri bolnikih s kognitivnim upadom in demenco. Raziskave kažejo, da je bolečina pri številnih bolnikih s kognitivnim upadom neprepoznana in nezdravljena. Večina lestvic in vprašalnikov temelji na bolnikovem doživljanju in zmožnosti komunikacije. Ker je ta pri osebah z demenco pogosto močno okrnjena, s klasičnimi vprašalniki praviloma nismo dovolj uspešni.

Bolniki lahko bolečino izražajo na različne načine. Pogosto se pojavijo vedenjski simptomi: postanejo glasni, nemirni, agresivni ali odklonilni. Bolečina se lahko kaže tudi s pospešenim srčnim utripom, povišanim krvnim tlakom in hitrejšim dihanjem. Ti znaki in simptomi se lahko pojavijo tudi pri sistemskih boleznih ali ob poslabšanju kognitivnega stanja, zato se lahko zgodi, da bolnik namesto ustrezne protibolečinske terapije prejme druga zdravila ali je izpostavljen nepotrebnim diagnostičnim preiskavam.

Za boljšo oskrbo so na voljo posebni, specializirani vprašalniki, od katerih so nekateri validirani tudi v slovenskem jeziku. Eden izmed njih je vprašalnik DOLOPLUS. Ti vprašalniki so zelo občutljivi, vendar od ocenjevalca zahtevajo določeno znanje in izkušnje, predvsem sposobnost natančnega opazovanja in prepoznavanja znakov bolečine.

Oskrba bolnikov z demenco prinaša številne izzive, med njimi prepoznavanje in zdravljenje bolečine. Pri tem bomo uspešni, če na bolečino pravočasno pomislimo, bolnika natančno opazujemo in uporabljamo prilagojena ocenjevalna orodja. Tako bomo lahko preprečili nepotrebno trpljenje in izboljšali njihovo kvaliteto življenja.

Prim.izr. prof. dr. Martin Rakuša, dr. med., spec. neurolog, je zaposlen na Kliniki za nevrologijo Univerzitetnega kliničnega centra Maribor. Medicinsko fakulteto je zaključil v Ljubljani, magistriral v Trstu ter doktoriral na Univerzi v Ljubljani. Med specializacijo neurologije se je dodatno strokovno izpopolnjeval v Zagrebu in Londonu. Njegovo raziskovalno delo je usmerjeno predvsem v Alzheimerjevo bolezen in druge kognitivne motnje. Skupaj s sodelavci je med drugim razvil Test risanja ure, ki se redno uporablja v klinični praksi v Sloveniji, na Slovaškem in v drugih državah.

Je vodja več mednarodnih raziskovalnih projektov ter mentor in somentor diplomskih, magistrskih in doktorskih del na Medicinski fakulteti, Fakulteti za zdravstvene vede in Filozofski fakulteti Univerze v Mariboru ter na Univerzi Alma Mater Europaea v Mariboru. Njegova bibliografija je dostopna v sistemu COBISS.

Na Kliniki za nevrologijo UKC Maribor obravnava bolnike s kognitivnimi motnjami in drugimi neurodegenerativnimi boleznimi. Trenutno se skupaj s sodelavci trudi vzpostaviti dnevno bolnišnico za zdravljenje bolnikov z Alzheimerjevo boleznijo z najsodobnejšimi biološkimi zdravili.

PAIN IN PATIENTS WITH DEMENTIA

Assoc. prof. Martin Rakuša, MD, PhD, Specialist in neurology
Department of Neurology, University Medical Centre Maribor, Slovenia

Pain is an unpleasant sensory and emotional experience, most often resulting from tissue damage or injury. It occurs in response to a harmful stimulus and typically subsides once homeostasis in the body is restored. People experience the same painful stimuli differently; therefore, an identical stimulus does not produce the same intensity of pain in different individuals. Sociological and psychological factors also significantly influence pain perception.

Pain cannot be assessed entirely objectively. In clinical practice, we rely on medical history, questionnaires, and, in rare cases, neurophysiological methods. The simplest way to assess pain is the visual analogue scale ranging from 0 to 10; values from 7 to 10 indicate very severe pain.

Recognising and assessing pain in patients with cognitive decline and dementia is particularly challenging. Research shows that pain in many patients with cognitive impairment remains unrecognised and untreated. Most scales and questionnaires are based on the patient's subjective experience and ability to communicate. Since this is often significantly impaired in people with dementia, conventional questionnaires are generally not sufficiently effective.

Patients may express pain in various ways. Behavioural symptoms are common: they may become vocal, restless, aggressive, or resistant to care. Pain may also manifest as increased heart rate, elevated blood pressure, and accelerated breathing. These signs and symptoms can also occur in systemic diseases or in the context of worsening cognitive status, which may lead to patients receiving inappropriate medications or being subjected to unnecessary diagnostic procedures instead of adequate pain management.

For improved care, specific specialised questionnaires are available, some of which have also been validated in the Slovene language. One of these is the DOLOPLUS scale. These instruments are highly sensitive but require a certain level of knowledge and experience from the assessor, particularly the ability to carefully observe and recognise signs of pain.

Caring for patients with dementia presents numerous challenges, among them the recognition and treatment of pain. We will be successful in this task if we consider pain in a timely manner, carefully observe the patient, and use adapted assessment tools. In this way, we can prevent unnecessary suffering and improve their quality of life.

Assoc. prof. Martin Rakuša, MD, PhD, Specialist in Neurology, is employed at the Department of Neurology, University Medical Centre Maribor. He graduated from the Faculty of Medicine in Ljubljana, obtained his master's degree in Trieste, and completed his PhD at the University of Ljubljana. During his neurology specialization, he further trained in Zagreb and London. His research work is primarily focused on Alzheimer's disease and other cognitive disorders. Together with colleagues, he co-developed the Clock Drawing Test, which is routinely used in clinical practice in Slovenia, Slovakia, and other countries. He is the principal investigator of several international research projects and serves as supervisor and co-supervisor of undergraduate, master's, and doctoral theses at the Faculty of Medicine, the Faculty of Health Sciences, and the Faculty of Arts of the University of Maribor, as well as at the Alma Mater Europaea University in Maribor. His bibliography is available in the COBISS system.

At the Department of Neurology, University Medical Centre Maribor, he treats patients with cognitive disorders and other neurodegenerative diseases. Together with colleagues, he is currently working to establish a day hospital for the treatment of patients with Alzheimer's disease using the most advanced biological therapies.



SPOMINČICA GRADI DEMENCI VKLJUČUJOČE SKUPNOSTI V SLOVENIJI

Štefanija L. Zlobec, univ. dipl. ekon., predsednica Združenja Spominčica
Spominčica – Alzheimer Slovenija – Nacionalno strokovno združenje za pomoč pri demenci, Slovenija

Združenje Spominčica izvaja celovit nacionalni program, ki ga sofinancira Ministrstvo za zdravje Republike Slovenije, ter krepi podporo osebam z demenco, njihovim svojcem in oskrbovalcem v lokalnih okoljih. To usklajeno delovanje odgovarja na izzive starajoče se družbe ter podpira izvajanje Strategije za obvladovanje demence v Sloveniji. Spodbuja dostopnosti in vključenosti, ozaveščanjem, zmanjševanjem stigme, širi informacije do zanesljivih informacij. S tem prispeva, da osebe z demenco ostanejo čim dlje doma in vključeni v družbo.

V okviru te pobude Spominčica v sodelovanju z župani nekaterih občin v Sloveniji razvija demenci prijazne lokalne skupnosti in mesta, ki program tudi delno finančno podpirajo. Od leta 2024 Spominčica tesno sodeluje z lokalnimi oblastmi pri vzpostavljanju odborov, ki združujejo predstavnike občin, zdravstvene delavce, predstavnike civilne družbe in družinske oskrbovalce. S podporo Spominčice odbori pripravljajo letne načrte, ki odražajo lokalne prednostne naloge, vključno z ozaveščanjem, izobraževanjem in podporo svojcem in oskrbovalcem.

Ta pristop predstavlja pomembno nadgradnjo De-

menci prijaznih točk, mreže, ki jo Spominčica širi že od leta 2017. V mreži je danes več kot 500 organizacij po vsej državi. Namen DPT točk je širjenje ozaveščenosti o demenci in njeno prepoznavanje. DPT točke povezujejo različne organizacije in ustanove, kot so pošte, knjižnice, banke, trgovine, zdravstveni domovi, bolnišnice, domovi starejših občanov ..., da usklajeno in povezano delujejo v pomoč in podporo svojcem oseb z demenco, kar je tudi uresničevanje nekaterih ciljev iz nacionalne Strategije za obvladovanje demence.

Pred otvoritvijo Demenci prijazne točke Spominčica predhodno organizira in izvede usposabljanje za zaposlene, da prepoznajo potrebe oseb z demenco ter se nanje odzovejo z občutljivostjo in razumevanjem. Točke so na vhodu označene z logotipom Demenci prijazna točka, nudijo pa informacije in usmeritve za podporo v lokalnem okolju.

Z razvojem v usklajene lokalne sisteme program predstavlja pomemben premik k skupni odgovornosti za oskrbo oseb z demenco. Vse večja vključenost občin in različnih organizacij odraža njegov prepoznani pomen ter prispeva k temu, da so osebe z demenco podprte, vključene in lahko živijo dostojanstveno v svojih skupnostih.

Štefanija L. Zlobec, predsednica Spominčice – Alzheimer Slovenija, je univ. diplomirana ekonomistka, Ekonomske fakultete, Univerze v Ljubljani, ki je na področju demence začela aktivno delati leta 2009, ko je bil njen soprog Jaša Lukič Zlobec pacient pri dr. Kogoj, psihiatru in ustanovitelju Spominčice. Skupaj z dr. Kogojem je bila pobudnica za ustanovitev interdisciplinarnih strokovnih delovnih skupin za pripravo nacionalnega programa za demenco, ki je bila ustanovljena leta 2010 z odlokom ministra za zdravje. Kot članica delovne skupine je sodelovala pri pripravi prve Strategije obvladovanja demence v Sloveniji 2016–2020. Sodelovala je tudi pri pripravi druge nacionalne Strategije za obvladovanje demence 2023–2030. Spominčico je uspešno vključila v mednarodni mreži Alzheimer's Disease (leta 2014) International in Alzheimer Europe (2012). Od leta 2014 do 2018 je bila članica odbora Alzheimer Europe, od leta 2026 pa članica odbora Svetovne Alzheimer organizacije. Leta 2018 je dobila priznanje predsednika RS zas delovanje na področju demence.

