**Appendix 1.** Sixteen national dementia strategies in 14 countries

|  |  |
| --- | --- |
| Country | Strategy included in analysis |
| England | Living well with dementia: A National Dementia Strategy 2009-2014 |
| Wales | National Dementia Vision for Wales 2011, Dementia stakeholder groups – action plans |
| Scotland | Scotland’s National Dementia Strategy 2010Second Scotland’s National Dementia Strategy 2013-2016 |
| Northern Ireland | Improving Dementia Services in Northern Ireland: A Regional Strategy 2011 |
| France | National Alzheimer Disease Plan (Plan << Alzheimer et maladies apparentées>>) 2008-2012 |
| The Netherlands | Integrated Dementia Care (Ketenzorg Dementie) 2008-2010 |
| Denmark | National Dementia Action Plan (National Handlingsplan for Demensindsatsen) 2010-2014 |
| Finland | National Memory Plan (Kansallinen Muistiohjelma) 2012-2020 |
| Norway | Holistic Dementia Plan (Demensplan) 2015 |
| Sweden | National Guideline for Care in Cases of Dementia (Nationella Riktlinjer för Vård och Omsorg vid Demenssjukdom) 2010 |
| United States | National Plan to Address Alzheimer’s Disease: 2013 Update |
| Australia | National Framework for Action on Dementia 2006-2010 |
| Japan | Five-Year Plan for Promotion of Measures Against Dementia (Orange Plan) 2013-2017 |
| South Korea | Dementia Comprehensive Management Measures (치매 종합관리대책)Second National Dementia Management Master Plan (제2차국가치매관리종합계획) 2013-2015 |

**Appendix 2.** Domains and recommendations from the European Association for Palliative Care (EAPC) identified in sections of national dementia strategies that were not specific to palliative care

