Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning

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Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15 year timespan

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**A full list of members appears in the Appendix (Additional File 6).*

Abstract

Background To support family caregivers of people with dementia in end-of-life decision making, a family booklet on comfort care has been adapted and adopted by several European jurisdictions since the original publication in Canada in 2005.

Methods We analyzed and compared the adaptations to the family booklets used in Canada, the Czech Republic, Italy, the Netherlands, the UK and Ireland that were made up to 2021. Qualitative content analysis was used to create a typology of changes to the original booklet. Interviews with the teams that adapted the booklets contributed to methodological triangulation. Further, using an established framework, we assessed whether the contents of the booklets addressed all domains relevant to optimal palliative dementia care.

Results The booklets differed in the types of treatment addressed, in particular tube feeding, euthanasia, and spiritual care. There was also variability in the extent to which medical details were provided, an emphasis on previously expressed wishes in medical decision making, addressing of treatment dilemmas at the end of life, the tone of the messages (indirect or explicit) and the discussion of prognosis (as more or less positive), and the involvement of various healthcare professionals and family caregivers in care. All booklets addressed all domains of palliative dementia care.

Conclusions We identified core elements in providing information on end-of-life care to family caregivers of people with dementia as related to optimal palliative care in dementia. Additionally, local adaptations and updates are required to account for socio-cultural, clinical, and legal differences which may also change over time. These results may inform development of educational and advance care planning materials for different contexts.

Background

Alzheimer’s disease and other neurodegenerative diseases causing dementia are progressive and life-limiting illnesses, characterized by symptoms such as behavioral symptoms and cognitive decline and, in later stages, food and fluid intake problems.[1] Therefore, a palliative care approach is appropriate. When dementia progresses to more severe stages, goals of care may shift from prolongation of life to maximizing comfort.[2] In order to provide person-centered care, these care goals should reflect individual wishes.[2] Due to cognitive impairment, family caregivers advocate for their relatives with dementia in conversations about goals of care and decision-making.[3, 4] This is a difficult task for which many family caregivers feel ill-prepared. They may not be aware of the terminal course of dementia and may lack knowledge about palliative care.[5] Such information may be crucial as nursing staff have reported higher comfort in dying for people with dementia whose family are aware of the disease prognosis, in part because their healthcare professionals are being able to provide better end-of-life care.[6]

The World Health Organisation (WHO) urges to assist family caregivers with information about dementia and palliative care.[1] In Canada in 2005 the Comfort Care Booklet,[7] a guide for caregivers of people with dementia, was developed with this aim and has been adopted by the WHO as an example of good practice.[1] This informational booklet informs family caregivers regarding the course of dementia and palliative care options. The booklet intends to help family caregivers understand that a palliative approach to care is appropriate and does not imply that ”nothing can be done”. Instead, a palliative approach to care can be considered a ‘low-tech’, but ‘high-touch’ approach.[8] Retaining its core, the booklet has been translated and adapted for use by healthcare professionals and researchers in several European jurisdictions since 2005: Italy (2008),[9] the Netherlands (2011),[10] the Czech Republic (2017),[11] Ireland (2020)[12] and the UK (2021).[13] Further, in 2021, a new edition of this Canadian Booklet was developed.[14]

Cross-national work about the Japanese, Italian, Dutch and original Canadian version showed that solely translating the information does not suffice. Adaptations to the local context are necessary for the booklets to be applicable and acceptable.[15] In addition, it is important that educational information is based on current evidence-based practice,[16] such as the recommendations by the European Association for Palliative Care (EAPC) about optimal palliative dementia care in older people first issued in 2013.[2] Furthermore, developments in evidence and evolving public perception require that information should be reviewed regularly to remain up to date.[17, 18]

In this paper, we aim to provide guidance about the contents of informational booklets for family caregivers about dementia and palliative care, considering (i) transnational legal and socio-cultural differences and developments over time, plus (ii) evidence and expert consensus-based recommendations regarding palliative dementia care. We compared informational booklets from six jurisdictions to determine key topics and we performed content analysis to highlight contextual differences. The EAPC recommendations for optimal palliative dementia care[2] were mapped onto the contents of the booklets.

Methods

This qualitative descriptive study[18] was conducted as part of an international multiple case study called *mySupport study*, which involves Canada, the Czech Republic, Italy, the Netherlands, Ireland and the UK. The *mySupport study* aims to support family caregivers of nursing home residents with advanced dementia in decision making about end-of-life care.[19] In addition to training staff in conducting family care conferences, family caregivers are provided with information about the progression of dementia and end-of-life care for nursing home residents with dementia via the Comfort Care Booklet.[20]

Comparison of content

To compare the booklets' contents transnationally, we took a deductive approach to identify (i) key topics of the Comfort Care Booklets, as they are presented in all the booklets, and (ii) topics that require adaptation to the specific socio-cultural, legal or temporal context, as they differ between the booklets.

First, the Czech, Dutch and Italian booklets were translated back to English. Next, two researchers (LB and JTvdS) read all the booklets thoroughly and compared the contents of all the booklets with the original Canadian booklet. Differences were marked and listed in a matrix. Then, semi-structured interviews with the editors of the local booklets provided input for methodological triangulation verifying the comparison exercise for completeness.[21, 22] A comparison between the original Canadian, the Italian and the Dutch version of the booklet has been reported previously.[15] Therefore, LB and JTvdS selected the editors of the Czech, UK, Irish and updated Canadian versions of the booklets for an interview. The interview guide asked about topics that were added, deleted, or revised compared with the original Canadian booklet, and about the stakeholders involved in adapting the booklet. Interviews were transcribed, summarized and fed back to the developers for member checking, clarification and elaboration.