V letu 2012 je bila pobudnica Alzheimer Caféjev, od 2017 pa vzpostavljanja Demenci prijaznih točk, ki jih je po vsej Sloveniji danes že skoraj 500. Svetovna zdravstvena organizacija (WHO) je leta 2022 prepoznala Demenci prijazne točke kot inovativni primer dobre prakse. Od leta 2022 je tudi predsednica Zveze organizacij pacientov Slovenije (ZOPS).

SPOMINČICA BUILDS DEMENTIA- INCLUSIVE COMMUNITIES IN SLOVENIA

Štefanija L. Zlobec, univ. dipl. oec., president of Spominčica Association
Spominčica – Alzheimer Slovenia – National Association for Dementia support, Slovenia

Spominčica – Alzheimer Slovenia is implementing a comprehensive national programme co-financed by the Ministry of Health of Slovenia, strengthening support for people with dementia and their caregivers within local environments. This coordinated effort addresses the challenges of an ageing population while supporting the implementation of the Dementia Strategy in Slovenia by promoting accessibility and inclusion, as well as raising awareness, reducing stigma, improving access to reliable information and creating conditions that enable people with dementia to remain active in everyday community life.

In this initiative Spominčica is developing Dementia-Friendly Local Communities and Cities in partnership with mayors of municipalities across Slovenia, who also provide financial support for the programme. Since 2024, Spominčica has been working closely with local authorities to establish multidisciplinary committees that bring together municipal representatives, healthcare professionals, civil society actors and family caregivers. With professional guidance from Spominčica, committees prepare annual plans reflecting local priorities,

including awareness activities, education, caregiver support and community-based care.

This approach represents an important step forward from the development of Dementia-Friendly Points, a network Spominčica has been building since 2017. Now numbering over 500 organisations nationwide, these points connect healthcare, social care and community services and are embedded in a wide range of settings, from healthcare and public institutions to shops and cultural venues. Spominčica trains employees at each location to recognise the needs of people with dementia and to respond with sensitivity and understanding. Identified with the Spominčica logo at the entrance, these spaces offer accessible information and guidance in a supportive atmosphere.

By evolving into coordinated local systems, the programme marks a vital shift toward shared responsibility for dementia care. The growing uptake by municipalities and organisations reflects its recognised importance, helping ensure that people with dementia are supported, included and able to live with dignity in their communities.

Štefanija L. Zlobec, President of Spominčica – Alzheimer Slovenia, holds a degree in economics and began working actively in the field of dementia in 2009, when her husband, Jaša Lukič Zlobec, was a patient of Dr. Kogoj, a psychiatrist and founder of Spominčica. Together with dr. Kogoj, she initiated the establishment of an interdisciplinary expert working group for the preparation of a national dementia program, which was set up in 2010 by decree of the Minister of Health. As a member of this working group, she contributed to the development of the first Slovenian Dementia Management Strategy 2016–2020, prepared in accordance with WHO guidelines and followed by an Action Plan. She also participated in drafting the second national Dementia Management Strategy 2023–2030. She successfully integrated Spominčica into the international networks Alzheimer's Disease International and Alzheimer Europe. In 2012, she initiated Alzheimer Café gatherings, and since 2017 has led the establishment of Dementia-Friendly Points, of which there are now nearly 500 across Slovenia. In 2022, the World Health Organization (WHO) recognized Dementia-Friendly Points as an innovative example of good practice. Since 2022, she has also served as President of the Slovenian Patients' Organizations Association (ZOPS).



DEJAVNOSTI V NARAVI, PRILAGOJENE OSEBAM Z DEMENCO

Dr. Zdenka Čebašek-Travnik, dr. med., spec. psihiatrije

Spominčica – Alzheimer Slovenija – Nacionalno strokovno združenje za pomoč pri demenci, Slovenija

Ana Hribar Podkrajšek, univ. dipl. kulturologinja

Arboretum Volčji Potok, Slovenija

Znano je, da je gibanje pomemben dejavnik ohranjanja kognitivnih sposobnosti v starosti, manj znane pa so ugotovitve o pomembnosti krepitev mišic na nogah. To ne vpliva le na mobilnost, ravnotežje in varnost, temveč tudi na izvršilne kognitivne funkcije. V nacionalno reprezentativnem vzorcu starejših odraslih v ZDA je bila dokazana pozitivna povezava med povečano mišično močjo spodnjih okončin in kognitivnim delovanjem in to neodvisno od izvajanja aerobnih telesnih dejavnosti. Takšne raziskave so močna spodbuda za telesne dejavnosti, ki ne le ohranjajo, temveč tudi povečujejo moč mišic v nogah in na ta način predstavljajo tudi močan preventivni dejavnik. Vendar pa moramo pripraviti tudi dejavnosti v naravi, ki bodo prilagojene osebam, ki že imajo znake demence. V ospredju so krajše, ponovljive in predvidljive aktivnosti, ki jih je mogoče vključevati v vsakdanje življenje. Takšen pristop prispeva k večjemu občutku varnosti, saj zmanjšuje zmedenost, preobremenjenost in občutek ogroženosti. Podani bodo rezultati raziskav, ki osvetljujejo,

kako osebe z demenco doživljajo naravo prek telesnih občutkov in čustev ter kako pri tem ohranjajo občutek lastne identitete in povezanosti z drugimi. V ospredju zato niso spominjanje niti storilnost, temveč občutenje korakov, zaznavanje vetra, poslušanje zvokov, dotik lubja, opazovanje ptic ter druge dejavnosti, ki omogočajo neposreden stik z naravo. Pomembno vlogo pri tem ima tudi oskrbovalec oziroma spremljevalec, saj stik z naravo ni le vprašanje dostopa, temveč tudi skupnega doživljanja, odnosa in podpore znotraj diade. Predstavljen bo projekt Modra palica ter Doživljajska pot za spomin v Arboretumu Volčji Potok kot pilotni primer demenci prijaznega naravnega okolja, ki združuje gibanje, podporno infrastrukturo, spremstvo usposobljenega vodnika in neposredno doživljanje narave. Glede na to, da so neformalni oskrbovalci dostikrat prikrajšani za preživljanje prostega časa in samostojno gibanje v naravi, projekt predstavlja možnost, da se na isti lokaciji izvajajo dejavnosti v naravi, ki so koristne tako za osebo z demenco kot za njene bližnje.

Dr. Zdenka Čebašek-Travnik je specialistka psihiatrije, ki se v zadnjem obdobju posveča delu s svojci oseb z demenco in sodeluje pri izobraževanju formalnih in neformalnih oskrbovalcev. Je članica strokovnega sveta Združenja Spominčica – Alzheimer Slovenija. Piše strokovne in poljudne članke, je tudi soavtorica knjige Kje so moji ključki – O življenju z demenco. V Arboretumu Volčji Potok je leta 2024 ustanovila študijsko skupino Modra palica, v kateri pripravljajo in izvajajo dejavnosti za osebe z demenco in usposablajo spremljevalce teh oseb za gibanje v naravi.

Ana Hribar Podkrajšek je certificirana izvajalka gozdne terapije, ki v Arboretumu Volčji Potok že tretje leto vodi program gozdne terapije za starejše. Kot doktorska študentka socialne gerontologije se raziskovalno posveča vplivu narave na dobro počutje in življenje starejših. Razvila je lastno metodo čuječega fotografiranja v naravi. Sodelovala je s Spominčico – Alzheimer Slovenija, Združenjem Dlan, Društvom paraplegikov ljubljanske pokrajine, Centrom aktivnosti Fužine ter drugimi sorodnimi organizacijami.

NATURE-BASED ACTIVITIES ADAPTED FOR PEOPLE WITH DEMENTIA

Dr. Zdenka Čebašek-Travnik, MD, Specialist in Psychiatry

Spominčica – Alzheimer Slovenia – National Association for Dementia support, Slovenia

Ana Hribar Podkrajšek, BA in Cultural Studies

The Volčji Potok Arboretum, Slovenia

It is well known that physical activity is an important factor in maintaining cognitive abilities in older age; however, less attention is given to findings on the importance of strengthening the leg muscles. This not only affects mobility, balance, and safety, but also executive cognitive functions. In a nationally representative sample of older adults in the United States, a positive association was demonstrated between increased lower-limb muscle strength and cognitive functioning, independent of aerobic physical activity. Such findings provide strong encouragement for physical activities that not only maintain but also enhance leg muscle strength and thus represent an important preventive factor.

However, it is also necessary to design nature-based activities that are adapted to people already showing signs of dementia. The focus is on shorter, repeatable, and predictable activities that can be integrated into everyday life. Such an approach contributes to a greater sense of safety, as it reduces confusion, overload, and feelings of threat. Research findings will be presented that shed light on how people with dementia experience nature

through bodily sensations and emotions, and how they maintain a sense of identity and connection with others in this context. The emphasis is therefore not on memory or performance, but on feeling one's steps, sensing the wind, listening to sounds, touching tree bark, observing birds, and other activities that enable direct contact with nature.

The role of the caregiver or companion is also essential, as contact with nature is not only a matter of access, but also of shared experience, relationship, and support within the dyad. The presentation will introduce the project Blue Walking Stick and the Memory Experience Trail at Arboretum Volčji Potok as a pilot example of a dementia-friendly natural environment, combining physical activity, supportive infrastructure, accompaniment by a trained guide, and direct engagement with nature.

Given that informal caregivers are often deprived of free time and independent access to nature, the project offers an opportunity for both the person with dementia and their relatives to engage in meaningful nature-based activities at the same location.