|  |  |  |
| --- | --- | --- |
| Country | Domain | Example from strategy documentation |
| England | 1. Applicability of palliative care ++ (1.1, 1.2) | (P.90) enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes. |
|  | 2. Person-centered care, communication and shared decision making +++ | Objective 3: Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available both at diagnosis and throughout the course of their care. |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.4) | (P.39) Information should also be available on what options exist for planning ahead for those diagnosed with dementia, to ensure that their desires and wishes are properly considered were they to lose mental capacity. |
|  | 4. Continuity of care +++ | Objective 4: Enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (P.54) Pathways out of hospital and to avoid hospitalisation, such as intermediate care, often exclude people with dementia, meaning that they cannot access rehabilitation services that could enable them to return home or prevent their admission to hospital. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (P.60) the formulation and deployment of non-pharmacological management strategies for behavioural disorder in dementia, so avoiding the initiation of anti-psychotic medication |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3, 9.4, 9.5, 9.6) | Objective 7: Implementing the Carers’ Strategy for people with dementia. (…) Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues ++(11.8) | (P.19) Those involved in developing the Strategy worked closely with other emerging policy initiatives such as the NHS Next Stage Review, the Carers’ Strategy, End of Life Care Strategy and Putting People First. |
| Wales | 1. Applicability of palliative care - | -- |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.3, 2.4) | (Vision, P.4) Improved access to better information and support for people with the illness and their carers, including a greater awareness of the need for advocacy |
|  | 3. Setting care goals and advance planning ++(3.1, 3.6) | (Action 2, P.8) Some people with dementia are not being given any assessments after the initial one; or at least if they are they are not aware of it and do not have it communicated to them. People with dementia and their carers must be made aware of the review and invited to contribute to it. |
|  | 4. Continuity of care +++ | (Vision, P.9) Crucially, all services will need to work together in an integrated way, adding value to each and enabling services to be tailored to the individual needs of people affected by dementia. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (Action 1, P.4) UHBs and LAs to publish plans for further developing intermediate care services (above and beyond the availability of integrated CMHTs for Older People providing out of hours/crisis support), aimed at preventing admissions to acute mental health wards, ‘social’ admissions to general hospital wards and breakdowns in home caregiving situations . |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.4) | (Action 1, P.10-11) UHBs to publish performance reports in relation to impact of Hospital Old Age Liaison Psychiatry Teams, including: (…) anti-psychotic prescribing and review for people with diagnosed dementia in line with intelligent targets (3 monthly reviews undertaken; people prescribed anti-psychotics after 9 months) |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.3, 9.4) | (Vision, P.10) creating training packages (learning resources) to support carers |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| Scotland | 1. Applicability of palliative care ++(1.2) | (Second, P.2-3) we must offer care and support to people with dementia and their families and carers in a way which promotes wellbeing and quality of life, protects their rights and respects their humanity. |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4) | (Second, P.3) we must continue to improve services and support from when someone presents for diagnosis, and throughout the course of the illness, including the support needs of carers. This support must be truly person centred, and should understand care and support from their perspective, not the perspective of service managers or clinicians.(Second, P.11) The dementia standards are based on six overarching statements of individual rights: (…) I have the right to be regarded as a unique individual and to be treated with dignity and respect |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.4, 3.7) | (Second, P.5) Timely diagnosis enables people to plan ahead while they still have capacity to do so and means they can get early and effective access to drug and other interventions which can sustain their cognition, mental wellbeing and quality of life.(Second, P.11) environments, especially in hospital, that are not sufficiently enabling for people with dementia a lack of individual care planning based on the individual’s life story variable practice in assessing capacity to consent to treatment and giving treatment lawfully. |
|  | 4. Continuity of care +++ | (Second, P.9) This 8 Pillar model focuses specifically on that stage of the illness where more intensive community services are needed to enable people to stay living well and as independently as possible at home for as long as possible. The model is based on a coordinated, holistic approach which also aims to provide continuity of care in the form of that key contact point for people with dementia and their carers.(Second, P.12) earlier identification of people with palliative care needs , to promote advance care planning, to facilitate the sharing of key information across settings through the development and roll out of the Electronic Palliative Care Summary |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (First, 64) A person with dementia should only be admitted to hospital when the necessary treatment cannot be provided where they live. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (Second, P.18) We will finalise and implement a national commitment on the prescribing of psychoactive medications, as part of ensuring that such medication is used only where there is no appropriate alternative and where there is clear benefit to the person receiving the medication. |