Finally, qualitative directed content analysis was performed on the identified differences of each booklet compared with the original Canadian booklet.[23] The tabulated differences were first read repeatedly to create familiarity with the data. Then, the differences were assorted into categories that were informed by the literature.[15, 24] Differences that could not be coded in this manner were identified and were assorted in an additional category or labeled as a subcategory of the existing categories. Next, the categories were reviewed and finalized.

Quality appraisal

A transnational quality appraisal was performed using a deductive approach to identify (i) if key topics according to evidence and expert consensus-based guidelines were represented in the

Comfort Care Booklets (cf. [25]), and (ii) if this differed for the various booklets. To facilitate a comparison between the booklets (aim ii), the quality appraisal was performed with a single international (EAPC) framework, rather than multiple national guidelines on palliative dementia care.

To support methodological validity, AM and LB first developed a protocol with accompanying grid for mapping the content of the booklets against the recommendations presented in the EAPC framework[2] as depicted in Box 1 (Additional File 1). The mapping did not include Domain 10: Education of the healthcare team and Domain 11: Societal and ethical issues, as these domains are not expected to be *explicitly* stated in the booklets—although ethical and moral challenges may be considered within the booklets. For each booklet, this protocol was shared with a researcher fluent in the local language and who was familiar with the content of the local booklet. The outcomes of the final consensus mappings were entered in a grid to facilitate comparison across the booklets.

Results

Comparison of content

When comparing the contents of the booklets, two versions appeared: booklets that were based on the 2005 Canadian Comfort Care Booklet (the 2021 Canadian booklet, the Czech booklet, the Italian booklet, the Dutch booklet and the UK booklet) and booklets that were based on the 2017 UK booklet (the Irish booklet and sections of the 2021 Canadian booklet), see Table 1 (Additional File 2). The booklets that were based on the UK booklet thus had not used the original Canadian booklet as the starting point, but were based on the UK booklet - retaining the adaptions that were made in the UK booklet. Both healthcare professionals and family caregivers were involved in evaluating the contents of the booklets and the adaptations. This involvement ranged from participation in a study leading up to the development of the booklet (indirect involvement), to “collaboration and co-production” which entailed team membership and contributing to key decisions.[27] Healthcare professionals largely influenced the content revisions. Revisions often concerned the local legal frameworks and shared decision making practice.

The key topics that were present in all the booklets were the progression of dementia and possible complications such as eating difficulties and infections, the decision-making process about treatment options at the end of life, palliative care and managing symptoms such as pain, breathing problems and anxiety, the dying process and common emotions and procedures after death. These key topics were retained from the original Canadian Comfort Care Booklet.

We arranged the textual revisions of the booklets compared with the original texts in six categories: 1.Typology of treatments and symptoms at the end of life, 2. Patient and family rights and wishes, 3. Typology of decisions at the end of life, 4. Indirect or explicit messages, 5. More or less positive about prognosis, and 6. Relationship between healthcare professionals and family caregivers.

1. Typology of treatments and symptoms at the end of life

The booklets differed in the treatment options that they described, and the level of medical detail that was provided about symptoms and treatments. Three topics related to treatment differed the greatest between the booklets: artificial nutrition, life-terminating or life-limiting treatments and spiritual care. Whereas all booklets discussed eating difficulties in advanced dementia, the UK booklet did not contain information about tube feeding or any objections to it (Table 2 (Additional File 3), quote A). Instead, extensive information about oral hygiene was provided and this was also included in the Irish and updated Canadian booklet. The Czech booklet provided detailed information about alternative feeding and food options to address eating difficulties. The Czech and Italian booklet provided more medical information about the complications of artificial nutrition during the dying process than the other booklets. This was included because it was considered difficult to convince family caregivers not to start artificial feeding at end of life. Regarding information about euthanasia, this was not included in the Irish and UK booklets, while more elaborate information was provided in the Dutch booklet and updated information in the Canadian booklet. The Czech and Italian booklets mentioned euthanasia only to state that it is not a viable option. The Dutch and Canadian booklets had included additional information about palliative sedation. The UK, Irish and updated Canadian booklet offered information on spiritual care, which was not included in the Czech, Dutch and Italian booklets.

The extent to which the booklets offered detail about medical issues varied, and this may relate to difference in whether healthcare professionals or family caregivers were the most influential in the revision process (see also Table 1 (Additional File 2) Stakeholder Involvement). The Czech, Dutch and Irish booklets contained the most information regarding medications and physical health and the UK booklet the least. For example, the Czech, Dutch and Irish booklet provided detailed information about the breathing pattern during dying or extra information about pain management options. In contrast, the UK booklet did not speak about the medical complications that could arise after hospitalization when addressing why transfer to hospital may not be appropriate, while the other booklets did.

2. Patient and family rights and wishes

The varying legal systems of the jurisdictions were apparent in diverging emphasis on patient rights and wishes between the booklets. The Czech and Irish booklets stood out the most in this respect. The Czech booklet included an entire section about living wills and legally binding wishes to refuse care, driven by the Health Services Act, No. 372/2011 Coll.[29] Emphasis was placed on acting in accordance with living wills throughout the booklet. The Irish booklet contained several sections that asked family caregivers to think about previous wishes of the person with dementia, to ensure that any decision making is aligned to the person's previously stated will and preference. Reference was made to Ireland's Assisted Decision-Making (Capacity) Act 2015.[30] The UK booklet and Dutch booklet only referred to patient wishes for specific treatment decisions, such as CPR and the use of antibiotics, respectively.

