

Supplementary Material

The Dementia Assessment of Service Needs (DEMAND): Development and Validation of a Standardized Needs Assessment Instrument

List of services from the focus group discussion

Memory clinic

Hospital

General practitioner

Ophthalmologist

Otolaryngologist (ENT specialist)

Dentist

Neurologist

Day hospital (psychogeriatric)

Counseling services for family caregivers

Care support centers (facilities with specialized counseling services for people in need of care or family caregivers)

Dementia hotline/helpline

Speech and language therapist (SALT)

Occupational therapist

Physiotherapist

Short-term care/support

Nursing home/care homes

Adult daycare

Nightcare/overnight care

Mobile nightcare/overnight care

Outpatient care/services

Supported living services

Shared housing

District nurse

Dementia-friendly pharmacy

Online-based interventions

Apps

Socio/milieu therapy

MAKS therapy (a German acronym for Motor, Activities of daily living, Cognitive, Social)

Ethical and legal advice

Care counseling services

Visiting care counseling services

Dementia counseling services

Rehabilitation services for people with dementia

Rehabilitation services for family caregivers

Anti-dementia medications

General drug treatment/medications (non-dementia specific)

Mental health services for family caregivers

Mental health services for people with dementia

Visiting specialized dementia diagnostics

Cognitive training

Case management

Culturally appropriate care

Around The Clock (home) care

Pain management

Respite care

Public relations

Dementia choir

Vacation offers

Hikes/walks

Dance events

Excursions

Support by the employers

Paid caregiving leave

Caregiver Training Programs for family caregivers

Care training services

Training services for dyads (person with dementia and family caregiver)

Organized neighborhood assistance (organized voluntary support, e.g., household support, leisure activities, etc.)

Voluntary support by trained volunteers

Self-help groups

Caregiver support groups for family caregivers

Breakfast meetings

Housekeeping assistance

Cook

Meals on wheels

Financial support

Driving services

Public transport/dementia bus

Supervision groups (care of people in need of care in a small group in community centers (i.e., outside the home like in a dementia café/memory café) provided by professionals and volunteers)

Palliative care/end-of-life-care

SAPV (specialized outpatient palliative care) (multi-professional medical teams that provide around-the-clock end-of-life-care at home or in specialized facilities, like hospices)

Dementia-specific hospice care

Dementia café/memory café

Nutrition management

Financial counseling

List of services for the online survey

District nurse Visiting contact person who provides organizational support, coordination, care, and advice.

Case management (e.g., by a social worker): Coordination of health care providers and integration of services to provide the best possible treatment, involving case-finding, assessment, care planning, and care coordination.

Dementia-friendly pharmacy: Pharmacy that is specifically tailored to the needs of people with dementia and offers low-threshold information on dementia.

Supported living and alternative housing services (e.g., shared housing): Accommodations for independent living with additional (bookable) services (e.g., nursing, housekeeping assistance).

Short-term care/support: Provision of care and nursing for the person in need of care temporarily in an inpatient facility (care home).

Nursing home/care home: Facility in which the person in need of care is cared for permanently (all day) by professional nursing staff.

Adult daycare: Care of the person in need of care during the day in a facility, including therapeutic, social, and health services. A transport service is offered.

Nightcare/overnight care: Facility in which care recipients are looked after and cared for overnight. The patient returns home in the morning.

Mobile nighttime/overnight care: Regular assistance with nursing and care activities at home during the night.

Outpatient care/services: Regular assistance with nursing activities at home during the day.

Around The Clock (home) care: The person in need of care is cared for around the clock in his or her own home by a professional caregiver.

Respite care: If the family caregiver is unavailable due to vacation, illness, etc., care can be provided at home by others (professionals, volunteers) or in a care home.

Day hospital (e.g., psychogeriatric): An outpatient facility where diagnostics, medical treatments, and various therapies can be received (e.g., especially for older people with mental illnesses).

Ophthalmological care: Diagnostics and treatment of disorders of the eye.

Otolaryngological (ENT) care: Diagnostics and treatment of disorders of the ears, nose, and throat.