Dr. Zdenka Čebašek-Travnik is a specialist psychiatrist who has recently focused on working with relatives of people with dementia and participates in the education of formal and informal caregivers. She is a member of the expert council of Spominčica – Alzheimer Slovenia. She writes professional and popular articles and is also co-author of the book Where Are My Keys – On Living with Dementia. At Arboretum Volčji Potok, she founded the Blue Walking Stick study group in 2024, where they develop and implement activities for people with dementia and train companions to support them in nature-based movement.

Ana Hribar Podkrajšek is a certified forest therapy practitioner who has been leading a forest therapy programme for older adults at Arboretum Volčji Potok for three years. As a PhD student in social gerontology, her research focuses on the impact of nature on the well-being and lives of older people. She has developed her own method of mindful photography in nature. She has collaborated with Spominčica – Alzheimer Slovenia, the Dlan Association, the Ljubljana Paraplegic Association, the Fužine Activity Centre, and other related organisations.



MODEL CELOVITE OBRAVNAVE DEMENCE V LOKALNI SKUPNOSTI V SLOVENIJI

Dr. Božidar Voljč, dr. med., dr. sci.

Spominčica – Alzheimer Slovenija – Nacionalno strokovno združenje za pomoč pri demenci, Slovenija

Namen projekta Spominčice-Alzheimer Slovenija »Celovita obravnava demence v lokalnih okoljih« je v urbanih in podeželskih okoljih, v sodelovanju s krajevnimi deležniki, razvijati koncept sodelujoče in usklajene skupnosti, s posebnim ozirom na pojavnost in prisotnost demence. Projekt na osebni in skupnostni ravni v obravnavo demence vključuje zdrav način življenja, partnerski odnos do kroničnih nenalezljivih bolezni in socialno sprejemanje ter oskrbo demence v različnih fazah njene pojavnosti. Za uspešnost projekta v posameznih skupnostih je pomembno aktivno sodelovanje krajevnih deležnikov; občine, zdravstva, socialnih služb in organizacij, bivalnih ustanov za starejše, upokojencev in mladine. Projekt je dolgoročnega značaja in ob epidemioloških in demografskih spremembah v krajevnih skupnostih krepi njihovo socialno in zdravstveno kulturo.

Dr. Božidar Voljč je upokojeni zdravnik, specialist splošne medicine, magister in doktor javnega zdravstva, predsednik Komisije Republike Slovenije za medicinsko etiko ter član strokovnega sveta in strokovni sodelavec Spominčice - Alzheimer Slovenija.

A MODEL OF COMPREHENSIVE DEMENTIA CARE IN THE LOCAL COMMUNITY IN SLOVENIA

Dr. Božidar Voljč, dr. med., dr. sci.

Spominčica – Alzheimer Slovenia – National Association for Dementia support, Slovenia

The aim of the Spominčica – Alzheimer Slovenia project “Comprehensive Dementia Care in the Local Community” is to develop, in both urban and rural environments and in cooperation with local stakeholders, a concept of a collaborative and coordinated community, with special attention to the prevalence and presence of dementia.

At both the individual and community level, the project integrates a healthy lifestyle, a partnership-based approach to chronic non-communicable diseases, and social acceptance and care of dementia across its different stages.

For the success of the project in individual communities, the active involvement of local stakeholders is essential: municipalities, healthcare services, social services, residential care institutions for older adults, retirees, and young people.

The project is long-term in nature and, in the context of epidemiological and demographic changes in local communities, strengthens their social and health culture.

Dr. Božidar Voljč, dr. med., dr. sci., is a retired physician, a specialist in general medicine, holds a master's degree and a PhD in public health- He's the Chair of the Republic of Slovenia Medical Ethics Commission, and an expert collaborator of Spominčica – Alzheimer Slovenia.



IZZIVI DOLGOTRAJNE OSKRBE LJUDI Z DEMENCO

Red. prof. dr. Jana Mali

Fakulteta za socialno delo, Univerza v Ljubljani, Slovenija

Na splošno je dolgotrajna oskrba v Sloveniji tradicionalno usmerjena institucionalno, zato je tudi za ljudi z demenco predvidena oskrba v institucijah. Takšna usmeritev je v nasprotju s sprejetimi usmeritvami za oskrbo ljudi z demenco na globalni ravni, ki poudarjajo njihovo samostojno življenje v skupnosti oz. domačem okolju, zato je institucionalizacija ljudi z demenco v Sloveniji grob poseg v njihove pravice.

Zakon o dolgotrajni oskrbi (2023) z vidika usmerjenosti v razvoj in spodbujanje skupnostne oskrbe pokaže, da ni jasnih nacionalnih usmeritev za razvoj dolgotrajne oskrbe, ki bi denimo ljudem z demenco omogočala čim daljše samostojno življenje v domačem okolju. Zakon ne ponuja dovolj novih storitev, ki bi učinkoviteje zadovoljevale potrebe ljudi z demenco in njihovih sorodnikov kot obstoječe storitve. Ponuja nekaj novosti (npr. e-oskrba; denarni prejemek), za katere pa ni mogoče trditi, da bodo zadržale ljudi z demenco v domačem okolju. Pričakujemo lahko, da se bo institucionalna kariera ljudi z demenco nadaljevala in to

kljub temu, da vemo, kakšno pomoč ljudje z demenco potrebujejo in kakšne so alternativne oblike pomoči zanje.

Novi zakon tudi ne omogoča večje dostopnosti do institucionalne oskrbe, kot je to omogočal dosednji sistem socialnega varstva. Prav tako ne spodbuja inovativnih oblik oskrbe, s katerimi so domovi že v preteklosti pokazali razvojni potencial skupnostne oskrbe dolgotrajne oskrbe in s katerimi so največ pomoči pridobili prav ljudje z demenco in njihovi sorodniki v skupnosti. Ne ponuja ustreznih rešitev za dolge čakalne vrste za sprejem v dom, za pomanjkanje kadrov za izvajanje institucionalne oskrbe in za nesprejemanje ljudi z demenco v domove zaradi kadrovskega primanjkljaja.

Odlaslanje sprejemanja zakona o dolgotrajni oskrbi nas je pahnilo v novo kadrovsko krizo na področju dolgotrajne oskrbe, ki bo le še dodatno otežila zagon za razvoj dolgotrajne oskrbe. Medtem pa se število ljudi z demenco povečuje, potrebe po pomoči se večajo, breme oskrbe pa se prenaša na neformalne oskrbovalce.

Red. prof. dr. Jana Mali svojo poklicno kariero posveča delu s starimi ljudmi. Na Fakulteti za socialno delo, Univerze v Ljubljani, znanstveno raziskovalno in pedagoško delo opravlja na naslednjih področjih: socialno delo s starimi ljudmi, socialno delo z ljudmi z demenco, supervizija v socialnem delu, metode socialnega dela, dolgotrajna oskrba in akcijsko raziskovanje. Njena bibliografija obsega prek 500 znanstvenih in strokovnih del, ki jih je objavila doma in v tujini. Iz njenega bogatega zbira pisnega gradiva velja omeniti pet znanstvenih monografij, v katerih obravnava institucionalno oskrbo starih ljudi, dolgotrajno oskrbo in socialno delo z ljudmi z demenco.

Na Fakulteti za socialno delo je razvila študijski program socialnega dela s starimi ljudmi, ki poteka na 1. in 2. stopnji študija. Je vodja Katedre za dolgotrajno oskrbo. Svoje mednarodno udejstvovanje pa izkazuje na področju mednarodnih projektov, nosilstva predmetov na tujih univerzah in kot direktorica mednarodnega izobraževalnega programa Social Work and Old Age na IUC School for Social Work Theory and Practice na Inter-University Centre, Dubrovnik.

CHALLENGES OF LONG-TERM CARE FOR PEOPLE WITH DEMENTIA

Prof. Jana Mali, PhD

Faculty of Social Work, University of Ljubljana, Slovenia

In general, long-term care in Slovenia has traditionally been institutionally oriented; therefore, care for people with dementia is also predominantly provided in institutional settings. Such an orientation is contrary to globally adopted approaches to dementia care, which emphasise independent living in the community or home environment. From this perspective, the institutionalisation of people with dementia in Slovenia represents a serious infringement of their rights. The Long-Term Care Act (2023), from the perspective of promoting and developing community-based care, shows that there are no clear national guidelines for the development of long-term care that would, for example, enable people with dementia to remain in their home environment for as long as possible. The Act does not offer sufficient new services that would more effectively meet the needs of people with dementia and their relatives compared to existing services. It introduces some innovations (e.g. e-care, cash benefits), but it cannot be said that these will keep people with dementia in their home environment. It can therefore be

expected that institutional trajectories of care will continue, despite knowledge of what kind of support people with dementia need and what alternative forms of care exist.

The new Act also does not improve access to institutional care compared to the previous social welfare system. It does not encourage innovative forms of care either, even though residential care homes have previously demonstrated developmental potential in community-based long-term care, and have provided significant support particularly to people with dementia and their relatives in the community. It does not offer adequate solutions for long waiting lists for admission to care homes, for staff shortages in institutional care, or for the refusal of admission due to lack of personnel.

Delays in adopting the Long-Term Care Act have led to a new staffing crisis in the field of long-term care, which will further hinder the development of the system. Meanwhile, the number of people with dementia is increasing, the need for support is growing, and the burden of care is being shifted onto informal caregivers.

Prof. Jana Mali, PhD, has dedicated her professional career to working with older people. At the Faculty of Social Work, University of Ljubljana, she conducts research and teaching in the following areas: social work with older people, social work with people with dementia, supervision in social work, social work methods, long-term care, and action research. Her bibliography includes over 500 scientific and professional publications in Slovenia and abroad. Among her extensive body of work, five scientific monographs are particularly noteworthy, addressing institutional care for older people, long-term care, and social work with people with dementia.