The Italian booklet clearly stated that family members provide only information for the decision-making process. This mirrors the updated Canadian booklet, that had adapted the terminology to current legislation regarding shared decision making (Table 2 (Additional File 3), quote B). That is: the family caregiver was referred to as "the patient's legal representative" instead of "the mandatory" (a term formerly used to indicate a representative by law) and a statement was added about variations in provincial laws across the country regarding the role and rights of this person. The updated Canadian booklet, and the Dutch booklet, introduced family wishes only in the section on providing the last care after death.

Further, no mentioning of settling disagreements in court was made in the Czech, Italian and Dutch booklets. The Czech booklet also did not refer to the assistance of ethics committees. A final difference between the booklets was that only the Dutch and Canadian booklets contained information about the legal requirements for life terminating treatments.

3. Typology of decisions at the end of life

A similar category of differences between the booklets related to the description of end-of-life decision making. The Irish and Czech booklets emphasized best interest decision making, involving the family caregiver. The UK booklet underscored the responsibility of the clinician or medical team to facilitate this.

When describing considerations for decisions or treatment, the booklets varied in whether they stated the underlying dilemma. The UK and Italian booklets often did not include the dilemma. For example, they did not refer to pneumonia as "the older person's best friend" (an argument against curative treatment of pneumonia, Table 2 (Additional File 3), quote C). Dilemmas were sometimes emphasized in the Czech booklet, for instance by adding the statement "even at the cost of reduced comfort" which suggests curative treatment can be incongruent with comfort care. The moral acceptability of treatment decisions was, at some places, omitted from the Dutch and Irish booklet. The decision to increase doses of morphine at the end of life to reduce suffering was therefore more a medical than a moral decision, for instance.

4. Indirect or explicit messages

An evident difference between the booklets was their layout. While the Dutch and original Canadian booklets contained images of moments of caring, the UK booklet contained images of nature. The Italian, Czech, Irish and updated Canadian booklets were in the middle of this spectrum and showed images of their local nursing home contexts. In addition, the Irish booklet contained images of nature.

Differences between explicit messages or more softened, indirect messages were also found in the text in terms of style. The UK booklet used more softened language, for example comparing breathing problems to asthma. This booklet also spoke about nausea or discomfort, similar to the Italian and Irish booklet. The Czech, Dutch and Canadian booklets instead mentioned vomiting and pain. The Czech booklet typified useless or harmful treatment in the last days or hours of terminal illness as “dysthanasia”, detained death, and mentioned more confrontational treatment details.

All booklets considered dementia as a terminal condition, but some booklets were more explicit about this. The Czech booklet further contained explicit statements about the non-curable and terminal nature of the disease causing dementia syndrome. Also the Irish booklet explicitly mentioned the dying phase several times. The Dutch booklet clearly related not eating and drinking to the dying phase (Table 2 (Additional File 3), quote D).

All booklets recommended a palliative care approach based on physical and psychological comfort; the Canadian and Italian booklets concluded with the statement that “That’s because the majority of people perceive that advanced and prolonged dementia is worse than death”. This statement was not incorporated in the other booklets.

5. More or less positive about prognosis

There was some variation within and between the booklets regarding the description of the prognosis. The Czech booklet started with the limited life expectancy and cause of death in the introduction (Table 2 (Additional File 3), quote E) and therefore appeared less positive about the prognosis compared with the other booklets. The symptoms that were described in this booklet were mainly possible causes of death, as was the case for the Canadian, Dutch and Irish booklets. The UK and Irish booklets had additionally included symptoms related to activities of daily living, describing less severe stages of dementia. This encompassed a more holistic tone and upstream approach regarding prognosis than referring only to symptoms around the end of life.

The Czech booklet was less positive about prognosis throughout the booklet, for example stating how certain treatments may not be tolerated by the person with dementia. The more positive tone about prognosis of the UK booklet was also present throughout, for example by not stating some negative consequences of treatments. The Dutch booklet was more positive about prognosis in some sections: a maximum estimate of survival was provided for people who do not eat (instead of a time window that included a shorter time estimate). However, in other sections, the Dutch booklet was less positive about prognosis: it included the statement that the “final stage can be long and exhausting”.

6. Relationship between healthcare professionals and family caregivers

Two booklets stood out regarding the relationship between healthcare professionals and family caregivers: the updated Canadian and Irish booklet. Both had included information about family involvement in care and this was particularly present throughout the Irish booklet

(Table 2 (Additional File 3), quote F). The other booklets did not include this information, apart from sitting in at the end of life. The Irish booklet additionally referred to several healthcare disciplines throughout the booklet, which supports the multidisciplinary nature of palliative care. The other booklets mainly referred to physicians and nursing staff.