|  | 8. Psychosocial and spiritual support ++(8.1) | (First, 31) More effective post-diagnostic support should include access to information about dementia, therapeutic support to help with emotional adjustment, support to self-manage the symptoms, help with legal, financial and future care planning and access to peer support. |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3, 9.4) | (Second, P.5) more people with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness. |
|  | 10. Education of the health care team ++(10.1) | (Second, P.11) The standards are designed to inform care providers of their responsibilities and to help them self-audit services and to empower people with dementia and their carers. (…) Rights-based training has been developed for care home staff. |
|  | 11. Societal and ethical issues ++(11.1,11.7, 11.8) | (Second, P.4) Our work on dementia is one strand of the wider work that we are taking forward to transform and improve health and social care services. Other key strands of that work include: Palliative Care: Living and Dying Well; a National Action Plan for Palliative and End of Life Care (2008) and Living and Dying Well: Building on Progress. Work (2011) promote the provision of palliative and end of life care to all, regardless of diagnosis, and is consistent with, and highly supportive of, improvements in care for people with dementia and their families.(Second, P.12) We will take more action specifically in relation to dignity and respect, including attention to human rights and the principles and requirements of mental health and incapacity legislation |
| Northern Ireland | 1. Applicability of palliative care - | -- |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4, 2.6) | (5.3) In assessing need and in planning and delivering care, it is essential to view the individual as a whole person, not simply as a set of symptoms. |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.4, 3.7) | (7.1) Early diagnosis is important as it allows the person with dementia to: (…) make choices and plans for the future, with their family, while the condition still permits this. |
|  | 4. Continuity of care +++ | (5.18) The HSC Board and PHA will draw up a service specification to inform regional and LCGs’ commissioning for dementia care with a focus on service re-design. The specification will focus on: (…) developing appropriate linkages across the HSC and with appropriate agencies outside the HSC to provide a seamless service from the user’s point of view |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (8.34) Intermediate care can provide an alternative to inappropriate admissions and a bridge to effective acute intervention. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.3, 7.4) | (8.16) There are concerns about the use of antipsychotic drugs among people with dementia for the management of behavioural and psychological symptoms, such as hallucinations, delusions, anxiety, agitation and associated aggressive behaviour. NICE guidance recommends the use of medication for such symptoms only if there is severe distress or an immediate risk of harm to the person or to others. |
|  | 8. Psychosocial and spiritual support ++(8.1) | (8.2) Getting a diagnosis of dementia is often distressing and the way in which information, advice and support are offered can make a big difference in helping people cope with the diagnosis. |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3, 9.4, 9.5, 9.6) | (11.8) Family members and other carers may have to make decisions on behalf of the person with dementia; these may be important decisions about their care or about their finances. |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| France | 1. Applicability of palliative care ++(1.2) | (measure 6) These specialized teams will considerably improve the care given to Alzheimer's patients, but also all dependent elderly people: it will improve their quality of life and that of their families, creating the conditions for a real choice between care at home and care in an institution |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.3, 2.4, 2.6) | (measure 13) A high-quality service will involve first, listening to the requirements of the person concerned and his or her carers, and then offering, on request and according to the social and psychological context, the necessary support and the fundamentals of the care and support plan, emphasising the essential ease of access to the primary-care doctor. |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.4, 3.6) | (measure 8) Given the specific characteristics of this disease, which call for long-term social care above and beyond the medical treatment itself, the diagnosis must be given as part of a package of information for the patient and the family, not only about the disease itself but also about how the treatment plan will work and the possibility of social support. |
|  | 4. Continuity of care +++ | (measure 4) A coordination centre bringing together the health sector and the medico-social sector will be created (on the basis of existing facilities, without superimposing a new structure): it will continue a “single desk”, a “single point of contact” for users. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.2) | (measure 14) Drug-related accidents arising in subjects suffering from Alzheimer's disease, and more generally in the very elderly, are inadequately reported to drug safety centres and the drug risk is incompletely evaluated in this population. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (measure 15) To deal with behavioural problems, sedative medication, although raising many questions, can nevertheless prove indispensable in certain specific cases. However, there are no data in the literature that would enable a particular class of medication to be recommended for these patients. |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3) | (measure 3) The role of family carers in looking after Alzheimer's sufferers is an essential one. Patients are confronted with many difficulties, including three specific periods when the burden is particularly heavy: information regarding the diagnosis, organisation of support and management of crises. |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| The Netherlands | 1. Applicability of palliative care ++(1.1, 1.2) | (P.3) The patient becomes incontinent, at one point loses the ability to walk and ultimately passes away in a completely weakened state. |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4, 2.5) | (P.12) By good dementia care we mean the range of services that people with dementia and their families would like to receive, according to the latest insights and from the perspective of clients and their families. |
