

How do Admiral Nurses and care home staff help people living with dementia and their family carers prepare for end-of-life?

Short Running Title: Services preparing for end-of-life dementia care

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Data availability: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Abstract

Objectives: To explore current practice and the role of UK care homes and Admiral Nurses in helping people living with dementia and their family carers prepare for end-of-life.

Methods: We conducted an online survey with all UK Admiral Nurses (59% response rate) and a random sample of Gold Standards Framework accredited care homes in England and Wales (38% response rate). We used descriptive statistics to report survey findings.

Results: While respondents commonly discussed the progressive nature of dementia with people living with dementia and family carers, they less frequently spoke to people with dementia or carers about the nature of dementia as life shortening, terminal or a disease you can die from. Admiral Nurses highlighted that where service models reduced continuity of care, opportunities for ongoing discussion and developing relationships that supported these discussions were reduced. Admiral Nurses and care homes raised concerns about conversations being left too late, when the person with dementia no longer had capacity to engage. There was a high level of agreement with all European Association of Palliative Care and NICE statements presented regarding end-of-life care planning and discussions.

Conclusions: Our survey of care homes and Admiral Nurses, combined with findings from our previous survey of UK memory services increases our understanding of how services help people with dementia and family carers prepare for end-of-life. We found fragmentation across the service system, lack of continuity and tensions regarding when these conversations should be initiated and by whom.

Keywords

Dementia, Family Carers, Preparation for end-of-life, care homes, nursing, Admiral Nurses, advance care planning, progressive, terminal

Key Points

- The number of people dying with dementia is projected to increase by 270% between 2014 and 2040. The European Association of Palliative Care (EAPC) has outlined recommendations for best practice dementia palliative care that endorse early discussions about dementia as a terminal condition and advance care planning.
- We surveyed Admiral Nurses (specialist dementia care nurses) and care homes with palliative care training in the UK to examine their practice and endorsement of the EAPC and national guidelines around dementia palliative care.
- We found these services highly endorsed these recommendations but faced numerous obstacles to implementing them. We found fragmentation across the service system with lack of continuity and tensions regarding when these conversations should occur and by whom.
- Discussing dementia as a terminal condition (or as a disease you can die from) was not a routine discussion with people with dementia or their carers across all services, yet this message may help to enable end-of-life care conversations.

Introduction

Over 46 million people worldwide have dementia and this is set to increase to 74.7 million in 2030¹.

Dementia is the leading cause of death in England and Wales². Most support received by people with dementia is provided by family and friends, hereafter referred to as carers, who provide an estimated 82 billion hours of support globally³. In the UK there are approximately 670,000 carers of people with dementia, estimating to save the state £11 billion per year⁴.

Providing care can be rewarding, however carers experience high rates of depression, grief and burden⁵⁻⁷. Carers of people with dementia experience higher levels of complicated grief after death than carers of people with cancer^{8,9} and preparing carers for end-of-life can protect against complicated grief¹⁰. Preparation for end-of-life has medical, psychosocial, spiritual and practical components^{11,12}, including having a named person to make decisions, knowing what to expect about the terminal condition and having financial arrangements in place¹³. Good communication with healthcare providers to discuss prognosis, treatments, cultural, spiritual and practical issues; and dealing with family conflict is critical¹¹. National Institute for Health and Care Excellence (NICE) guidelines¹⁴ and the European Association for Palliative Care (EAPC) White paper¹⁵ recommend a supportive palliative care approach that maximises planning, comfort and quality of life from diagnosis and while the person still has capacity.

In 2017 we surveyed UK memory services, whose remit is to diagnose dementia, on how they prepared carers for end-of-life¹⁶. Most services routinely discussed the progressive nature of dementia, the implications of loss of capacity and the need for a Lasting Power of Attorney, but only 41% discussed the terminal nature of dementia. Services varied in the extent to which they could follow-up patients after diagnosis. The need for ongoing discussions and building relationships was highlighted. The lack of consistency and explicit discussion about end-of-life care that we reported in this survey could indicate a significant unmet need and variance from stated national policy. Services

working with people with dementia in the later stages of illness might deliver this information differently.