Quality appraisal

According to the final consensus mapping, all EAPC first nine domains defining optimal palliative dementia care were addressed in all the booklets, as depicted in Table 3 (Additional File 4). However, not all specific recommendations within the domains were addressed by all booklets. Recommendations with regards to `setting care goals and advance care planning' were addressed the least, especially in the Canadian and Italian booklet, while the Irish booklet addressed some of the specific recommendations. Supporting people with mild dementia in advance care planning (recommendation 3.4) was not mentioned in any of the booklets, as all booklets described the advanced stages of dementia since the booklets are positioned at the end of life, where decision making capacity may be limited. Recommendations that were also not addressed by any of the booklets related to `Continuity of care' (having a central care coordinator and appropriate information transfer between healthcare professionals) and to `Optimal treatment' (interdisciplinary consultation between dementia and palliative care specialists).

The Czech booklet was the only booklet that addressed recommendation 2.5 about previously expressed preferences regarding place of care (domain 2: Person-centered care). An explicit statement about avoiding the use of restraints (recommendation 6.3, domain: Avoiding burdensome treatment) was found only in the Irish Booklet.

Based on our overall findings, we present guidance statements regarding the contents of informational booklets for family caregivers about dementia and palliative care in Box 2 (Additional File 5). This may inform future updates or wider adoption of the booklets and support the development of other educational materials for family caregivers in this area.

Discussion

The Comfort Care Booklet provides family caregivers with information concerning the trajectory of advanced dementia and a palliative approach to care. In this paper, we compared Comfort Care Booklets across six jurisdictions that were developed between 2005 and 2021. One of the most striking differences between the booklets was the distinction between the UK booklet and the original Canadian booklet. The UK booklet has been under extensive review in practice by various stakeholders since 2014, originally used in Northern Ireland, it was adapted for broader application in the UK between 2019 and 2021. In the Irish and updated Canadian booklets, the involvement of family caregivers over the last year was evident from the addition of sections that engaged family caregivers, stipulating their role in providing comfort care. Interesting in this respect is the addition of a new section on spirituality for the UK, Irish and updated Canadian booklets. This addition could thus reflect increasing awareness for spiritual care as a key component in palliative care.[32] Also, it is likely that the dominant ideology in the stakeholders' jurisdiction and the greater representation of stakeholders involved, healthcare professionals or family caregivers, influenced topics to be included in the booklets. These findings highlight the need to involve stakeholders and have appropriate levels of representation in the development and evaluation of family and patient educational materials[16] and to be transparent in reporting the process.

In addition to the impact of stakeholder involvement, sociocultural differences emerged too. End-of-life decision making and disclosing prognostic information are both significantly influenced by socio-cultural factors.[33, 34] The UK booklet was more positive about prognosis and did not include many medical details or explicit messages, as one of the developers stated: "we tend not to talk about death". The aim of the booklet was therefore to inform family caregivers without causing distress. In contrast, the Czech booklet was less positive about prognosis and included more detailed information and explicit messages. The historically strong paternalistic culture in the Czech health care is reported to be a barrier for patient engagement;[35] although health care regulations recognize this, reform is in progress to be more inclusive of patient autonomy. The primary aim of the booklet was thus to inform and prepare family caregivers to stimulate family caregiver engagement.

Differences in legal contexts between jurisdictions were further apparent in the status of best interests and patient autonomy or previously expressed wishes in medical decision making, and the extent to which family was involved in shared decision making. While the Czech and Irish booklet emphasized best interest decision making informed by living wills and advance directives, the updated Canadian booklet did not refer to advance directives as this term is not consistent within the legal frameworks for all Canadian provinces. Differences in legislation[34] and interpretation of decision-making processes[35, 36] are therefore important to consider when providing information about end-of-life decision making.

Finally, differences over time were apparent from our analysis. The evidence base for advance care planning for people with dementia has been growing.[37] While hardly present in most of the booklets, the recent Irish booklet contained information about end-of-life care planning to ensure that any decision making is aligned to the person's previously stated will and preference. The updated Canadian booklet included information about Medical Assistance in Dying, while the original version referred to an illegal status of euthanasia. In addition, the text was gender-neutral and did not include male pronouns. The UK booklet had removed information about tube feeding due of the wider consensus on tube feeding being inappropriate for people with dementia at the end of life; this could reflect developments in public perception making such a statement obsolete.[18]

Compared with a systematic review that mapped the components of palliative care interventions according to the EAPC domains,[25] the outcome of our mapping was different. The systematic review found that interventions hardly addressed ‘applicability of palliative care’. Further, ‘prognostication and timely recognition of dying’, ‘avoiding overly aggressive, burdensome or futile treatment’ and ‘setting care goals and advance care planning’ were not always included in interventions. The Comfort Care Booklets addressed all these domains as they formed the key message of the information, except for ‘setting care goals and advance care planning’. Possibly, more information about end-of-life care planning practice could be included in future editions; advance care planning that includes the person with dementia needs to be addressed at earlier disease stages.

A strength of this study is that this cross-national comparison not only focuses on different cultures, but also captured some key developments over time. This is also a limitation of this study that compared the booklets at one point in time, and we propose to review and update information materials regularly to adopt socio-cultural and evidence-base developments. Intervals for updating the booklets should be determined by developments in evidence and public perception.[17, 18] Furthermore, although both English speaking/Northern European cultures and Mediterranean/Eastern European cultures were included in our analysis,[33] our study primarily focused on western documents that were all based on an original Canadian piece and does not provide information about possible issues to consider for documents in other cultures.

Conclusions

In conclusion, the Comfort Care Booklet covers all domains of good-quality palliative care for older people with dementia,[2] but more attention for end-of-life care planning and spirituality is required. We present guidance statements regarding family information. When developing informational materials that are appropriate for the local context, it is important to consider the legal and socio-cultural environment and developments over time. We also recommend stakeholder involvement throughout the development process, end-users in particular.