|  | 3. Setting care goals and advance planning ++(3.1, 3.2, 3.3, 3.4, 3.6, 3.7) | (P.15) For the sake of continuity in the care process, the diagnosis of dementia should be immediately followed by the compilation of a ‘care-live plan’ in consultation with the client system. |
|  | 4. Continuity of care +++ | (P.13) During this phase too, it is necessary and crucial to provide effective case management in order to be able to monitor the burden on the informal carer on an ongoing basis and to anticipate the patient’s future care needs. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (original language, P.95) Door goede afspraken te maken over respijtzorg en monitoren van cliënten en mantelzorgers kunnen ketens het aantal crisisopnamen zo laag mogelijk houden. Bijvoorbeeld door voorkoming van overbelasting van de mantelzorger (vermijdbare opname). (By making good agreements on respite care and monitoring of clients and caregivers chains of care can keep the number of crisis admissions as low as possible. For example by preventing overload of the caregiver (avoidable admission).) |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.4) | (P.20) The case manager’s tasks at the very least include care diagnosis, cyclic coordination (identification, arrangement, assessment and adjustment) of care and treatment, providing psychosocial system support (information, psychoeducation, family discussions, coping with grief), offering practical support (e.g. care mediation) and therapeutic treatment (cognitive and behavioral). |
|  | 8. Psychosocial and spiritual support ++(8.1) | (P.3) Contrary to popular belief, dementia patients can, disordered thought notwithstanding, experience psychological pain and become depressed, sad or anxious as a result of losing a broad array of abilities. |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3, 9.6, 9.7) | (P.3) For family and friends, dementia means a long-term mourning process for the loss of a loved one. |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| Denmark | 1. Applicability of palliative care - | -- |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4) | (P.17) Personen med demens skal så vidt muligt udøve sin selvbestemmelsesret, samtidig med at medarbejderne har de rette rammer til at kunne yde den bedst mulige social- og sundhedsfaglige indsats og efterleve deres pligt til at yde omsorg og behandling. (The person with dementia should, as far as possible, exercise its right to self-determination, while the employees have the right framework to be able to provide the best possible health and social care professional efforts and comply with their obligation to provide care and treatment.) |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.4, 3.7) | (P.17) En person med demens kan udarbejde et plejetestamente for at tilkendegive ønsker for den fremtidige pleje og omsorg, mens vedkommende stadig er i stand til dette. (A person with dementia may prepare a care testament to express wishes for future nursing and social care while he is still able to do so.) |
|  | 4. Continuity of care +++ | (P.9) Det er derudover afgørende, at samarbejdet formaliseres, så personen med demens og de pårørende har klarhed over, hvor de kan henvende sig om hjælp og behandling, og hvem der har ansvaret for at yde den nødvendige indsats. (It is also essential that cooperation is formalized so that the person with dementia and their relatives are clear about where they can turn for help and treatment, and who is responsible for providing the necessary support.) |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment - | -- |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1) | (P.14) I mange kommuner opleves de socialfaglige indsatser både af medarbejdere, personer med demens og pårørende at have en positiv effekt, blandt andet i forhold til at undgå brugen af magt. (In many municipalities, the social work interventions both by professional caregivers and people with dementia and their relatives had a positive effect among other things in relation to avoid use of force.) |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.2) | (P.20) Samtidig kan arbejdsgruppen konstatere, at der i dag findes en meget bred vifte af tilbud om støtte og rådgivning, dag- og aktivitetstilbud samt afløsning og aflastning til personer med demens og deres pårørende. Det er væsentligt, at disse tilbud er målrettede den enkelte families behov og gives fra et tidligt tidspunkt i sygdomsforløbet. (At the same time, the working group noted that today there is a very wide range of support services, counselling, and day-care and activities as well as respite care for people with dementia and their relatives. It is essential that these offers are targeted to the individual family’s needs and given from early stage of dementia.) |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| Finland | 1. Applicability of palliative care ++(1.2, *1.2, 1.4*) | (P.13) Rehabilitation includes services aimed at improving or maintaining patients’ability to function as well as services designed to decelerate the rate of decline; whatever the circumstances, the goal is always to optimise functional capacity and the quality of life.(P.14) Palliative care becomes relevant for people with dementia when prolonging life is no longer meaningful. (…) The provision of timely support, care and services is based on a) comprehensive assessments of patients’ health and resources and their ability to function; b) maintaining and promoting patients’ rehabilitation and coping, controlling behavioural and psychological symptoms and treating illnesses efficiently; and c) good palliative and end-of-life care when prolonging life is no longer meaningful. |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4, 2.6) | (P.11) The basic rights and 1 of people with dementia and their right to make decisions about their own lives independently are guaranteed. |