*At the Faculty of Social Work, she developed the study programme in social work with older people, which is offered at both first- and second-cycle levels. She is Head of the Chair for Long-Term Care. Her international engagement includes participation in international projects, teaching at foreign universities, and serving as Director of the international educational programme *Social Work and Old Age* at the IUC School for Social Work Theory and Practice, Inter-University Centre, Dubrovnik.*



RAZVOJ DINAMIČNIH BIOMARKERJEV ZA ZGODNJE ODKRIVANJE POSPEŠENEGA KOGNITIVNEGA UPADA

Prof. dr. Vojko Kavčič

Inštitut za gerontologijo, Wayne State University, Detroit, Michigan, ZDA

Starost je najpomembnejši dejavnik tveganja za razvoj nevrodegenerativnih bolezni, vendar tradicionalni biomarkerji pogosto zaznajo spremembe šele v relativno poznih fazah patološkega procesa. V zadnjih letih se zato povečuje zanimanje za razvoj novih neurofizioloških markerjev, ki bi lahko zaznali zgodnje spremembe v delovanju možganskih mrež še pred pojavom izrazitih kliničnih simptomov. Poseben izziv predstavlja tudi dejstvo, da večina študij možgansko aktivnost obravnava kot statično stanje, medtem ko so možganski procesi v resnici izrazito dinamični.

V prispevku je predstavljen pristop, ki temelji na analizi dinamične ponovne stabilizacije možganskih mrež po kognitivni obremenitvi. V laboratoriju so razvili paradigmo resting-state EEG Task Aftereffect (rsEEG-TA), ki primerja EEG aktivnost v mirovanju pred in po kratki kognitivni nalogi. Prejšnje raziskave so pokazale, da se po koncu naloge možganska aktivnost ne vrne takoj v

izhodiščno stanje; spremembe v oscilatorni aktivnosti in funkcionalni povezanosti lahko trajajo več minut. Pri starejših osebah z blago kognitivno motnjo (MCI) so ti učinki izrazitejši kot pri kognitivno zdravih posameznikih, kar nakazuje zmanjšano sposobnost možganskih mrež za hitro ponovno stabilizacijo.

Na podlagi teh ugotovitev predstavi nov konceptualni okvir, ki se imenuje dinamična reorganizacija EEG mrež (dynamic EEG Network Reconfiguration; dENR). Ta pristop kvantificira tako velikost perturbacije možganskih mrež kot tudi hitrost njihovega okrevanja, kar omogoča oceno nevrnalne odpornosti oziroma „nevronske rezilience“. Takšni dinamični kazalniki lahko predstavljajo obetaven smer razvoja novih biomarkerjev za zgodnje odkrivanje pospešenega kognitivnega upada ter prispevajo k boljšemu razumevanju mehanizmov kognitivnega staranja.

Prof. dr. Vojko Kavčič (Voyko Kavcic) je psiholog in kognitivni nevroznanstvenik. Njegovo delo in življenje sta razpeta med Slovenijo in ZDA. V Sloveniji vodi Mednarodni inštitut za aplikativno gerontologijo, je profesor in vodja projekta na Univerzi Alma Mater Europaea v Mariboru, kjer predava geropsihologijo, v ZDA pa izredni profesor raziskovalec na Inštitutu za gerontologijo na Wayne State University v Detroitu, ZDA. Publiciral je več kot 70 znanstvenih člankov v vodilnih strokovnih revijah in akademskih knjigah (v bazi Google Učenjaka najdemo preko 5.500 citatov, h-index: 33). Je avtor knjige Umovadba. Njegov glavni raziskovalni interes je kognitivno staranje in zgodnje odkrivanje kognitivnih upadov, ki vodijo v demenco. Raziskuje tudi uporaba kognitivnega treninga za preprečevanje s starostjo povezanih umskih upadov pri zdravih starejših odraslih. Dr. Kavčič redno obiskuje Slovenijo, kjer ze nekaj časa sodeluje s kolegi in raziskovalci z Univerze na Primorskem, Univerze v Ljubljani, ter Univerze v Mariboru. Dr. Kavčič tudi redno sodeluje s Spominčico – Alzheimer Slovenija, predvsem s predavanji o Alzheimerjevi bolezni.

DEVELOPMENT OF DYNAMIC BIOMARKERS FOR THE EARLY DETECTION OF ACCELERATED COGNITIVE DECLINE

Prof. Vojko Kavčič, PhD

Gerontology Institute, Wayne State University, Detroit, Michigan, USA

Age is the most important risk factor for the development of neurodegenerative diseases; however, traditional biomarkers often detect changes only at relatively late stages of the pathological process. In recent years, there has therefore been growing interest in the development of new neurophysiological markers that could detect early changes in brain network functioning even before the onset of pronounced clinical symptoms. A particular challenge is the fact that most studies treat brain activity as a static state, whereas in reality brain processes are highly dynamic.

This presentation introduces an approach based on the analysis of dynamic re-stabilisation of brain networks following cognitive load. In the laboratory, a paradigm called resting-state EEG Task Aftereffect (rsEEG-TA) has been developed, which compares EEG activity at rest before and after a short cognitive task. Previous research has shown that after task completion, brain

activity does not immediately return to its baseline state; changes in oscillatory activity and functional connectivity may persist for several minutes. In older adults with mild cognitive impairment (MCI), these effects are more pronounced than in cognitively healthy individuals, indicating a reduced capacity of brain networks for rapid re-stabilisation.

Based on these findings, a new conceptual framework is introduced, termed dynamic EEG Network Reconfiguration (dENR). This approach quantifies both the magnitude of brain network perturbation and the speed of recovery, enabling the assessment of neural resilience. Such dynamic indicators may represent a promising direction for the development of new biomarkers for the early detection of accelerated cognitive decline and contribute to a better understanding of the mechanisms of cognitive ageing.

*Prof. Vojko Kavčič, PhD (Voyko Kavcic) is a psychologist and cognitive neuroscientist. His work and life are based between Slovenia and the USA. In Slovenia, he leads the International Institute for Applied Gerontology and is a professor and project leader at Alma Mater Europaea University in Maribor, where he teaches geropsychology. In the USA, he is an Associate Research Professor at the Institute of Gerontology at Wayne State University in Detroit. He has published more than 70 scientific articles in leading peer-reviewed journals and academic books (with over 5,500 citations in Google Scholar; h-index: 33). He is the author of the book *Mind Exercise (Umovadba).*

His main research interest is cognitive ageing and the early detection of cognitive decline leading to dementia. He also studies the use of cognitive training to prevent age-related cognitive decline in healthy older adults. Dr. Kavčič regularly visits Slovenia, where he has for some time collaborated with colleagues and researchers from the University of Primorska, the University of Ljubljana, and the University of Maribor. He also regularly collaborates with Spominčica – Alzheimer Slovenia, mainly through lectures on Alzheimer's disease.



NEUROPLASTIČNOST MOŽGANOV IN DEMENCA

Vida Drame Orožim, dr. med., spec. psihiatrije in neurologije

Spominčica – Alzheimer Slovenia – Nacionalno strokovno združenje za pomoč pri demenci, Slovenija

Nevroplastičnost možganov je edinstvena sposobnost, ki je drugi organi nimajo. Izraz nevroplastičnost nima zveze s plastiko. Gre za sposobnost nevronskih mrež v možganih, da se spreminjajo z razvojem rasti in reorganizacijo tkiva in delovanja.

Donald Hepp, kanadski nevroznanstvenik, je bil prvi, ki je opisal izraz nevroplastičnost. Mitja Peruš, slovenski nevroznanstvenik, pa je vpeljal v nevroznanost izraz nevronske mreže.

V drugi polovici 20. stoletja so znanstveniki dokazali, da se številni vidiki delovanja možganov ne spreminjajo samo v otroštvu, adolescenci in zgodnji odraslosti, ampak tudi v odraslosti, celo v obdobju starosti, po 70. letu so dokazali nastajanje novih astrocitov.

Nevroplastičnost, pogojena z možgansko aktivnostjo, ima velik vpliv na zdrav razvoj, učenje, spomin in celo na sanacijo tkiva po poškodbah možganovine.

Nevroplastičnost pomeni nastajanje spre-

memb na nivoju strukturnih, funkcionalnih in biokemičnih aktivnosti. Nevronske tkivo ima to naravno nevrobiološko danost, ki pa sama po sebi ni dovolj. Pomemben dejavnik pri njenem razvoju je trud vsakega posameznika, da to biološko danost aktivira in jo vedno znova in znova nadgrajuje in vzdržuje skozi vse življenje.

V obdobju, ko se aktivnost možganovine močnejše upočasni, zanemari, se proces nevroplastičnosti začne krhati in že sama mentalna lenoba, brez posebnih patoloških učinkov, ustvarja podlago za upadanje možganskega funkcioniranja in sproži proces razgradnje v smislu demence.

Sposobnost nevroplastičnosti uporabljamo, kadar se želimo naučiti v življenju nova znanja, navade, vedenja in ustvariti kvalitetne spremembe v svojem življenju. Za to potrebujemo veliko časa in truda. Z dolgoletno in trajno aktivacijo možganovine lahko tudi v veliki meri preveniramo demenco.

Vida Drame Orožim, dr. med., je specialistka psihiatrije in neurologije, nekdanja strokovna vodja Pro Bono ambulante s posvetovalnico za ljudi brez zdravstvenega zavarovanja ter častna članica Zdravniške zbornice Slovenije. Je zunanja strokovna sodelavka in članica strokovnega sveta Spominčice – Alzheimer Slovenia.

NEUROPLASTICITY OF THE BRAIN AND DEMENTIA

Vida Drame Orožim, MD, Specialist in psychiatry and neurology

Spominčica – Alzheimer Slovenia – National Association for Dementia support, Slovenia

Neuroplasticity of the brain is a unique ability that other organs do not possess. The term neuroplasticity has no connection to plastic. It refers to the ability of neural networks in the brain to change through growth and the reorganisation of tissue and function.

Donald Hebb, a Canadian neuroscientist, was the first to describe the concept of neuroplasticity. Mitja Peruš, a Slovenian neuroscientist, introduced the term neural networks into neuroscience.

In the second half of the 20th century, scientists demonstrated that many aspects of brain function do not change only in childhood, adolescence, and early adulthood, but also in adulthood and even in old age; after the age of 70, the formation of new astrocytes has been observed.

Neuroplasticity, which is driven by brain activity, has a major impact on healthy development, learning, memory, and even the repair of brain tissue after injury.

Neuroplasticity involves changes at the structural, functional, and biochemical levels. Neural tissue has this natural neurobiological capacity; however, it is not sufficient on its own. An important factor in its development is the effort of each individual to activate this biological potential and continuously strengthen and maintain it throughout life.