Abbreviations

CPR: cardiopulmonary resuscitation; EAPC: European Association for Palliative Care; WHO: World Health Organisation

Declarations

Ethics approval and consent to participate

Formal ethics approval was not required as the Medical Research Involving Human Subjects Act (1998, 26 March, https://wetten.overheid.nl/BWBR0009408/2021-07-01) was not applicable. All editors provided verbal consent to participate in the interviews.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

LB and JS contributed to the concept and design of the work; acquisition, analysis and interpretation of the data; drafted the article and substantially revised it. AM contributed to the design of the work; acquisition and analysis of the data and substantially revised the article. KB contributed to the concept of the work and substantially revised the article. NC, IH, SK, PG, HV, LV and MA contributed to the analysis and interpretation of the data and substantially revised the article. All authors read and approved the final manuscript.

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Appendix

Additional File 1

Box 1 Protocol for mapping the Comfort Care Booklets' contents against the EAPC framework

To be performed by two individuals independently:

1. Read the Comfort Care Booklet
2. Per section, assess if and which recommendation(s) of the first 9 EAPC domains is addressed, including the explanatory text[26]*

To be performed in a consensus discussion between the two individuals:

3. Compare and discuss the mappings to reach consensus, using the following criteria:
   - The text addressed the EAPC statement as found in the *recommendation and/or the explanatory text*
   - The text addressed the EAPC statement *explicitly*, a statement that is implied is not specifically addressed
   - The *context* of the statement may differ between the text in the Comfort Care Booklet and the EAPC framework (that is: the EAPC framework states that family caregivers need explanation without providing detail and the Comfort Care Booklet directly provides the explanation)

*The first 9 EAPC domains and 47 recommendations:

Domain 1. Applicability of palliative care

- 1.1 Dementia can realistically be regarded as a terminal condition. It can also be characterized as a chronic disease or, in connection with particular aspects, as a geriatric problem. However, recognizing its eventual terminal nature is the basis for anticipating future problems and an impetus to the provision of adequate palliative care.
- 1.2 Improving quality of life, maintaining function and maximizing comfort, which are also goals of palliative care, can be considered appropriate in dementia throughout the disease trajectory, with the emphasis on particular goals changing over time.
- 1.3 Palliative care for dementia should be conceived as having two aspects. The baseline is a palliative care approach. For patients with complex problems, specialist palliative care should be available.
- 1.4 A palliative care approach refers to all treatment and care in dementia, including adequate treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problems.

Domain 2. Person-centred care, communication and shared decision making

- 2.1 Perceived problems in caring for a patient with dementia should be viewed from the patient's perspective, applying the concept of person-centred care.
- 2.2 Shared decision making includes the patient and family caregiver as partners and is an appealing model that should be aimed for.
- 2.3 The health care team should ask for and address families' and patients' information needs on the course of the dementia trajectory, palliative care and involvement in care.
- 2.4 Responding to the patient's and family's specific and varying needs throughout the disease trajectory is paramount.

Box 1 (Continued)

- 2.5 Current or previously expressed preferences with regard to place of care should be honoured as a principle, but best interest, safety and family caregiver burden issues should also be given weight in decisions on place of care.
- 2.6 Within the multidisciplinary team, patient and family issues should be discussed on a regular basis.

Domain 3. Setting care goals and advance planning

- 3.1 Prioritizing of explicit global care goals helps guide care and evaluate its appropriateness.
- 3.2 Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.
- 3.3 Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.
- 3.4 In mild dementia, people need support in planning for the future.
- 3.5 In more severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximization of comfort.
- 3.6 Advance care planning is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.
- 3.7 Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.

Domain 4. Continuity of care

- 4.1 Care should be continuous; there should be no interruption even with transfer.
- 4.2 Continuous care refers to care provided by all disciplines.
- 4.3 All patients should benefit from the early appointment of a central coordinator from within their care team.
- 4.4 Transfers between settings require communication on care plans between former and new professional caregivers and patient and families.

Domain 5. Prognostication and timely recognition of dying

- 5.1 Timely discussion of the terminal nature of the disease may enhance families' and patients' feelings of preparedness for the future.
- 5.2 Prognostication in dementia is challenging and mortality cannot be predicted accurately. However, combining clinical judgement and tools for mortality predictions can provide an indication which may facilitate discussion of prognosis.

Domain 6. Avoiding overly aggressive, burdensome or futile treatment

- 6.1 Transfer to the hospital and the associated risks and benefits should be considered prudently in relation to the care goals and taking into account also the stage of the dementia.
- 6.2 Medication for chronic conditions and comorbid diseases should be reviewed regularly in light of care goals, estimated life expectancy, and the effects and side effects of treatment.
- 6.3 Restraints should be avoided whenever possible.
- 6.4 Hydration, preferably subcutaneous, may be provided if appropriate, such as in case of infection; it is inappropriate in the dying phase (*only moderate consensus*).
- 6.5 Permanent enteral tube nutrition may not be beneficial and should as a rule be avoided in dementia; skillful hand feeding is preferred (*only moderate consensus*).

Box 1 (Continued)

- 6.6 Antibiotics may be appropriate in treating infections with the goal of increasing comfort by alleviating the symptoms of infection. Life-prolonging effects need to be considered, especially in case of treatment decisions around pneumonia.