|  | 3. Setting care goals and advance planning ++(3.1, 3.2, 3.3, 3.6, 3.7) | (P.14) Personalised palliative care plans and clear documentation help to coordinate the work of the professionals involved, alleviate the anguish of patients’ families and improve patients’ quality of life even as they near death.(P.15) Clinical pathways will be designed so as to take into account the changing circumstances of the patients and the possibility of them requiring urgent attention as well as their need for good end-of-life care. |
|  | 4. Continuity of care +++ | (P.13) Case management and coordination are vital for ensuring that the services provided to people with dementia make up a seamless and comprehensive bundle. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (P.14) Ideally, people with dementia should be able to stay in the same place and services be brought to them. This is due to the fact that transitions are especially challenging for them. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (P.18) They treat people with memory disorders and dementia and their families with respect in all service areas, take the characteristics of different memory disorders and types of dementia into consideration when deciding on the appropriate treatment, are able to control the onset of behavioural symptoms and situations arising from them by means of preventive action and support patient’s ability to function. |
|  | 8. Psychosocial and spiritual support + | (P.14) Palliative care focuses on alleviating pain and other symptoms while also being considerate of patients’ psychosocial and spiritual views and beliefs. |
|  | 9. Family care and involvement ++(9.1) | (P.13) Case management also involves an assessment of the opportunities of the patient’s family and friends to form a support network to help the patient cope with daily life. |
|  | 10. Education of the health care team ++(10.1) | (P.18) education authorities and organisations give particular attention to ensuring that basic, further and supplementary social welfare and health care training include enough elements aimed at promoting brain health, detecting memory disorders in their early stages, treating and rehabilitating patients, providing palliative and end-of-life care and supporting people with dementia and their families |
|  | 11. Societal and ethical issues ++(11.1) | (P.14) One of the most important tasks is to widen the range of services available at units offering 24-hour care so that residents there have access to any health care and rehabilitation services that they require as well as endof-life care. |
| Norway | 1. Applicability of palliative care ++(1.2) | (P.9) The aim of the measures in the Dementia Plan is for the individual to have a good quality of life, feel secure and have a meaningful day-to-day existence despite serious illness and functional impairment. |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.3, 2.4) | (P.14) Persons with dementia and their families are to receive the information and assistance they need as well as individually adapted services from the municipal government and specialist health service. |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3) | (P.16) A large number of persons with dementia need several coordinated services and thus are entitled to an individual plan. |
|  | 4. Continuity of care ++(4.1, 4.2, 4.4) | (P.9) Services offered shall be based on a holistic view of the person and characterised by continuity and interaction between various service providers. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (P.9) For persons with dementia, moving may often exacerbate the symptoms and create confusion and passivity. For that reason one should avoid as much as possible moving between different living arrangements and treatment offerings, and aim for continuity and a sense of belonging. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (P.12) Persons with dementia who have behavioural problems need specially adapted services in small and reinforced units. In this area skills development and collaboration between professions and municipalities are necessary. |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.3, 9.4) | (P.12) Families need information about dementia disorders, relevant treatment and available support mechanisms and they need to be included in the evaluation. |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| Sweden | 1. Applicability of palliative care ++(1.2) | (P.71) Ett viktigt mål för vården och omsorgen om den demenssjuke är att minska dennes illabefinnande och öka välbefinnandet, det vill säga livskvaliteten. (One important objective in caring for dementia sufferers is to reduce their sense of ill-being and increase their well-being, i.e. their quality of life.) |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4, 2.6) | (P.22) Hälso- och sjukvården och socialtjänsten bör ge personer med demenssjukdom en personcentrerad omvårdnad (prioritet 1). (Healthcare, nursing and social services personnel should provide person-centered care to persons with dementia (priority 1).) |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.6) | (P.76) Vård- och omsorgsplanering baserad på ett reellt samarbete mellan den demenssjuke, närstående och personal kan öka möjligheten till att den enskildes självbestämmande och inflytande tillgodoses och att vården och omsorgen individualiseras. (Care and nursing planning based on true cooperation between the dementia patient, his/her close relatives, and the healthcare and nursing staff can increase the their ability to affirm the self-determination and influence of the individual and to individualize their care and nursing.) |