When brain activity significantly slows down or is neglected, the process of neuroplasticity begins to weaken. Even mental inactivity, without specific pathological causes, can create a basis for declining brain function and trigger degenerative processes in the sense of dementia.

We use neuroplasticity when we want to acquire new knowledge, habits, and behaviours in life and create meaningful changes in our lives. This requires considerable time and effort. With long-term and sustained brain activity, it is also possible to a large extent to prevent dementia.

Vida Drame Orožim, MD, is a specialist in psychiatry and neurology, a former head of the Pro Bono outpatient clinic with a counselling service for people without health insurance, and an honorary member of the Medical Chamber of Slovenia. She is an external expert associate and a member of the expert council of Spominčica – Alzheimer Slovenia.



PRILOŽNOSTI ZA PALIATIVNO PODPORO V ČASU POTEKA DEMENCE

Mag. Mateja Lopuh, dr. med., mag. sci.

Splošna bolnišnica Jesenice, Center za interdisciplinarno zdravljenje bolečine in paliativno oskrbo,
Mobilna paliativna enota, Slovenija

Čeravno so potrebe po paliativni podpori v času napredovanja demence dobro prepoznane, ostajajo osebe z demenco med dejanskimi uporabniki paliativne podpore še vedno med manj vključenimi, sploh kar se tiče določanja primerne časa za vključitev, vrste in oblike paliativne podpore ter načina prehoda med ravnmi oskrbe.

Demenco zaznamuje dolgotrajen potek s postopnim izgubljanjem kognitivnih in telesnih sposobnosti. Gre za bolezen, pri kateri so bolniku pomembni bližnji izjemno zaznamovani s potekom bolezni, in ob skrbi za bolnika, težko usklajujejo svoje profesionalne in družbene obveznosti. Paliativna oskrba, ki se osredotoča na kvaliteto življenja, na načrtovanje medicinskih in socialnih intervencij, ki lahko vplivajo na kvaliteto življenja, obenem pa vključuje tudi bolniku pomembne bližnje, jih usmerja skozi pričakovan potek bolezni, se zdi idealna za obolele za demenco.

Ob splošno zmotnem prepričanju, da je paliativna oskrba namenjena le bolniku, ki se mu življenje izteka, in da je demenca bolezen, zaradi katere bolnik ne bo umrl, le redki bolniki dobijo pravočasno pomoč. Prav zato so osebe z demenco pogosto soočene z neprepoznanimi simptomi, bolečino, neustreznimi diagnostičnimi preiskavami in napotitvami v bolnišnico, ki ne vplivajo na kvaliteto življenja. Njihovi bližnji pa s stalnim nihanjem med upanjem in brezupom, potrebo po negovalni pomoči, razpetostjo med načrtovanjem aktivnosti in opuščanjem svojega življenja.

Oskrba oseb z demenco v domačem okolju je možna ob združitvi strokovnih služb in skupnostne pomoči. Paliativna podpora je lahko osnovna ali specialistična, pri čemer je izjemno pomembno, da njena vloga dopolnjuje skupnostne oblike pomoči, in da so strokovnjaki na voljo, kadar jih potrebujejo.

Mag. Mateja Lopuh, dr. med, mag. sci., je specialistka anesteziologije in perioperativne medicine, vodja Centra za interdisciplinarno zdravljenje bolečine in paliativno oskrbo ter mobilne paliativne enote SB Jesenice. Ima diplomo specialnega znanja zdravljenja bolečine in diplomo dodatnih znanj iz paliativne oskrbe. Je predana zdravnica, ki je večino svoje profesionalne kariere posvetila razvoju paliativne oskrbe in prva v Sloveniji začela z oskrbovanjem bolnikom v domačem okolju. Model razvoja skupnostne skrbi in vpletenosti mobilne paliativne enote je v letu 2024 prejel priznanje za najboljšo zdravstveno prakso v Sloveniji. Je aktivna predavateljica in utemeljiteljica podiplomskega izobraževanja iz veččin paliativne oskrbe, sprva pod naslovom Drznete si vedeti, kasneje Korak za korakom. Je avtorica številnih publikacij iz področja paliativne oskrbe, zdravljenja bolečine in anesteziologije. Vodi različne, tudi mednarodne, projekte za razširitev vedenja o paliativni oskrbi in njeni pravilni umeščenosti v skupnost. Je sopredsedujoča pri Evropski delovni skupini za razvoj paliativne oskrbe v manj privilegiranih okoljih, kjer je ljudem odvzeta prostost.

OPPORTUNITIES FOR PALLIATIVE CARE ALONG DEMENTIA'S DISEASE TRAJECTORY

Mateja Lopuh, dr. med, mag. sci.

General hospital Jesenice, Center for interdisciplinary pain treatment and palliative care,
Mobile palliative care unit, Slovenia

Although the need for palliative support during the progression of dementia is well recognised, people with dementia remain among the less included users of palliative care in practice—particularly regarding the timing of its introduction, the type and form of support provided, and the transitions between levels of care.

Dementia is characterised by a prolonged course with a gradual loss of cognitive and physical abilities. It is a condition in which the patient's close relatives are profoundly affected by the course of the illness and often struggle to balance caregiving responsibilities with their professional and social obligations. Palliative care, which focuses on quality of life and on planning medical and social interventions that can influence it, while also involving those close to the patient and guiding them through the expected course of the disease, appears particularly well suited for people living with dementia.

Due to the widespread misconception that palliative care is intended only for patients at the very end of life, and that dementia is not a life-limiting disease, only a small number of patients receive timely support. As a result, people with dementia are often faced with unrecognised symptoms, untreated pain, inappropriate diagnostic procedures, and hospital referrals that do not improve their quality of life. Their relatives, meanwhile, frequently oscillate between hope and despair, facing the need for caregiving support while being torn between maintaining their own lives and gradually giving them up.

Care for people with dementia in the home environment is possible through the integration of professional services and community-based support. Palliative care may be generalist or specialist, and it is crucial that its role complements community-based forms of support, with professionals available when needed.

Mag. Mateja Lopuh, dr. med., is a specialist in anaesthesiology and perioperative medicine, Head of the Centre for Interdisciplinary Pain Management and Palliative Care, and Head of the Mobile Palliative Care Unit at Jesenice General Hospital. She holds a diploma in advanced pain management and an additional qualification in palliative care. She is a dedicated physician who has devoted most of her professional career to the development of palliative care and was the first in Slovenia to introduce home-based care for patients. In 2024, the model of community-based care and the integration of the mobile palliative care unit received an award for best healthcare practice in Slovenia. She is an active lecturer and the founder of postgraduate training in palliative care skills, initially titled Dare to Know and later Step by Step. She is the author of numerous publications in the fields of palliative care, pain management, and anaesthesiology. She leads various projects, including international ones, aimed at expanding knowledge of palliative care and its appropriate integration into the community. She is Co-Chair of the European working group for the development of palliative care in underprivileged settings where people are deprived of their liberty.



INTIMNOST – POMEMBNA TUDI V STAREJŠIH OBDOBJIH ŽIVLJENJA, TUDI PRI OSEBAH Z DEMENCO

Darinka Klemenc, dipl. m. s.

Zbornica zdravstvene in babiške nege Slovenije – Zveza strokovnih društev medicinskih sester, babic in zdravstvenih tehnikov Slovenije, Častno razsodišče I. stopnje, Slovenija

Spolnost in intimnost predstavljata pomemben vidik človekovega življenja v vseh obdobjih. Spolnost vključuje spolno identiteto, spolno usmerjenost, spolno izražanje in spolna dejanja. Vpliva na človekovo samopodobo in samospoštovanje, tudi na duševno in telesno zdravje, družbene odnose in kakovost življenja nasploh. Staranje lahko spremeni način izražanja spolnosti in intimnosti. Kljub temu mnogi starejši še vedno vzdržujejo zdravo spolno življenje. Intimnost, zlasti telesna, lahko pomaga preprečevati depresijo, izboljša samozavest in telesno zdravje. Vsakdo, ne glede na starost, potrebuje ljubezen, bližino in dotik. Intimnost lahko razložimo kot posameznikovo osebno čustveno doživljanje, spolnost pa predstavlja ravnanje, ki izhaja iz spolnega nagona, vključuje čustveno, socialno in telesno bližino (npr. dotikanje, objemanje, spolni odnos). Želja po intimnosti s starostjo nujno ne upada in ni obdobja, ko bi bila intimnost, vključno s spolnostjo, neprimerna. Spremembe, kot so (kronično) bolezensko stanje, invalidnost, kognitivne motnje in čustvene spremembe, ki se

pojavi s staranjem, lahko otežujejo razvoj in vzdrževanje intimnega razmerja. O pravici do spolnosti pri starejših se v družbi premalo ali sploh ne govori. Eden od vzrokov je stereotipna predstava o starosti in staranju; gre za omalovažujoče, sistemsko diskriminirano področje, saj se danes poudarjajo predvsem mladost, lepota in vitalnost. Ko se z leti pojavijo še spremenjena telesna ali duševna (ali oboja) podoba in vedenje, ko nastopi bolezensko stanje, ki človeka zaznamuje, tudi katera od oblik demence, je izziv za prizadetega in njegove bližnje velik, in pogosto se s pravico do njegove spolnosti nihče ne ukvarja. Odnosi z drugimi, tudi pri osebah z demenco, (p)ostanejo posebej pomembni; dobri odnosi so ključni, da se te osebe počutijo cenjene, ljubljene, zaželeno. Prav demenca in LGBTQ+ identiteta sta še močno stigmatizirani. A spolnost in intimnost se s tem nujno ne zmanjšata, zlasti ne pri ustaljenih parih, kar pomeni, da bi morali področje spolnosti pri starejših tako zdravstveni delavci kot bližnji in družba nasploh bolj upoštevati in tudi detabuizirati.