Domain 7. Optimal treatment of symptoms and providing comfort

- 7.1 A holistic approach to treatment of symptoms is paramount because symptoms occur frequently and may be interrelated, or expressed differently (e.g., when pain is expressed as agitation).
- 7.2 Distinguishing between sources of discomfort (e.g., pain or being cold) in severe dementia is facilitated by integrating views of more caregivers.
- 7.3 Tools to assess pain, discomfort and behaviour should be used for screening and monitoring of patients with moderate and severe dementia, evaluating effectiveness of interventions.
- 7.4 Both non-pharmacological and pharmacological treatment of physical symptoms, challenging behaviour or discomfort should be pursued as needed.
- 7.5 Nursing care is very important to ensure comfort in patients near death.
- 7.6 Specialist palliative care teams may support staff in long-term care settings in dealing with specific symptoms, while maintaining continuity of care. In managing behavioural symptoms, however, palliative care teams may need additional dementia care specialist expertise.

Domain 8. Psychosocial and spiritual support

- 8.1 In mild dementia, as also in the later stages, patients may be aware of their condition, and patients and families may need emotional support.
- 8.2 Spiritual caregiving in dementia should include at least assessment of religious affiliation and involvement, sources of support and spiritual well-being; in addition, referral to experienced spiritual counsellors such as those working in nursing homes may be appropriate.
- 8.3 Religious activities, such as rituals, songs, and services may help the patient because these may be recognized even in severe dementia.
- 8.4 For dying people, a comfortable environment is desirable.

Domain 9. Family care and involvement

- 9.1 Families may suffer from caregiver burden, may struggle to combine caring with their other duties and may need social support.
- 9.2 Families may need support throughout the trajectory, but especially upon diagnosis, when dealing with challenging behaviour, with health problems, with institutionalization, with a major decline in health and when death is near.
- 9.3 Families need education regarding the progressive course of the dementia and (palliative care) treatment options; this should be a continuous process addressing specific needs in different stages, examining family receptiveness.
- 9.4 Family involvement may be encouraged; many families may wish to be involved in care even when the patient is admitted to an institution providing long-term care.
- 9.5 Families need support in their new role as (future) proxy decision maker.
- 9.6 Professional caregivers should have an understanding of families' needs related to suffering from chronic or prolonged grief through the various stages, and with evident decline.
- 9.7 Bereavement support should be offered.
- 9.8 Following the death of the patient, family members should be allowed adequate time to adjust after often a long period of caring for the patient.

Additional File 2

Table 1 Summary of comfort care booklet development process

Location, ed (year)	**Based on**	**Stakeholder involvement [type of involvement]***	**Most influence on revisions**	**Focus of revisions [derived from interview]**
CA, *1 (2005)*	*Literature;* [28]	*Researchers / Healthcare professionals; current and bereaved family caregivers* *[undefined involvement]*		
IT, **1 (2008)**	CA, 1 (2005)	Researchers; ethicists, physicians (LTC), nurses (LTC), bereaved family caregivers [targeted consultation]	?	Layout (showing Italian setting), legal context of shared decision making and euthanasia[14]
NL, **2 (2011)**	CA, 1 (2005)	Researchers; ethicists, physicians (LTC), nurses (LTC), bereaved family caregivers [targeted consultation]	LTC physicians	Order of topics (and Table of contents), legal context of shared decision making and euthanasia, treatment considerations[14]
CZ, **1 (2017)**	CA, 1 (2005)	Researchers; nurses, geriatricians, palliative team members, physicians (hospice care, palliative care), psychologists, social care professionals, ethicist, law specialist, family caregivers [targeted consultation]	All (multidisciplinary approach)	Adaptation to the Czech laws; the role of family in shared decision making [derived from interview]
IE, **1 (2020)**	UK, 2 (2017)	Researchers; GP, geriatricians, speech and language therapist, nurses, family caregivers [collaboration and co-production]	GP, geriatricians	Legal context of shared decision making; focus on end-of-life care planning; addition of family involvement [derived from interview]
UK, **3 (2021)**	CA, 1 (2005)	Researchers; geriatricians, nurses (dementia, palliative care), nursing home manager, facilitator (oncology and palliative care), hospice consultant, Alzheimer Society consultant, service user, policy officers, family caregivers [embedded consultation]	Facilitator (oncology and palliative care), hospice consultant, Alzheimer Society	Deletion of not-applicable material (PEG, euthanasia); addition of a section on spirituality; use of softer language and layout to prevent distress [derived from interview]

Table 1 (Continued) Summary of comfort care booklet development process

Location, ed (year)	Based on	Stakeholder involvement [type of involvement]*	Most influence on revisions	Focus of revisions [derived from interview]
CA, 2 (2021)	CA, 1 (2005); UK, 2 (2017)	Researchers; care director (LTC), nurses (LTC), family caregivers [undefined involvement]	Family caregivers	Additions of sections on spirituality, Medical Assistance in Dying, oral hygiene and mouth care; use of inclusive language and (shared decision making) terminology in accordance with current legal framework [derived from interview]

CA: Canada, IT: Italy, NL: the Netherlands, CZ: the Czech Republic, UK: the United Kingdom, IE: Ireland, LTC: Long Term Care