In the current study, we surveyed Admiral Nurses and care homes to explore how they help people living with dementia and their carers prepare for the end-of-life and manage grief. Admiral Nurses are UK specialists in dementia care, and provide a case management approach to support families affected by dementia from the point of diagnosis through to support of family carers in bereavement^{17, 18}. Dementia UK is the charity that has developed this approach and is responsible for upholding standards and supporting Admiral Nurses in practice¹⁸. Recent benchmarking by Dementia UK identified that the Admiral Nurse gold standard model of case management was consistent with EAPC recommendations¹⁹. Residential aged care and care homes, including nursing homes provide supported group accommodation for people who can no longer live independently in their own home. In high income countries an estimated 31% of people with dementia live in a care home³ and most will die in a care home^{20, 21}. These settings have also been the focus of research on Advance Care Planning (ACP) in dementia²². In the UK, the Gold Standards Framework in Care Homes (GSFCH) is a training and accreditation programme aimed at improving end-of-life care²³. We aimed to examine how Admiral Nursing services and staff working in care homes prepare people living with dementia and their carers for end-of-life and whether these services perceive the NICE and EAPC guidelines relevant to their services.

Methods

We conducted an online survey with a random sample of care homes with GSFCH Accreditation and all UK Admiral Nurses. We selected these services as being likely to provide best practice in relation to dementia and palliative care.

Development of the surveys

The surveys were adapted from the previous memory clinic survey¹⁶ and used the online programme Opinio. The survey began by asking information about the respondent's gender and experience and characteristics of their service (size, age, and support for carers). The second section explored current practice regarding information provided by the service (e.g. dementia progression, the terminal nature of dementia, spirituality, mental capacity, end-of-life preferences and legal arrangements) and the format of this information (in direct discussion with the person with dementia or carer, in a group setting or in written format). We then presented respondents with relevant NICE and EAPC guidelines and asked whether these guidelines were consistent with their role. We also asked them to describe barriers and facilitators to these discussions.

Two Admiral Nurses reviewed the survey to ensure that it was applicable to Admiral Nurses. This led to some minor changes in the demographic questions. We sent the care home survey to two care home managers; one responded and advised to send surveys electronically. A clinician who works closely with care homes (CC) and a researcher who has worked in care homes also checked the survey was suitable for care homes.

Ethical review

We obtained ethics approval from the University College London Research Ethics Committee (ID 12541/001). Participants had to tick that they agreed to take part in the survey to access the survey.

Prizes

We offered respondents the chance to win a £30 gift voucher for completing the survey. We awarded two vouchers each to Admiral Nurse and care home respondents.

Admiral Nurse Survey

Dementia UK emailed information about the survey with the link to complete it to all 232 practising Admiral Nurses on their mailing list in July 2018. A further three reminder emails were sent by early September 2018. At this point we had received 95 surveys (41% response rate). To increase the response rate KM and SC attended the 2018 Dementia UK forum in September. We ran a workshop on carer grief and ran a stand during breaks encouraging people to complete paper versions of the survey. After this, Dementia UK distributed paper surveys and reply-paid envelopes to Professional Development Facilitators to distribute at eight regional professional development sessions (approximately 80 nurses). The survey closed in December 2018.

Care home survey

We generated a database of care homes with GSFCH Accreditation using the website list:

<http://www.goldstandardsframework.org.uk/accredited-care-homes> in February 2018. At this time 352 care homes in England had accreditation. Our statistician advised that due to the exploratory nature of the survey a power calculation was not applicable. We randomly sampled 130 care homes for pragmatic reasons: a large sample but feasible for to follow-up. Our statistician generated a random numbers list using Excel to identify our sample.

Emails were obtained via the GSFCH database or from the care home's website. We intended for the care home manager or a clinical lead to complete the survey. We telephoned care homes where an email was not found. We emailed all care homes inviting them to complete the survey in September 2018. We sent three personalised reminders to each email address up to December 2018. By January we had obtained 27 responses. In February 2019 we telephoned all care homes to attempt to speak to the manager to check they had seen the email and would consider completing. During these phone calls we were often requested to send the survey to another address. For those who

indicated not receiving previous emails we sent three emails to this new address during February and closed the survey in March 2019.