Darinka Klemenc je v svoji poklicni karieri 20 let posvetila zdravstveni negi uroloških pacientov v UKC Ljubljana in 15 let koordinaciji specialističnih ambulant. Je ena prvih enterostomalnih terapeutk v Sloveniji, ena od pobudnic in ustanoviteljic šole in prva predsednica strokovne sekcije medicinskih sester za to področje, vodilna presojevalka kakovosti za ISO 9001, ima post diplomsko izobraževanje iz bolnišnične higiene, je mediatorica v zdravstvu. 11 let je predsedovala Društvu medicinskih sester, babic in zdravstvenih tehnikov Ljubljana, dva mandata Zbornici – Zvezi. S poklicno etiko se ukvarja vsaj 30 let, tudi s človekovimi/pacientovimi pravicami, z (ne)nasiljem na področju zdravstva, z ranljivimi skupinami ... Je pobudnica in članica Delovne skupine (DS) za nenasilje in članica DS za ohranjanje zgodovine pri Zbornici - Zvezi. En mandat (2022-2026) je predsedovala Častnemu razsodišču I. stopnje pri Zbornici – Zvezi, zdaj je njegova članica. Več kot 10 let predava poklicno etiko medicinskim sestram in babicam za vzdrževanje licenc, je članica IO Srebrne niti.

INTIMACY – IMPORTANT ALSO IN OLDER AGE, INCLUDING FOR PEOPLE WITH DEMENTIA

Darinka Klemenc, BSc (Nursing)

Nurses and Midwives Association of Slovenia – Professional Association of Nurses, Midwives and Health Technicians of Slovenia, Honorary Court of First Instance, Slovenia

Sexuality and intimacy are important aspects of human life at all stages. Sexuality encompasses sexual identity, sexual orientation, sexual expression, and sexual activity. It influences a person's self-image and self-esteem, as well as mental and physical health, social relationships, and overall quality of life. Aging may change the way sexuality and intimacy are expressed; nevertheless, many older adults continue to maintain a healthy sexual life. Intimacy, especially physical intimacy, can help prevent depression and improve self-confidence and physical health. Everyone, regardless of age, needs love, closeness, and touch. Intimacy can be understood as an individual's personal emotional experience, while sexuality refers to behavior arising from sexual drive and includes emotional, social, and physical closeness (e.g., touching, hugging, sexual intercourse). The desire for intimacy does not necessarily decline with age, and there is no period in life when intimacy, including sexuality, would be inappropriate. However, changes associated with aging—such as (chronic) illness, disability, cognitive impairment, and emotional changes—

can make it more difficult to develop and maintain intimate relationships.

The right to sexuality in older age is rarely discussed in society. One reason lies in stereotypical perceptions of old age and aging; this is a marginalized and systemically neglected area, as contemporary society tends to emphasize youth, beauty, and vitality. When aging is accompanied by changes in physical or mental (or both) condition and behavior, and when illness occurs—including forms of dementia—the challenges for the individual and their loved ones are significant, and the person's right to sexuality is often overlooked. Relationships with others, including for people with dementia, become especially important; good relationships are key to feeling valued, loved, and desired. Dementia and LGBTQ+ identity are both still strongly stigmatized. However, sexuality and intimacy do not necessarily diminish, particularly in long-term partnerships. This underscores the need for healthcare professionals, relatives, and society as a whole to give greater consideration to sexuality in older age and to help remove the associated taboos.

Darinka Klemenc devoted 20 years of her professional career to the nursing care of urology patients at the University Medical Centre Ljubljana, and 15 years to coordinating specialist outpatient clinics at the same institution. She is among the first enterostomal therapists in Slovenia, a co-initiator and founder of the training school in this field, and the first president of the professional section of nurses dedicated to this specialty. She is a lead quality auditor for ISO 9001, has postgraduate training in hospital hygiene, and works as a healthcare mediator. She served for 11 years as president of the Ljubljana Association of Nurses, Midwives and Health Technicians, and for two terms as president of the national Chamber – Association. She has been engaged in professional ethics for at least 30 years, including work on human and patient rights, violence and non-violence in healthcare, and vulnerable groups. She is an initiator and member of the Working Group for Non-Violence and a member of the Working Group for Preserving History at the Chamber – Association. For one term (2022–2026), she served as president of the Honorary Court of First Instance at the Chamber – Association and is now one of its members. For more than 10 years, she has lectured on professional ethics to nurses and midwives as part of license renewal, and she is also a member of the executive board of Srebrna nit.



USPOSABLJANJE ZA SVETOVANJE O DEMENCI NA MADŽARSKEM

Dr. Agnes Egervari, spec. neurologije

Katoliška univerza Pázmány Péter, Fakulteta za humanistične in družbene vede, Madžarska

Demenca predstavlja enega najnujnejših javnozdravstvenih in družbenih izzivov našega časa. Poleg kliničnih razsežnosti demenca močno vpliva na družine, sisteme oskrbe in strukture v skupnosti. Na Madžarskem zdravstveni in socialni delavci pogosto prihajajo v stik z osebami z demenco in njihovimi skrbniki, vendar doslej ni bilo strukturiranega podiplomskega izobraževanja, ki bi se posebej osredotočalo na svetovanje pri demenci.

Na podlagi izkušenj programa INDA smo oblikovali nov dvosemestrski (120 ECTS) podiplomski program z naslovom Usposabljanje za svetovanje pri demenci. Program smo razvili kot odgovor na naraščajočo potrebo po strokovnjakih, ki so sposobni obravnavati kompleksne psihosocialne, etične in komunikacijske izzive, povezane z demenco skozi celoten potek bolezni.

Učni načrt temelji na celostnem in medpoklicnem pristopu. Vključuje temeljna znanja o demenci skupaj s psihosocialnimi vidiki, vključujočimi pristopi za zmanjševanje stigme in socialne izključenosti, strukturirano delo na

študijah primerov, usposabljanje o komunikaciji ter etične in pravne vidike, pa tudi poglede na oskrbo ob koncu življenja in paliativno oskrbo. Poseben poudarek je namenjen realnim situacijam pri odločanju, podpori družinam in refleksiji strokovnih praks.

Program izvajajo izkušeni akademski in klinični strokovnjaki ter je umeščen v vrednostno zasnovan institucionalni okvir, ki temelji na načelih bioetike in katoliškega socialnega nauka.

Cilj usposabljanja je opremiti socialne in zdravstvene strokovnjake z naprednimi kompetencami na področju svetovanja, interdisciplinarnega sodelovanja in na stigmo občutljive prakse. Program z okrepitevijo strokovnih zmogljivosti prispeva k boljši kakovosti življenja oseb z demenco in njihovih družin ter spodbuja bolj vključujoč družbeni odziv na demenco.

Program je inovativen, saj z vidika krščanske perspektive obravnava etična in bioetična vprašanja, povezana z demenco.

Prispevek predstavlja program usposabljanja ter orisuje konceptualni okvir, strukturo učnega načrta in pričakovane učinke te pobude.

Dr. Agnes Egervari je specialistka neurologije, nevropatologinja in strokovnjakinja v socialni. Po začetnem delu v bolnišnici in na Nacionalnem inštitutu za psihiatrijo in nevrologijo je več kot 25 let delala na področju strokovne oskrbe starejših. Je ustanoviteljica in vodja integrirane zasebne socialne ustanove za stalno in začasno oskrbo starejših oseb, specializirane za osebe z demenco. Med letoma 2015 in 2020 je delovala kot izvoršna direktorica Katoliške karitativne službe. Je avtorica številnih člankov v mednarodnih in madžarskih revijah s področja neurologije in nevropatologije ter gostujoča predavateljica na dodiplomskih in podiplomskih zdravstvenih in socialnih izobraževanjih ter univerzitetnih programih. Sodelovala in vodila je več projektov na področju dolgotrajne zdravstvene in socialne oskrbe (2007–2011 HGCS I–III, projekt standardizacije, INDA, EFOP, VEKOP). Njena glavna področja zanimanja so kakovost oskrbe oseb z demenco, medpoklicna oskrba, praksa in izobraževanje. Je predsednica Združenja Social Cluster, članica upravnega odbora Madžarskega združenja za gerontologijo in geriatrijo ter članica Strokovne sekcije za geriatrijo in kronično oskrbo starejših. Leta 2019 je prejela viteški križ Madžarskega reda za zasluge »za razvoj sistemov socialnih storitev, zlasti za izboljšanje kakovosti življenja in dobrega počutja starejših ter oseb z demenco in njihovih družin«. Leta 2025 je prejela Srebrno medaljo za zasluge Republike Madžarske.

DEMENTIA COUNSELLING TRAINING IN HUNGARY

Dr. Ágnes Egervári, Specialist in Neurology

Pázmány Péter Catholic University, Faculty of Humanities and Social Sciences, Hungary

Dementia represents one of the most pressing public health and social challenges of our time. Beyond its clinical dimensions, dementia profoundly affects families, care systems, and community structures. In Hungary, while health and social care professionals frequently encounter people living with dementia and their caregivers, structured postgraduate training specifically focusing on dementia counselling has been lacking. Building on the experiences of the INDA program, we have created our new two-semester (120 ECTS) postgraduate program, the Dementia Counseling Training. The programme was developed in response to the growing need for professionals capable of addressing the complex psychosocial, ethical, and communicational challenges associated with dementia across its trajectory.

The curriculum is built on a holistic and interprofessional framework. It integrates foundational knowledge of dementia with psychosocial perspectives, inclusive approaches addressing stigma and social exclusion, structured case-based practice, communication training as well as ethical and legal considerations, and end-of-life and

palliative care perspectives. Particular emphasis is placed on real-life decision-making situations, family support, and reflective professional practice.

The programme is delivered by experienced academic and clinical experts and is embedded within a value-based institutional context informed by principles of bioethics and Catholic social teaching.

The training aims to equip social and health-care professionals with advanced competencies in counselling, interdisciplinary collaboration, and stigma-sensitive practice. By strengthening professional capacity, the programme seeks to contribute to improved quality of life for people living with dementia and their families, and to foster a more inclusive societal response to dementia.

The program is innovative because it addresses the ethical-bioethical issues related to dementia from a Christian perspective.

The presentation introduces the training program, will outline the conceptual framework, curriculum structure, and anticipated impact of this initiative.