*Undefined involvement: stakeholders act as participants/respondents/research subjects in a study leading up to the development of the booklet, thus were indirectly involved; Targeted consultation: stakeholders are approached to provide feedback/comments; Embedded consultation: stakeholders are regularly consulted throughout the process; Collaboration and co-production: stakeholders are part of the team and contribute to key decisions; User-led research: stakeholders take lead in designing and conducting research[27]

Additional File 3

Table 2 Themes of textual revisions across the booklets with example quotes

Theme	Example quote (identifier, source)
Typology of treatments and symptoms at the end of life	UK editor about the deletion of the section on tube feeding treatment: *In the UK, there was a PEG-tube plead. So some of the carers were a bit confused about why [information on tube feeding] was in the book, because they then said, you know: can we have that? Or: I don't actually want that to happen. So our facilitator felt it be better to not include that part of it, because it wasn't standard practice in the nursing homes.* (A, interview)
Patient rights and wishes	Canada editor (of updated Canadian booklet) about the adaptions in terminology referring to the status of the family caregiver in decision making: *(…) we have this very strict legal framework (..) and there's a lot of emphasis right now within our palliative care organizations to make sure that all of our advance care planning, goals of care programs and educational materials are compliant with that legal framework. (…) And then we have consent as well. So for any kind of treatment, you have to have consent from families. So that's why we had to change the language around values and goals and wishes and then treatment plans (…).* (B, interview)
Typology of decisions at the end of life	Original Canadian text, with section about the moral dilemma underlying treatment decisions excluded in Italian version in **bold**: *(…) The doctor can prescribe an antibiotic if the individual develops a fever and if it is judged, from a medical standpoint, that the individual has pneumonia. However, as mentioned earlier, the chance of recovering from pneumonia in the advanced stages of these types of neurological diseases is limited, and the possibility of this problem re-occurring shortly thereafter is elevated.* ***William Osler, a well-known early 20th-century doctor, said that pneumonia may very well be the older person's best friend because it can bring suffering to an end. That is why many doctors prefer to abstain from prescribing antibiotics for pneumonia at the end of life, and select a palliative care approach such as the one described further on in this document.*** *Each situation is evaluated on a case-by-case basis. (…)* (C, comfort care booklets)

Table 2 (Continued) Themes of textual revisions across the booklets with example quotes

Theme	Example quote (identifier, source)
Indirect or explicit messages	Original Canadian version: *People who are lucid and who are suffering from cancer or degenerative, neurological diseases say that the feeling of thirst and hunger is not common near the end of life. Most patients refuse all or even small amounts of food that are offered to them and say that they feel a sensation of dryness in the mouth*. Netherlands version with added explicit message about the dying phase: *Patients with dementia often gradually start drinking or eating less. The body adapts to this, which makes the patient appear not to be hungry or thirsty. Patients barely want to eat or drink in the final phase. A well-known saying is: 'people do not die because they do not eat and drink; they do not eat and drink because they are dying'. (…)* (D, comfort care booklets)
More or less positive about prognosis	Original Canadian introduction, first paragraph: *This guide is intended for caregivers of a person whose health has been severely affected by Alzheimer's disease or by another type of degenerative disease of the brain, such as Parkinson's disease, the effects of multiple strokes, or even certain forms of multiple sclerosis.* Czech Republic version introduction, first paragraph with added section implying a less positive perspective on prognosis: *This guide is intended for those who care for people with Alzheimer's disease or any other type of brain disease, such as Parkinson's disease or vascular dementia. All these diseases can cause dementia syndrome. A disease causing dementia is a life-limiting disease in its effects. Everyone knows someone who has been living with dementia for ten or even fifteen or more years. However, the most common survival time from the diagnosis of dementia is four to five years. Some people also have other serious illnesses at the time of diagnosis of dementia, such as heart disease, while others develop cancer. Others, however, die because dementia reduces their life expectancy. This guide focuses on the challenging times of the very advanced and final stages of the disease.* (E, comfort care booklets)
Relationship among healthcare professionals and family caregivers	Irish editor about the addition of sections for family caregivers as partners in care: *Yes, like I think, in particularly, some of the information was very kind of, kind of soft touch in one sense, and it was kind of 'nice to know'-material, you know. But we weren't sure exactly what the family could learn from it, in one sense. So that's why we divided sections up in two: 'What the healthcare professional does' and 'What you can do as a family'. Kind of around the oral care in particular, you know, so it's kind of giving them something to do, they feel useful, but it's also informing them this is what to expect the healthcare professional is going to be doing, you know.* (F, interview)

Additional File 4

Table 3 Outcome of the EAPC Framework mapping: recommendations* addressed from domains 1-9