Response rate

We obtained 138 responses from Admiral Nurses (59% response rate). During the distribution of the care home survey, 13 care homes advised us that they did not fulfil the criteria for completing the survey; one did not have GSFCH accreditation, two had closed down, nine indicated they did not have residents with dementia, and one was removed from the sample as it was the nursing home unit within a care home already included. Our potential sample size was therefore reduced to 117. We received 44 surveys (38% response rate).

Analysis

We present summary data as number of respondents and percentages. The main aim was not to compare Admiral Nurses with care homes so we did not statistically compare the two groups. Open text responses were summarised using a thematic analysis. We took the responses provided for each question and grouped them in related themes to identify the main content of responses. Many responses were only a sentence or two long and were readily grouped with other similar responses. We aimed to capture all the core themes and issues raised by respondents. A small number of responses which we did not consider relevant to the topic were excluded.

Results

Description of respondents

Admiral Nurses: Most worked in a range of settings, though the most common was community care (44%; Table 1). There was large variation in the duration in which nurses typically worked with carers, however, 47% worked with carers for a year or less. Many indicated that there was no

'typical' case and that they supported carers according to need. Many indicated that carers may need support at a particular time and then are not followed up but have the option of resuming if needs increase. Most Admiral Nurses were working with families across all stages of dementia, except pre-diagnosis, though continuity was dependent upon how it was commissioned. Approximately a quarter of respondents were not involved in early stages of dementia or post death.

Insert Table 1 here

Care homes: Most care home respondents were managers/deputy managers working in a care home that had been operating for more than ten years (87%), privately owned (77%) with between 40-99 beds (66%; Table 2). Five were no longer GSFCH accredited and one was working towards it. We included these services given the low response rate and given that they had either previously completed the training or were working towards it.

Insert Table 2 here

Current practice

Eighty two percent of Admiral Nurses discussed the progressive nature of dementia with carers and 36% discussed this with people with dementia. In care homes, 59% of respondents talked to residents with dementia who they considered had capacity to have these discussions and 68% talked to family carers about dementia being progressive. Respondents less commonly spoke to people with dementia or carers about the nature of dementia as life shortening, terminal or a disease you can die from. Responses regarding related topics including spirituality, legal arrangements and ACP are provided in Table 3.

Insert Table 3 here.

Open-text comments to this question indicated respondents would discuss these topics if they felt it was 'appropriate' or they felt the carer or person with dementia was ready for that information. Others described the importance of an individualised response. Some indicated they mainly worked with carers and therefore it was not relevant for them to discuss with the person with dementia or that the person with dementia would not have capacity to understand. Some indicated that they raised these topics in training with other healthcare professionals.

All except four Admiral Nurses and one care home manager indicated that these discussions were within the remit of their role. Fifty-one nurses and 18 care home respondents elaborated on their response. Comments from Admiral Nurses indicated that talking about end-of-life care and death and dying were "bread and butter" parts of their roles; "The key is having the confidence to initiate the conversation and knowing when is the right time." Some described the importance of early conversations and that having a role throughout all stages of dementia and developing a relationship enabled this. Respondents from the helpline, a carer led service, indicated that their role was to respond to the issue raised by the carer, which may or may not have been about end-of-life care.

Care home respondents discussed the importance of training for staff and issues around mental capacity. Often by care home placement these conversations were too late as the person with dementia did not have capacity to be involved; "Timing can be an issue... residents with dementia can be very advanced when they arrive, living longer in their homes. Often have already lost capacity so it is with the carer rather than resident that the discussion takes place." They also raised issues around confidence, time and resources, but also lack of trust from other 'professionals' who did not see care home staff as qualified to have these discussions.

EAPC and NICE Guidelines

Table 4 shows the level of agreement with topical NICE guidelines and EAPC recommendations. At least seventy-seven percent of respondents agreed or strongly agreed with all recommendations.