Dr. Agnes Egervari is a neurologist, neuropathologist and social expert. After starting in a hospital and then working in National Institute for Psychiatry and Neurology, she has 25 years experience in professional elderly care. She is founder and leader of an integrated private social institution for permanent and temporary care of elderly people, specialized for people with dementia. Between 2015 – 2020 she worked as CEO of Catholic Church Aid Service.

She's an author of numerous articles in both international and Hungarian periodicals in the field of neurology and neuropathology, invited teacher at graduate and post-graduate health care and social trainings and university programs. She participated /led several projects in long term health and social care (2007-11 HGCS I-III, standardization project, INDA, EFOP, VEKOP) Her main fields of interest are the quality of care for people with dementia, interprofessional care, practice and education.

She's a President of the Social Cluster Association, board member of the Hungarian Association of Gerontology and Geriatrics and member of Geriatrics and Chronic Care Section of The Professional College and the Professional College for Elderly.



OD SODELOVANJA V SKUPNOSTI DO NASTAJAJOČIH KLINIČNIH UPORAB

Sandra Kerovec, univ. mag. rehab. eduk.
Univerzitetna psihiatrična bolnišnica Vrapče, Zagreb, Hrvaška

Nefarmakološki pristopi so vse bolj prepoznani kot pomemben del izboljševanja kakovosti življenja oseb, ki živijo z demenco. Sodelovanje med zdravstvenimi ustanovami in organizacijami v skupnosti lahko ustvarja smiselne, na posameznika usmerjene dejavnosti, ki podpirajo kognitivno, čustveno in socialno dobrobit.

V naši ustanovi se je sodelovanje z nevladno organizacijo OZANA začelo z izdelavo in uporabo pletenih senzoričnih pripomočkov (t. i. »senzoričnih rokavov«) za osebe z demenco. Sčasoma je to sodelovanje odprlo širši pogled na potencial pletenja in kvačkanja kot strukturiranih in namenskih dejavnosti, ki spodbujajo pozornost, gibanje, ustvarjalnost in socialno interakcijo.

Koncept terapevtskega pletenja, ki so ga razvili pionirji, kot je Betsan Corkhill, ponuja uporaben okvir za razumevanje teh izkušenj. Ritmična in smiselna narava pletenja in kvačkanja omogočata udeležencem, da ostanejo aktivno vključeni v smiselni proces, ki združuje kognitivno stimulacijo, fino motoriko in socialno interakcijo. Poleg neposrednih koristi za osebo, ki ustvarja, imajo izdelani predmeti, kot so pleteni senzorični

pripomočki, tudi dodatno funkcijo, saj nudijo udobje, senzorično stimulacijo in priložnosti za povezovanje. Na ta način dejavnost podpira tako ustvarjalca kot širšo skupnost ter ustvarja krog vključenosti in smiselne participacije.

Te dejavnosti lahko koristijo tudi skrbnikom, zdravstvenim delavcem in prostovoljcem, saj ustvarjajo priložnosti za skupne izkušnje, sodelovanje in socialno povezanost. Prav tako lahko dodatno krepijo povezave med bolnišničnim okoljem in širšo skupnostjo.

Zaradi svoje preprostosti, dostopnosti in prilagodljivosti terapevtsko pletenje kaže potencial kot podporni nefarmakološka dejavnost v bolnišničnih okoljih, ki lahko presega področje obravnave demence. Prihodnje delo bi moralo raziskati izvedljive načine za vključevanje teh dejavnosti v klinično prakso ter sistematično preučiti njihove učinke, vključno z nevrokognitivnimi, fiziološkimi in psihosocialnimi mehanizmi.

Ta predstavitev predstavlja pot od skupnostnega sodelovanja do nastajajoče klinične uporabe ter razmišlja o možnostih nadaljnega vključevanja terapevtskega pletenja v zdravstveno prakso in raziskovanje.

Sandra Kerovec je specialistka edukacijske rehabilitacije z več kot dvajsetletnimi strokovnimi izkušnjami in nevladni organizaciji OZANA, kjer dela z otroki in odraslimi z motnjami v duševnem razvoju. Je ustanoviteljica in koordinatorka programa Štrikeraj Café, vključujočega skupnostnega programa, ki povezuje ljudi z in brez invalidnosti prek skupnih dejavnosti pletenja in kvačkanja ter spodbuja socialno vključenost, ustvarjalnost in smiselno sodelovanje.

Pred kratkim se je pridružila Univerzitetni psihiatrični bolnišnici Vrapče, kjer sodeluje pri diagnostičnem in terapevtskem delu v multidisciplinarnem timu. Trenutno se osredotoča na raziskovanje načinov uvajanja strukturiranih dejavnosti pletenja in kvačkanja kot nefarmakoloških podpornih intervencij v klinično in rehabilitacijsko prakso, s čimer nadgrajuje dolgoletne izkušnje s skupnostnimi ustvarjalnimi programi.

FROM COMMUNITY COLLABORATION TO EMERGING CLINICAL APPLICATION

Sandra Kerovec, univ. mag. rehab. educ.
University Psychiatric Hospital "Vrapče", Zagreb, Croatia

Non-pharmacological approaches are increasingly recognised as an important part of improving the quality of life of people living with dementia. Collaboration between healthcare institutions and community organisations can create meaningful, person-centred activities that support cognitive, emotional, and social well-being.

At our institution, cooperation with the non-governmental organisation OZANA began with the creation and use of knitted sensory aids (twiddle muffs) for people with dementia. Over time, this collaboration opened a broader perspective on the potential of knitting and crochet as structured and purposeful activities that engage attention, movement, creativity, and social interaction.

The concept of therapeutic knitting, developed by pioneers such as Betsan Corkhill, provides a useful framework for understanding these experiences. The rhythmic and purposeful nature of knitting and crochet allows participants to remain actively engaged in a meaningful process that combines cognitive stimulation, fine motor coordination, and social interaction. Beyond the immediate benefits for the person creating them, the objects produced, such as knitted sensory

aids, have an additional function, offering comfort, sensory stimulation, and opportunities for connection. In this way, the activity supports both the maker and the wider community, creating a cycle of engagement and meaningful contribution.

These activities can also benefit caregivers, healthcare professionals, and volunteers by creating opportunities for shared experience, collaboration, and social connection. They may further strengthen links between hospital environments and the wider community.

Due to its simplicity, accessibility, and adaptability, therapeutic knitting shows promise as a supportive non-pharmacological activity in hospital settings, potentially extending beyond dementia care. Future work should explore feasible ways of integrating these activities into clinical practice and systematically study their effects, including neurocognitive, physiological, and psychosocial mechanisms.

This presentation outlines the pathway from community collaboration to emerging clinical application and reflects on possibilities for further integrating therapeutic knitting into healthcare practice and research.

Sandra Kerovec, univ. mag. rehab. educ., is an educational rehabilitation specialist with more than twenty years of professional experience at the NGO OZANA, working with children and adults with intellectual disabilities. Founder and coordinator of Štrikeraj Café, an inclusive community programme that brings together people with and without disabilities through shared knitting and crochet activities, promoting social inclusion, creativity, and meaningful participation. Recently joined the University Psychiatric Hospital Vrapče, contributing to diagnostic and therapeutic work within a multidisciplinary team. Current focus includes exploring ways to introduce structured knitting and crochet activities as non-pharmacological supportive interventions in clinical and rehabilitative practice, building on long-standing experience with community-based creative programmes.



AVSTRIJA NA RAZPOTJU: NOVA ZDRAVILA ZA DEMENCO, A POMANJKLJIVA OSKRBA PO POSTAVITVI DIAGNOZE

Friederike De Maeyer, predsednica avstrijskega krovnega združenja za samopomoč
Demenz Selbsthilfe Austria
Dachverband Demenz Selbsthilfe Austria, Avstrija

Avstrija se sooča s prelomnim trenutkom na področju oskrbe oseb z demenco. Medtem ko nove terapije in napredna orodja za zgodnjo diagnostiko ponujajo izjemno upanje, obstoječi zdravstveni sistem razkriva pomembne vrzeli v podpori po postavitvi diagnoze.

Kot oskrbovalka in vodja organizacije Dementia Self-Help Austria Friederike de Maeyer poudarja, da zgodnja diagnoza prinaša le malo koristi, če ji ne sledi takojšnja celovita in proaktivna podpora.

Predstavitev zagovarja obvezno, na terenu delujoče (outreach) upravljanje primerov demence, podobno nizozemskim modelom, ki bi posameznike in družine usmerjalo skozi medicinske, socialne in finančne izzive od trenutka diagnoze dalje. Prav tako poudarja

potrebo po dostopnih rehabilitacijskih in v sodelovanje usmerjenih storitvah, zlasti za mlajše osebe z demenco, da se prepreči socialna izključenost in ohrani kakovost življenja.

Ključno je, kar Friederike de Maeyer poudarja, da mora biti zgodnja diagnoza vedno prostovoljna ter da je treba varovati »pravico ne vedeti«. Medicinski napredek ne sme voditi v družbeno krivdo. Končna odgovornost je na družbi, da ustvari pravne okvire za celovito oskrbo in preoblikuje priporočila v zanesljive pravice.

Ta predstavitev poziva k konkretnim zakonodajnim korakom v Avstriji, da se premosti vrzel med medicinskim napredkom in resnično življenjsko podporo za vse osebe, ki jih prizadene demenca.

Friederike de Maeyer je neformalna oskrbovalka in predsednica krovne organizacije Dachverband Demenz Selbsthilfe Austria (DDSA) – organizacije, ki združuje skupine medsebojne podpore za osebe z demenco in njihove oskrbovalce.

AUSTRIA AT A CROSSROADS: NEW DEMENTIA MEDICATIONS, BUT MISSING POST-DIAGNOSTIC CARE

Friederike de Maeyer, Chairwoman of the Austrian National
Association for Dementia Self-Help
Demenz Selbsthilfe Austria, Austria

Austria faces a critical juncture in dementia care. While new therapies and advanced early diagnostic tools offer unprecedented hope, the existing healthcare system reveals significant gaps in post-diagnostic support. As a caregiver and Chairwoman of the Austrian National Association for Dementia Self-Help, Ms. de Maeyer highlights that early diagnosis provides little benefit if not immediately followed by comprehensive, proactive support.