Dental care: Diagnostics and treatment of oral, dental, and jaw disorders.

Primary care by a general practitioner: Treatment of all common medical conditions and referral of patients to hospitals and other medical services for urgent and specialist treatment.

Specialist care (e.g., ophthalmologist, otolaryngologist (ENT specialist), dentist)

Geriatric holistic care/services: Specialized and holistic health care for older adults.

Visiting specialized dementia diagnostics: Early/differential diagnostics of memory disorders and dementia, e.g., in the home setting.

Specialized dementia diagnostics; Early/differential diagnosis of memory disorders and dementia, e.g., in memory clinics or at neurologists.

Provision of psychosocial interventions (e.g., MAKS therapy, cognitive training, occupational therapy, speech and language therapy (SALT), physical therapy):

Psychosocial interventions include memory exercises/cognitive training, psychosocial activation, and exercise programs, intending to maintain and strengthen existing skills.

Online-based interventions and apps

Ethical and legal advice for dementia: Specialized counseling on topics such as health care proxy, force-feeding, sedation, or assisted suicide.

Care counseling services (e.g., provided in care support centers): Specialized counseling on topics such as the need for and utilization of social benefits or care services as well as general issues concerning the support for people in need of care and their family caregivers.

Dementia counseling services (e.g., counseling services for family caregivers, dementia hotline/helpline): Specialized counseling and support on issues concerning dementia.

Housing advice for dementia: Specialized advice concerning adjustments of the home because of dementia: That includes aids for wandering tendencies, reducing the risk of injury, orientation aids, etc.

Counseling services (e.g., dementia counseling services, care counseling services, housing advice)

Rehabilitation services for people with dementia: Special healthcare services that help a person regain physical, mental, and/or cognitive (thinking and learning) abilities that have been lost or impaired as a result of a disease, e.g., massages, physiotherapy, or psychotherapeutic talks. The services can be provided on an outpatient, or inpatient basis.

Rehabilitation services for family caregivers: Special healthcare services that help a person regain physical, mental, and/or cognitive (thinking and learning) abilities that have been lost or impaired as a result of a disease, e.g., massages, physiotherapy, or psychotherapeutic talks. These services can be provided on an outpatient, or inpatient basis.

Drug treatment/medications (e.g., anti-dementia medications, neuroleptics, anti-depressants, painkillers): Use of drugs to treat the symptoms of dementia or comorbidities.

Mental health services for family caregivers: Prevention, early detection, and treatment of mental disorders using medication and/or talks.

Leisure activities (e.g., breakfast meetings, dementia choir, hikes/walks, dance events): Entertainment for people with dementia and their family caregivers/members.

Caregiver Training Programs for family caregivers (e.g., group psychoeducation): Information about the disease and treatment, promotion of self-responsible handling and support in coping with the disease as well as teaching skills for independent caregiving.

Caregiver support groups for family caregivers/self-help groups: A guided group for regular exchange of experience and information as well as mutual support.

Services for support in everyday life (e.g., voluntary support by trained volunteers, organized neighborhood assistance): All services provided by trained volunteers to people suffering from dementia. The volunteers do not perform any nursing activities.

Housekeeping assistance: Service to assist in the household, e.g., shopping, cooking, tidying up, cleaning, washing, gardening, etc.

Meals on Wheels: Service in which prepared meals are delivered to the home.

Nutrition management

Mobility assistance: This service can be provided by (public) transport services or dementia buses, in order to transport people to medical facilities (e.g., general practitioners, hospitals, physiotherapists, etc.). This does not refer to the transport service offered by adult daycare facilities.

Supervision groups: Care of people in need of care in a small group in community centers (i.e., outside the home like in a dementia café/memory café) provided by professionals and volunteers.

Palliative care/end-of-life-care: Care of people and their relatives who are facing the problems associated with a life-threatening illness in the last months or years of their life.

Support for problems with alcohol/drugs/smoking

Acquisition of aids: Facility where aids can be purchased or obtained on prescription, e.g., medical supply store or orthopedic clinic.