|  | 4. Continuity of care ++(4.1, 4.4) | (P.40) Socialtjänsten bör förbereda flytten genom att i god tid ge information och om möjligt engagera närstående, ge möjlighet till platsbesök samt ta del av personernas sjuk- och livshistoria (prioritet 2). (Social services should prepare for the move by providing timely information and potentially engage the patient’s relatives, provide the opportunity to visit the premises and review the person’s medical and life history (priority 2).) |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.2, 6.3) | (P.54) Hälso- och sjukvården och socialtjänsten bör erbjuda sin personal utbildning och handledning för att minska användandet av fysiska begränsningsåtgärder (prioritet 1). (Healthcare, nursing and social services personnel should offer the staff training and guidance to reduce the use of physical restraints (priority 1).) |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.2, 7.3, 7.4) | (P.34) De olika beteendemässiga och psykiska symtom som kan uppträda vid demenssjukdom kan inte alla behandlas på ett och samma sätt. Behandlingen inriktas istället på att i varje enskilt fall åtgärda orsakerna eller de utlösande faktorerna till symtomen. (The different behavioral and psychotic symptoms that can appear during dementia cannot all be treated in the same way. Treatment is therefore targeted to remedy the causes or triggering factors for the symptoms in each individual case.) |
|  | 8. Psychosocial and spiritual support + | (P.45) Anhöriga kan också få så kallat psykosocialt stödprogram vilket kan ges individuellt, i par, familj eller i form av ledarledda gruppsammankomster, där de tillsammans delar med sig av sin situation och sina känslor som anhörigvårdare. (Relatives can also receive a so-called psychosocial support program, which can be provided on an individual basis, in pairs, with the family, or in the form of guided group meetings, where they can share their situation and feelings as family caregivers.) |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3, 9.4) | (P.45) Det finns också utbildningsprogram som ofta sker i grupp och som består av strukturerad information och utbildning om demenssjukdomen, dess symtom, orsaker och förväntad utveckling. (There are also training programs that often occur in groups and consist of structured information and education regarding dementia, its symptoms, causes and expected course of the disease.) |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| United States | 1. Applicability of palliative care - | -- |
|  | 2. Person-centered care, communication and shared decision making ++(2.3, 2.4) | (P.18) Further, once a diagnosis is made and disclosed, as few as half of patients and families receive counseling, support, or information about next steps. This information is important, especially for early-stage patients who experience positive outcomes when they are involved in planning and receive appropriate services. |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.4) | (P.18) Outside of the clinical-care setting, families and people with AD need specialized assistance in planning for AD-specific needs and accessing appropriate services. |
|  | 4. Continuity of care +++ | (P.20) Coordinating the care received by people with Alzheimer’s disease in different settings by different providers can help reduce duplication and errors and improve outcomes. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (P.19) People with AD are at high risk of adverse events due to poor communication and other care process deficiencies during transitions and need support to help them determine the best timing for transition and site of care. |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (P.26) CMS is leading a collaborative effort to reduce inappropriate and off-label use of antipsychotic and behavior modifying agents in nursing homes. |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.2, 9.3, 9.4) | (P.23) Caregivers report that they feel unprepared for some of the challenges of caring for a person with Alzheimer’s disease -- for example, caring for a loved one with sleep disturbances, behavioral changes, or in need of physical assistance can be an enormous challenge. |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |
| Australia | 1. Applicability of palliative care ++(1.2) | (P.7) The five priority areas for action have been identified in consultation with people living with dementia, their carers and families and other stakeholders and are fundamental to improving quality of life for people with dementia. |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.2, 2.3, 2.4, 2.6) | (P.9) Effective, appropriate, quality and accessible care is provided: (…) focusing on person centred planning; through involving carers and family members |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.7) | (P.13) Availability of legal framework to enable inter-jurisdiction recognition of Guardianship, advance care planning and advance care directives, wills and powers of attorney. |
|  | 4. Continuity of care ++(4.1, 4.2, 4.4) | (P.7) Australian Governments, along with service providers and the broader community, working together to create an accessible, seamless pathway for people with dementia, their carers and families. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment - | -- |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.4) | (P.11) Behavioural issues: identify and promote evidence based service models and funding arrangements for the assessment, management, support and accommodation of people with dementia and behavioural issues. |
|  | 8. Psychosocial and spiritual support + | (P.13) The need to support and recognise the emotional, psychological and physical needs of carers. |
|  | 9. Family care and involvement ++(9.1, 9.3, 9.4, 9.6) | (P.13) Carers require different information at different stages of dementia, including advice and guidance from professionals as well as information about the experiences of other carers. |
|  | 10. Education of the health care team ++(10.1) | (P.11) develop workforce, education and training initiatives for health professionals and community care providers that inform them about palliative care and the needs of people with dementia. |