Insert Table 4 here

Barriers and enablers to implementing guidelines reported by Admiral Nurses

Seventy three percent of Admiral Nurses offered comments indicating things that made it easier or more difficult to implement these guidelines. Many barriers to discussions were raised. The key ones were reluctance of the family or person with dementia to have these discussions, or that the person with dementia no longer had capacity. Training on end-of-life conversations and bereavement counselling was helpful: “The support and training from Dementia UK in Master classes, PD sessions and peer support has helped me to gain the skills and confidence to have these conversations”. The context was also critical. Hospitals were seen as stressful time-pressured environments that were not conducive to relationship building for these conversations, as was the helpline. In contrast having ‘end-of-life care’ in your Admiral Nurse title and those employed in hospices felt that these contexts meant that people expected them to be addressing end-of-life conversations. Having more time as well as guidelines/resources to support conversations were seen as enablers.

Many barriers related to the right time for conversations while the person with dementia had capacity. However, there were issues relating to how soon after diagnosis was appropriate and who took ultimate responsibility. Some reported other healthcare professionals provided poor information or did not set up expectations that these conversations were important. One Admiral Nurse summarised the key issues as: “health and social commissioning 'carves' up the role of Admiral Nursing and adapts to small areas of the dementia trajectory. In principle if the 'gold standard' model of community based Admiral Nursing were employed where nurses have open

referral and case manage (with other services inputting) throughout the trajectory... then all EAPC recommendations would be fulfilled in one role/model of practice.”

Should discussions occur before admission to a care home?

We asked care home managers whether discussions should occur prior to care home placement and 77% agreed. However, in practice, only 13% reported that these conversations often happened before care home admission while most reported they only sometimes (69%), rarely (15%) or never happened (3%). Open comments to these questions indicated care homes often triggered this process on admission or were guided by individual circumstances. Some reported it was helpful if ACP had begun prior to care home placement and that ideally this would occur as early as possible. Barriers to these discussions occurring before admission included difficulties having these conversations in hospital, lack of understanding of Lasting Power of Attorney and family not wanting to have these discussions. Some referred to the importance of ongoing discussions and that ACP was more than just completing a DNAR or funeral arrangements.

Discussion

This survey explored the role of UK Admiral Nurses and staff working in care homes in helping people with dementia and their family carers to prepare for end-of-life. This and our earlier survey with memory clinics are the first to explore how these issues are discussed across key services supporting people living with dementia. This is an important area given the number of people dying with dementia in the UK is set to increase by 270% between 2014 and 2040 ²⁴.

In our previous survey, memory services routinely described dementia as progressive but were less likely to describe it as terminal¹⁶ in discussions with patients and their family carers. We felt the wording ‘terminal’ may be considered too strong to use with people with dementia and carers, so in the current survey we asked about dementia as ‘a disease you can die from’ and ‘a life-shortening

illness'. We found that there was no distinction in these three categories for respondents to the current survey. Our findings indicate that just under a half of family carers and four-fifths of people living with dementia are not routinely being told that dementia is life-shortening. Most services did offer this information in at least one format, whether it was written, verbal or at a carer support group/meeting.

The current survey found conversations more readily occurred in relevant contexts: if the staff member's job role included supporting 'end-of-life care' or they were working in a hospice. Perhaps indicating that dementia is life-shortening at diagnosis may help people with dementia and their families feel more prepared for these discussions, which will seem relevant within the context of a terminal condition. Reluctance to have these conversations may also be due to the confidence of the healthcare professional. Another survey of Admiral Nurses indicated experience in ACP, resources to aid initiating ACP conversations and opportunities for supervised practice of completing ACPs would increase their confidence in this skill²⁵. Our findings from care homes indicate that discussions more commonly occurred with residents who had capacity than with family, however, the frequency in which residents have capacity was not elicited and may be uncommon. Our previous work has found that care home staff need support in having these discussions with family and tend to view ACP as a tick box exercise^{26,27}. Experience working in a palliative care setting may help develop these communication skills and may explain why carers with a relative who accesses hospice care report higher preparation for end-of-life²⁸.