The presentation argues for mandatory, outreach-based dementia case management, similar to Dutch models, to guide individuals and families through medical, social, and financial challenges from the moment of diagnosis. It also stresses the need for accessible rehabilitation and participation-oriented

services, especially for younger individuals with dementia, to prevent social exclusion and maintain quality of life.

Crucially, Ms. de Maeyer emphasizes that early diagnosis must always be voluntary, safeguarding the “right not to know”. Medical progress should not lead to societal blame. The ultimate responsibility lies with society to create legal frameworks that ensure comprehensive care, transforming recommendations into reliable entitlements. This presentation calls for concrete legislative steps in Austria to bridge the gap between medical advancement and real-life support for all affected by dementia.

Friederike de Maeyer is an informal caregiver and Chairwoman of the Dachverband Demenz Selbsthilfe Austria (DDSA) – an umbrella organisation of self-help support for people with dementia and carers.



NEVROLOŠKA GLASBENA TERAPIJA: POT DO CELOSTNEGA ZDRAVJA PRI STARANJU IN DEMENCI

**Dr. Vidya Shenoy, integrativna terapevtka, specialistka
za staranje in oskrbo oseb z demenco**

Alzheimer's & Related Disorders Society of India, podružnica Mumbai, Indija

Glasba, na dokazih temelječ nefarmakološki pristop, je eno izmed obetavnih orodij integrativnih terapij, saj je dostopna, nizko tvegana intervencija z dokazano pozitivnim vplivom. Ohranja nevronske poti, vključene v čustveni spomin, ritmično usklajevanje in senzomotorično integracijo, izboljšuje grobo motoriko ter avtonomno regulacijo. Dolgoročno uporaba glasbene terapije izboljšuje kakovost življenja in dobrobit starajočega se prebivalstva, oseb z demenco in drugim pridruženimi boleznimi ter njihovih družin in primarnih ali profesionalnih oskrbovalcev.

Vsaka glasbena zvrst, bodisi instrumentalna bodisi pesmi z besedilom, vpliva na podzavest ter pomaga pri uravnavanju telesnega, čustvenega, kognitivnega, socialnega in duhovnega področja, z različnimi učinki pri različnih ljudeh in v različnih trenutkih. Glasbeno terapijo lahko izvajajo le usposobljeni strokovnjaki, poteka pa lahko individualno ali v skupinah. Ko je prilago-

jena posameznikovim potrebam, pomaga pri izražanju čustev, obvladovanju stresa, uravnavanju nihanj razpoloženja, lajšanju bolečine in izboljšanju komunikacijskih veščin.

Pri osebah z demenco spodbuja telesno in duševno rehabilitacijo ter omogoča in spodbuja spominjanje ter ohranjanje pomembnih življenjskih trenutkov. Je vsestranska in se lahko izvaja tudi v domačem okolju, v domovih za starejše, v ustanovah za asistiranje bivanja, v izobraževalnih ustanovah, šolah s prilagojenim programom, klinikah in bolnišnicah.

V tesnem sodelovanju z medicinskim multidisciplinarnim timom so izkušnje pokazale, da je glasbena terapija z neomejenimi viri prilagodljivo orodje za celostno "vadbo" možganov, ki prispeva k zdravljenju uma, telesa in duha. Ima pomembno vlogo pri kognitivnem izboljšanju, socialni povezanosti in čustvenem blagostanju ter s tem spodbuja celostno zdravje.

Dr. Vidya Shenoy, integrativna terapevtka in specialistka za staranje ter oskrbo oseb z demenco, je predana zagovornica demence, zmanjševanja tveganj, celostnega življenjskega sloga in nefarmakoloških pristopov s prilagojenimi programi za izboljšanje kakovosti življenja in dobrobiti. Je častna sekretarka ARDSI (Mumbai), ustanoviteljica iniciative Smriti Vishvam: Universe of Memory v Mumbaiju (Indija) in Purple Citizens' Brigade. Je strokovna članica tehničnega odbora Healthcare Sector Skill Council of India, ocenjevalka in izobraževalka na področju veščin oskrbe oseb z demenco, članica Indian Federation of Neuro-Rehabilitation, članica posebne interesne skupine Women in Neuro-Rehabilitation pri World Federation of Neuro-Rehabilitation ter International Association for Music & Medicine. Je članica upravnega odbora EDSiG, ambasadorica pobude Dementia Alliance International v Indiji in ambasadorica programa Purple Angel (UK), članica in učiteljica pri Shri Ambika Yoga Kutir ter Indian Music Therapy Association. Objavlja članke in knjige, uporablja različne platforme za promocijo zdravega življenjskega sloga in ozaveščanja o demenci, sodeluje v raziskavah, vodi delavnice na mednarodni ravni ter je prejemnica številnih nagrad.

NEUROLOGIC MUSIC THERAPY: CONDUIT TO HOLISTIC HEALTH IN AGING AND DEMENTIA

Dr. Vidya Shenoy, Integrative Therapist, Ageing and Dementia Care Specialist

Alzheimer's & Related Disorders Society of India, Mumbai, India

Music, an evidence-based, non-pharmacological intervention, is one of the encouraging tools in integrative therapies that is accessible, low-risk application, which has been deemed positively impactful. It preserves neural circuits involved in emotional memory, rhythmic entrainment, sensory-motor integration, improves gross motor skills and autonomic regulation. In the long run, deployment of music therapy improves quality of life and wellbeing of ageing population, those living with dementia and other comorbidities, their immediate family, and primary or professional caregivers. Each genre of music, instrumental or songs with lyrics, taps into the subconscious to manage physical, emotional, cognitive, social and spiritual domains with varied effects on people at different times. Music therapy must be practiced only by trained professionals and can be conducted as person-centered or

in groups. When customized to individual needs, it helps subjects to express feelings, manage stress, control mood swings, alleviate pain and improve communication skills. For those with dementia, it promotes physical and mental rehabilitation, facilitates and stimulates memory to recall and retain special moments. It is versatile and can also be practiced in homes, assisted living facilities, educational institutions, special, needs schools, clinics and hospitals.

Working closely as part of a medical, multi-specialty team, have experienced that music therapy with unlimited resources is adaptable to give the brain a holistic workout leading to healing of the mind, body and soul. It plays a significant role in cognitive enhancement, social connectedness, emotional wellbeing leading to wellness as it ameliorates and braces capacity to holistic health.

Dr. Vidya Shenoy, Integrative Therapist and Ageing & Dementia Care Specialist, is a passionate advocate of dementia, its risk reduction, holistic lifestyle and practices non-pharmacological interventions with customized modules to improve quality of life and wellbeing.

She is the Honorary Secretary of ARDSI (Mumbai), founder of the initiative Smriti Vishvam: Universe of Memory in Mumbai (India), and of the Purple Citizens' Brigade. She is a professional member of the technical committee of the Healthcare Sector Skill Council of India, as well as an assessor and trainer in dementia care skills, a member of the Indian Federation of Neuro-Rehabilitation, a member of the Women in Neuro-Rehabilitation Special Interest Group at the World Federation of Neuro-Rehabilitation, and a member of the International Association for Music & Medicine. She serves as a board member of EDSiG, an ambassador of the Dementia Alliance International initiative in India, and an ambassador of the Purple Angel programme (UK), as well as a member and teacher at Shri Ambika Yoga Kutir and the Indian Music Therapy Association. She publishes articles and books, uses various platforms to promote a healthy lifestyle and raise awareness about dementia, participates in research, leads workshops at the international level, and is the recipient of numerous awards..



STRUKTURA OSKRBE OSEBE Z DEMENCO V AVSTRALIJI

Daniela Car Jones

Predstavitev ponuja pregled možnosti podpore, ki so v Avstraliji na voljo družinam, ki skrbijo za osebo z demenco. Predstavlja strukturo sistema dolgotrajne oskrbe, primerjave različnih izvajalcev storitev ter pojasnjuje postopke za dostop do državnih oblik pomoči. Posebna pozornost je namenjena neodvisnim

oblikam oskrbe, zlasti storitvam, ki temeljijo na spletnih platformah, kot je Mable, pri čemer je poudarjena njihova prilagodljivost in možnost izbire za uporabnike. Namen predstavitve je opremiti družine s praktičnim znanjem za sprejemanje informiranih odločitev, prilagojenih njihovim potrebam in okoliščinam.

Daniela Car Jones že 32 let živi in dela v Avstraliji. Zadnjih 16 let dela z osebami z demenco in ima izkušnje kot negovalka in delovna terapevtka, z delom v paliativni oskrbi oseb z demenco, kot predstavnica za stike med ljudmi z demenco in njihovimi svojci ter izobraževalnimi organizacijami. Vodi »Dementia Cafe« za svojce oseb z demenco, oskrbo na domu in administracijo oskrbe na domu. Za delo z ostarelimi in osebami z demenco ima opravljene vse potrebne certifikate ter diplomu (Dementia Care) na univerzi v Tasmaniji.

STRUCTURE OF CARE FOR PEOPLE WITH DEMENTIA IN AUSTRALIA

Daniela Car Jones

The presentation provides an overview of the support options available in Australia for families caring for a person with dementia. It outlines the structure of the aged care system, compares different service providers, and explains the procedures for accessing government-funded forms of assistance. Particular attention is given to in-

dependent care options, especially services based on online platforms such as Mable, highlighting their flexibility and the degree of choice they offer to users. The aim of the presentation is to equip families with practical knowledge to help them make informed decisions tailored to their individual needs and circumstances.

Daniela Car Jones has lived and worked in Australia for 32 years. For the past 16 years, she has worked with people living with dementia and has experience as a caregiver and occupational therapist, including work in palliative care for people with dementia, as a liaison between people with dementia, their family members, and educational organizations. She leads a "Dementia Café" for family caregivers of people with dementia and is involved in in-home care and home care administration. She holds all the necessary certifications for working with older adults and people with dementia, as well as a Diploma in Dementia Care from University of Tasmania.



MAKING BREAKTHROUGHS HAPPEN

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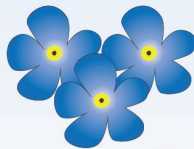
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