|  | 11. Societal and ethical issues ++(11.4, 11.8) | (P.8) Other national initiatives relating to broader health, ageing and community care issues that have influenced the development of the National Framework for Action on Dementia 2006–2010 include: (…) National Palliative Care Strategy (2000)(P.11) Develop palliative care workforce, education and training initiatives for health professionals and community care providers. |
| Japan | 1. Applicability of palliative care - | -- |
|  | 2. Person-centered care, communication and shared decision making ++(2.1, 2.3, 2.4) | (P.12) 標準的な認知症ケアパスの作成に当たっては、「認知症の人は施設に入所するか精神科病院に入院する」という従来の考えを改め、「施設への入所や精神科病院への入院を前提とせず、認知症になっても本人の意思が尊重され、できる限り住み慣れた地域のよい環境で暮らし続ける」という考え方を基本とする必要がある。(The traditional norm, that people with dementia will be generally admitted to residential facility or hospital, should be transformed. The establishment of standardized dementia care pathway should be based on the concept that people with dementia will not be premised on admitting to residential facilities or psychiatric hospitals; they will be treated with respect to their own wishes; and they will remain living in good environment at their familiar communities as long as possible regardless of having dementia.) |
|  | 3. Setting care goals and advance planning ++(*3.2*, 3.3, *3.6*, 3.7) | (P.16) アセスメント結果や地域ごとに作成した標準的な認知症ケアパスを活用し、ケアマネジャーがケアプラン（将来的に状態が変化し重症となった場合や緊急時対応等を含む。）を作成する。(Care managers should plan care of people with dementia (including advanced care plans for increasingly impaired condition and interventions at crisis) by taking into account results from assessment and the standardized dementia care pathway in the region.) |
|  | 4. Continuity of care +++ | (P.4) 「早期支援機能」として期待されるのが、「認知症初期集中支援チーム」である。このチームは、地域での生活が可能な限り維持できるようにするための初期集中支援を、発症後できる限り早い段階で包括的に提供するものであり、新たな認知症ケアパスの「起点」に位置づけられる。(The Initial-Phase Intensive Support Team is expected as an early support functioning in dementia care. This team will provide early intensive supports in a holistic approach to people with dementia at the earliest stage of developing dementia to enable them remain living at their community as long as possible, and is designated as new starting point of the dementia care pathway.) |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.1) | (P.15) 「身近型認知症疾患医療センター」の医師が、一般病院や介護保険施設・事業所に訪問して、行動・心理症状の認知症の人に対する専門的な医療を提供すること等により、行動・心理症状の増悪による転院や入院の回避を支援する。(Physicians at the Regional Medical Center for Dementia will help people with dementia avoid changing hospital or new hospitalization due to increasing behavioral and psychological symptoms by outreach service of specialized medical interventions for behavioral and psychological symptoms to people with dementia at general hospitals, residential facilities, or home care providers under the public long-term care insurance program.) |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.4) | (P.17) 認知症に対する薬物の影響や行動・心理症状に対する適切な薬物治療と非薬物治療についての検証、ならびに実践的なガイドラインを策定し、普及を図る。(The national government will examine effects of medication on people with dementia and appropriate pharmacological and non-pharmacological treatment for behavioral and psychological symptoms, and establish and disseminate a practical guideline.) |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1) | (P.23) 地域包括支援センター職員やケアマネジャーなどが、認知症の人のアセスメントを行う際に、認知症の人だけでなく、家族との間の関係性の中に生ずる問題にも十分焦点を当てるとともに、その理解や対応を通じて、家族の過重な負担の軽減につながる可能性も踏まえて行うよう徹底する。(The national government should ensure that personnel of the Community General Support center and home care managers employ full assessment of issues in relationship between people with dementia and their families as well as people with dementia, in consideration with possible reduction of families’ heavy care burden throughout comprehension and interventions to the relation issues.) |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues ++(11.5) | (P.20) 「グループホーム」入所者の重度化や看取りの対応を強化する観点から、「医療連携体制加算」や「看取り介護加算」として評価しており、この評価を継続して実施する。(The national government will continue additional benefit schedules for “coordination system with healthcare provider” and “provision of end of life care” under the public long-term care insurance program to enhance service provision for increasing impairment and end-of-life care of residents in “group homes”.) |
| South Korea | 1. Applicability of palliative care ++(*1.1*) | (Second, 치매예방관리 10대 수칙 10 tips for dementia prevention and management) 치매 초기에는 치료 가능성이 높고, 중증으로 가는 것을 방지할 수 있다. (In early phase of the disease, dementia is curable and progression is preventable.)  |
|  | 2. Person-centered care, communication and shared decision making ++(2.3, 2.4) | (Second, IV 세부 추진과제 detailed initiatives, 과제 issue 2) 치매환자 보호의 질 제고를 위해 치매 유형별, 중증도별 특성에 적합한 치료 및 보호서비스 지원 강화 (To improve quality of protection for people with dementia, the national government will enhance support services for treatment and protection of people with dementia should be according to characteristics of type of dementia and severity.) |
|  | 3. Setting care goals and advance planning - | -- |
|  | 4. Continuity of care ++(4.3) | (Second, IV세부 추진과제 detailed initiatives, 과제 issue 3①) 치매환자 방문•사례관리를 위해 필요한 지원인력 (사례관리사) 은 최소 1명 이상 확보하고 보건소 포괄보조금사업의 우선사업으로 실시 (Support personnel needed for visitation/case management for people with dementia (case manager) should be staffed with at least one person, and their activities should be implemented as a priority of comprehensive projects at health center.) |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment + | (Second, IV 세부 추진과제 detailed initiatives, 과제 issue 2④) 말기 치매환자는 효과를 기대하기 어려운 의료 행위 지양, 양질의 관리서비스 제공을 위한 말기 치매환자 관리 지침 확립•보급 (Medical practices that are unlikely to have effects on people with dementia at last stage should be avoided. The guideline should be established and disseminated for management of people with dementia at end-of-life stage to provide high-quality care services.) |
|  | 7. Optimal treatment of symptoms and providing comfort - | -- |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement ++(9.1, 9.3) | (Second, IV세부 추진과제 detailed initiatives, 과제 issue 4) 치매환자의 60%는 가족이 간병, 주 부양자 1명(배우자 40%, 며느리 17%)이 전담하고 있어 가족에 대한 부담 완화 필요 (60% of people with dementia are cared by their family member, mainly one person (spouse of the person 40%, spouse of the person’s son 17%) so that reduction of care burden among families is needed.) |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues - | -- |