There was a slight trend (no statistical analysis) for memory services to be more reluctant to endorse EAPC recommendations to start ACP as soon as possible after diagnosis (60% endorsement) and to offer bereavement support to carers following diagnosis (40% endorsement); both of which were endorsed by approximately 80% of Admiral Nurses and care home managers. As memory services are engaged in the earlier diagnostic phase, they perhaps identify more challenges to implementing these recommendations. They described how discussions of end-of-life might be counter to their

message of living well with dementia. It is also possible that as Admiral Nurses and care homes were surveyed approximately 12 months after memory services, that knowledge and integration of the 2014 EAPC recommendations were becoming more common.

These findings, however, do suggest a tension in the service system regarding when and who should initiate these conversations, as has been previously highlighted²⁹. Memory services tended to have concerns about initiating end-of-life conversations too early and some were only able to offer limited post-diagnostic support, while Admiral Nurses and care homes indicated that conversations were not occurring when the person with dementia had capacity and rarely before care home admission. Dementia UK have argued that commissioning of Admiral Nurse posts often addressed only part of the dementia trajectory leading to care fragmentation¹⁹. Our survey verifies this barrier to providing relationship-centred care; essential for supporting end-of-life care discussions.

Limitations

Despite the provision of a prize award and four contacts, we obtained a low response rate from care homes. We had a better response rate from Admiral Nurses which was higher than our previous survey of memory clinics (51% responses rate)¹⁶. The generalisability of the care home findings are therefore limited. Given that approximately 70% of UK care home residents in 2013 had dementia and this proportion is rising³⁰, we were surprised that some care homes indicated that they did not provide care to people with dementia, even though they were not registered for other groups such as younger people with physical disabilities.

Anonymous responses aimed to reduce socially desirable reporting, however, it is possible respondents overestimated the extent to which they feel that these practices should be, or are undertaken within their services. Also, we focused on what we considered were best practice services. Non-specialist nurses and care homes without GSFCH Accreditation are likely to have less understanding of dementia and confidence to discuss end-of-life care.

We only surveyed managers who may not accurately reflect practice provided within their care homes. Residents' General Practitioners or other nurses working in the care home may hold different views and their practice may differ from that reported by the manager.

Conclusions

Our survey of care homes and Admiral Nurses combined with findings from memory services in the UK found fragmentation across the service system, lack of continuity and tensions regarding when these conversations should be initiated and by whom. Admiral Nurses highlighted the value of ongoing discussion and developing relationships but that service models tended to split their role to specific stages of dementia. Memory services faced obstacles and concerns about initiating conversations too early, while concerns about leaving conversations too late, when the person with dementia no longer had capacity to engage were raised by Admiral Nurses and care homes. Discussing dementia as a terminal condition (or as a disease you can die from) was not a routine discussion with people with dementia or their carers across all services, yet this message may help to enable end-of-life care conversations.

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Table 1: Demographic information of responding Admiral Nurse Services (N=138)

Variable	Response	N (%)
Gender of respondent	Male	9 (6.5)
	Female	128 (92.8)
	Rather not say	1 (0.7)
Respondent's length of time working as an Admiral Nurse	Less than 1 year	31 (22.5)
	1-3 years	54 (39.1)
	4-6 years	27 (19.6)
	7-10 years	16 (11.6)
	More than 10 years	10 (7.2)
Type of service	Acute care	11 (8.0)
	Care Home and/or nursing home	10 (7.2)
	Community care	60 (43.5)
	Hospice	10 (7.2)
	Mental Health Services and Memory services	18 (13.0)
	Primary Care/General Practice	7 (5.1)
	Telephone helpline	17 (12.3)
	Other (e.g. joint/research/regional roles)	5 (3.6)
Service user population	Urban	37 (26.8)
	Rural	9 (6.5)
	Mixed	92 (66.7)
Length of time service has been operating	Less than a year	25 (18.1)
	1-3 years	42 (30.4)
	4-6 years	19 (13.8)
	7-10 years	27 (19.6)
	More than 10 years	25 (18.1)
Service provider	NHS	60 (43.5)
	Local Authority	1 (0.7)
	Private	6 (4.3)
	Charity	58 (42.0)
	Other	13 (9.4)
Typical length of time working with carers	1 or 2 sessions	29 (21.0)
	Less than 3 months	5 (3.6)
	3-6 months	15 (10.9)
	7-12 months	22 (15.9)
	>1 year, but typically discharge clients	16 (11.6)
	Until death of client	7 (5.1)
	Until death of client and can provide post death support for carers	44 (31.9)
Service takes clients from a catchment area in	England	118 (85.5)
	Wales	7 (5.1)
	UK Wide	15 (10.9)
	Internationally	12 (8.7)
Typical stage of involvement with carers	Pre diagnosis	59 (42.8)
	At diagnosis and early stages of dementia	107 (77.5)
	During the moderate stages of dementia	128 (92.8)
	During the advanced stages of dementia	134 (97.1)
	In the last days or weeks of life	121 (87.7)
	After death	103 (74.6)