Location, ed (year)	Domain 1 Applicability of palliative care (1.1-1.4)	Domain 2 Person-centered care, communication and shared decision making (2.1-2.6)	Domain 3 Setting care goals and advance care planning (3.1-3.7)	Domain 4 Continuity of care (4.1-4.4)	Domain 5 Prognostication and timely recognition of dying (5.1-5.2)	Domain 6 Avoiding overly aggressive, burdensome or futile treatment (6.1-6.6)	Domain 7 Optimal treatment of symptoms and providing comfort (7.1-7.6)	Domain 8 Psychosocial and spiritual support (8.1-8.4)	Domain 9 Family care and involvement (9.1-9.8)
IT, 1 (2008)	1.1-1.4	2.1-2.4, 2.6	3.5	4.1-4.2	5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.2	9.2-9.5, 9.7-9.8
NL, 2 (2011)	1.1-1.2, 1.4	2.1-2.4, 2.6	3.3, 3.5	4.1-4.2	5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.2-8.4	9.2-9.5, 9.7
CZ, 1 (2017)	1.1-1.2, 1.4	2.1-2.5	3.2, 3.3, 3.5	4.1-4.2	5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.2, 8.4	9.2-9.5, 9.7-9.8
IE, 1 (2020)	1.1-1.4	2.1-2.4, 2.6	3.1-3.3, 3.5-3.7	4.1	5.1-5.2	6.1-6.6	7.1-7.5	8.1-8.3	9.2-9.7
UK, 3 (2021)	1.1-1.2, 1.4	2.1-2.4, 2.6	3.2, 3.5, 3.7	4.1-4.2	5.1-5.2	6.1-6.2, 6.4-6.6	7.1-7.5	8.1-8.4	9.1-9.5, 9.7-9.8
CA, 2 (2021)	1.1-1.2, 1.4	2.1-2.4, 2.6	3.5	4.1-4.2	5.1-5.2	6.1-6.2, 6.4-6.6	7.1, 7.3-7.5	8.1-8.4	9.2-9.5, 9.7

*Numbers in the table refer to recommendation numbers as listed in the EAPC Framework[2]

Additional File 5

Box 2 Guidance statements

Core statements of information for family caregivers about dementia and comfort care

Information for family caregivers of nursing home residents with advanced dementia should advise a palliative approach and cover

the course of the dementia and expected complications:

1. Advanced dementia should be considered a terminal illness with the majority of patients dying from nutrition/hydration or infectious problems, especially pneumonia.*

the decision-making process:

2. In decisions regarding whether or not to use life-prolonging therapy in advanced dementia, the ideal decision-making process is to reach a consensus between the physician, the substitute decision maker and other significant relatives or friends of the patient.*
3. In the decision-making process, the medical options that are most suited to the patient’s best interests (e.g. according to patient values and written or verbal advance directives) should be strived for and options that would not presumably be acceptable to the patient should be refused.**

symptom management:

4. Use of parenteral hydration (IV or hypodermoclysis) may be helpful in selected cases but can also contribute to discomfort.**
5. A patient who no longer eats and drinks will generally not experience discomfort if there is adequate mouth care.**
6. When ‘comfort care without life prolongation’ is the goal of care, antibiotics can be withheld and treatment will then aim at symptom control.*
7. Prescription of opioids may be necessary to control pain or breathing difficulties to relieve the patient.**

avoiding burdensome treatment:

8. Cardiopulmonary resuscitation is not recommended in advanced dementia because it can harm the patient and has very little chance of success.*
9. Hospital transfer of the patient with advanced dementia should be exceptional e.g. only to provide comfort by technical means not available in the nursing home (such as hip fracture surgery).*

dying and grief:

10. It is difficult to estimate the moment of death, family caregivers should be accommodated to stay with the patient during the end of life.
11. Family caregivers should be offered bereavement support to cope with feelings of grief, relief, anger, loneliness, exhaustion and guilt.

Box 2 (Continued)

In addition, information needs to be provided about

advance care planning:

12. Prioritizing explicit care goals, if possible together with the patient, should start as soon as possible and should be evaluated regularly to help guide care.

spiritual care:

13. Patients and family caregivers should be offered spiritual care, religious activities or support by spiritual counsellors for psychosocial and spiritual support.

<u>Flexible elements of information for family caregivers about dementia and comfort care</u>

Information for family caregivers of nursing home residents with advanced dementia that requires adaption to the local context includes:

- Information about withholding/withdrawing of artificial nutrition/hydration
- Information about the roles and responsibilities of the patient, substitute decision makers, healthcare professionals and others involved in medical decision making and caregiving
- Information about life terminating treatments
- Information about (palliative) sedation to relieve anxiety or agitation
- The use of medical details or terminology
- The expression of moral considerations underlying treatment decisions
- The use of imagery and tone of voice

<u>Process of developing information for family caregivers about dementia and comfort care</u>

Information for family caregivers of nursing home residents with advanced dementia should be developed

1. with the involvement of stakeholders (family caregivers, healthcare professionals, ethicists, law specialists) in constructing and evaluating the content
2. continuously, that is: regularly updated to keep information in line with current practice and public perception
3. in a manner that is sensitive to the legal and socio-cultural context
4. with a clear reporting about the process and people involved

** These statements are retained from the core statements by Arcand et al.*[31] ***These statements are adapted from the core statements by Arcand et al.*[31]

Additional File 6

mySupport study group

mySupport study group members:

Marcel Arcand, Jackson Hagner, Danielle Just, Sharon Kaasalainen, Tamara Sussman, Martin Loucka, Hana Vankova, Karolina Vlckova, Ladislav Volicer, Marco Clari, Paola Di Giulio, Silvia Gonella, Laura Simionato, Wilco Achterberg, Laura Bavelaar, Jenny T. van der Steen, Mandy Visser, Catherine Buckley, Nicola Cornally, Serena Fitzgerald, Tony Foley, Siobhan Fox, Irene Hartigan, Dominika Lisiecka, Ronan O'Caoimh, Selena O'Connell, Catherine Sweeney, Suzanne Timmons, Kevin Brazil, Christine Brown Wilson, Gillian Carter, Emily Cousins, Kay De Vries, Josie Dixon, Andrew Harding, Karen Harrison Dening, Catherine Henderson, Adrienne McCann, Sophie Morris, Nancy Preston, Catherine Walshe