No official English translation was available of the full contents of the national dementia strategies in Denmark, Sweden, Japan, and the Republic of Korea, and for some portions of the Netherlands strategy; professional translation services were used to translate them into English.

+++, all recommendations of the white paper were addressed.

++, some of the recommendations were addressed.

+, only the domain was mentioned (superficially, no recommendation).

-, not addressed at all.

*Italic*, the contents contradicted the recommendations.

**Appendix 3.** Domains and recommendations from the European Association for Palliative Care (EAPC) identified in independent sections of national dementia strategies that explicitly refer to palliative care

|  |  |  |
| --- | --- | --- |
| Country | Domain | Example |
| England | 1. Applicability of palliative care ++(1.1) | (P.62) For a given disorder, people with dementia have 4–6 times the mortality than the cognitively intact. |
|  | 2. Person-centered care, communication and shared decision making - | -- |
|  | 3. Setting care goals and advance planning ++(3.2, 3.3, 3.6, 3.7) | (P.61) Developing better end of life care for people across care settings which reflects their preferences and makes full use of the planning tools in the Mental Capacity Act. |
|  | 4. Continuity of care - | -- |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.5) | (P.63) So there are major problems in end of life care for people with dementia. One report has summarised the situation as follows: “…people with dementia often die with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care.” |
|  | 7. Optimal treatment of symptoms and providing comfort ++(7.1, 7.5) | (P.61) Developing better pain relief and nursing support for people with dementia at the end of life. |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement - | -- |
|  | 10. Education of the health care team - | -- |
|  | 11. Societal and ethical issues ++(11.1, 11.3, 11.4, 11.5, 11.8) | (P.61) Ensuring that palliative care networks, developed as part of the End of Life Care Strategy, support the spread of best practice on end of life care in dementia. |
| Northern Ireland | 1. Applicability of palliative care + | (8.40) The DHSSPS 5 year strategy for Palliative and End of Life Care sets out a vision for palliative and end of life care across all conditions and care settings based on what people value most and expect from such care. This vision emphasises the importance of: understanding palliative and end of life care; |
|  | 2. Person-centered care, communication and shared decision making ++(2.3, 2.5) | (8.40) This vision emphasises the importance of: (…) timely information and choice; |
|  | 3. Setting care goals and advance planning - | -- |
|  | 4. Continuity of care ++(4.1) | (8.40) This vision emphasises the importance of: (…) co-ordinated care, support and continuity. |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment - | -- |
|  | 7. Optimal treatment of symptoms and providing comfort + | (8.39) Services for patients with palliative and end of life care needs have developed considerably over the past decade. Management of pain and other physical symptoms and provision of psychological, social and spiritual support for both the person and their family and carers are key elements of such care. |
|  | 8. Psychosocial and spiritual support - | -- |
|  | 9. Family care and involvement + | (8.39) Services for patients with palliative and end of life care needs have developed considerably over the past decade. Management of pain and other physical symptoms and provision of psychological, social and spiritual support for both the person and their family and carers are key elements of such care. |
|  | 10. Education of the health care team ++(10.1) | (8.41) In support of the strategy Trusts have multi -disciplinary palliative and end of life care teams in place. It will be important to ensure that team members have awareness of the needs of people with dementia. |
|  | 11. Societal and ethical issues ++(11.3, 11.4, 11.8) | (8.41) trusts to develop palliative and end of life services for people with dementia within the framework of the palliative and end of life care strategy. |
| Sweden | 1. Applicability of palliative care ++(1.2) | (P.37-38) Personer med demenssjukdom har samma behov av palliativ vård i livets slutskede som andra. Den palliativa vården syftar, enligt Världshälsoorganisationens (WHO) definition, till att (…) främja livskvalitet och även påverka sjukdomsförloppet i positiv bemärkelse (People with dementia have the same need for palliative care at the end of life as other people. According to the definition of the World Health Organization (WHO), palliative care is designed to: (…) promote the quality of life and also positively affect the course of disease) |
|  | 2. Person-centered care, communication and shared decision making ++(2.4) | (P.37-38) Den palliativa vården syftar, enligt Världshälsoorganisationens (WHO) definition, till att (…) genom ett tvärprofessionellt förhållningssätt inrikta sig på patientens och de närståendes behov (According to the definition of the World Health Organization (WHO), palliative care is designed to: (…) use a multi-professional approach to focus on the patient’s and relatives’ needs) |
|  | 3. Setting care goals and advance planning - | -- |
|  | 4. Continuity of care - | -- |
|  | 5. Prognostication and timely recognition of dying - | -- |
|  | 6. Avoiding overly aggressive, burdensome or futile treatment ++(6.5) | (P.38) Det händer att sondmatning används för att ge vätska och näring, men det saknas vetenskapligt underlag som visar att sondmatning i livets slutskede förbättrar nutritionsstatus, ger ökad livslängd eller livskvalitet. (Tube feeding may be used to provide proper fluids and nutrition, but there is no scientific evidence to show that tube-feeding at the end of life improves the patient’s nutritional status, extends the patient’s life or quality of life.) |
|  | 7. Optimal treatment of symptoms and providing comfort + | (P.38) Smärta, lunginflammation, ångest och andnöd är vanliga tillstånd i livets slut. Det är viktigt att hälso- och sjukvården och socialtjänsten identifierar, behandlar och lindrar dessa tillstånd. (Pain, lung inflammation, anxiety and difficulty breathing are normal conditions at the end of life. It is important for healthcare and social services staff to identify, treat and alleviate these conditions.) |
|  | 8. Psychosocial and spiritual support + | (P.37) Den palliativa vården syftar, enligt Världshälsoorganisationens (WHO) definition, till att (…) integrera de psykosociala och andliga aspekterna av patientvården (According to the definition of the World Health Organization (WHO), palliative care is designed to: (…) integrate the psychosocial and spiritual aspects of patient care) |
|  | 9. Family care and involvement ++(9.7) | (P.37-38) Den palliativa vården syftar, enligt Världshälsoorganisationens (WHO) definition, till att (…) stödja de närstående under patientens sjukdom och i deras sorgearbete (According to the definition of the World Health Organization (WHO), palliative care is designed to: (…) support the patient’s close relatives during the patient’s illness and support their grieving) |
|  | 10. Education of the health care team ++(10.1) | (P.37-38) Den palliativa vården syftar, enligt Världshälsoorganisationens (WHO) definition, till att (…) genom ett tvärprofessionellt förhållningssätt inrikta sig på patientens och de närståendes behov (According to the definition of the World Health Organization (WHO), palliative care is designed to: (…) use a multi-professional approach to focus on the patient’s and relatives’ needs) |
|  | 11. Societal and ethical issues ++(11.1) | (P.38) Rekommendationerna avser personer med demenssjukdom i både ordinärt boende och särskilt boende. (The recommendations concern persons with dementia in both regular housing and specialized housing.) |

No official English translation was available of the national dementia strategies from Sweden; professional translation services were used to translate the Swedish into English.

+++, all recommendations of the white paper were addressed.

++, some of the recommendations were addressed.

+, only the domain was mentioned (superficially, no recommendation).

-, not addressed at all.