Table 2 Demographic information of responding Care Homes (N=44)

Variable	Response	N (%)
Gender of respondent	Male	6 (13.6)
	Female	38 (86.4)
Length of time working in care home	Less than 1 year	5 (11.4)
	1-3 years	6 (13.6)
	4-6 years	7 (15.9)
	7-10 years	6 (13.6)
	More than 10 years	20 (45.5)
Role in care home	Manager	35 (79.5)
	Deputy manager	6 (13.6)
	Other	3 (6.8)
Number of residents care home accommodates	<20	2 (4.5)
	20-39	11 (25.0)
	40-59	10 (22.7)
	60-99	19 (43.2)
	100+	2 (4.5)
Length of time care home has been operating	4-6 years	3 (6.8)
	7-10 years	3 (6.8)
	More than 10 years	38 (86.5)
Service provider	Local Authority	2 (4.5)
	Private	34 (77.3)
	Charity	8 (18.2)
Gold Standards Framework accreditation	Yes currently accredited	38 (86.4)
	No, but working towards accreditation	1 (2.3)
	No, but we were previously accredited	5 (11.4)
Support offered to carers	No	11 (25.0)
	Family meetings	30 (68.2)
	Family education sessions	3 (6.8)

Table 3 Topics on preparation for end-of-life: discussions and information provided by Admiral Nurses (N=138) and Care Homes (N=44)

		Dementia as a progressive illness	Dementia as a life-shortening illness	Dementia as a disease you can die from	Dementia as a terminal illness†	Spirituality or interpretations of the meaning of death	Importance of support for carers from their social network	Meaning and implications of loss of mental capacity	ACP discussions about patient's wishes for the future	Legal health care arrangements	Legal financial arrangements ‡
Verbally with all Patients/Residents with capacity	AN	50 (36.2)	29 (21.0)	25 (18.1)	27 (20.0)	18 (13.0)	41 (29.7)	42 (30.4)	53 (38.4)	54 (39.1)	50 (36.5)
	CH	26 (59.1)	15 (34.1)	12 (27.3)	16 (36.4)	22 (50.0)	12 (27.3)	22 (50.0)	33 (75.0)	29 (65.9)	21 (47.7)
Verbally with all carers	AN	112 (81.2)	82 (59.4)	72 (52.2)	79 (58.5)	30 (21.7)	115 (83.3)	100 (72.5)	92 (66.7)	105 (76.1)	100 (73.0)
	CH	30 (68.2)	27 (61.4)	26 (59.1)	25 (56.8)	26 (59.1)	28 (63.6)	32 (72.7)	34 (77.3)	23 (52.3)	17 (38.6)
If raised by a patient/carer	AN	72 (52.5)	86 (62.3)	85 (61.6)	80 (59.3)	93 (67.4)	61 (44.2)	80 (58.0)	83 (60.1)	77 (55.8)	77 (56.2)
	CH	24 (54.5)	24 (54.5)	25 (56.8)	25 (56.8)	26 (59.1)	21 (47.7)	26 (59.1)	26 (59.1)	25 (56.8)	21 (47.7)
During Carer Support Groups	AN	59 (42.8)	50 (36.2)	44 (31.9)	42 (31.1)	19 (13.8)	63 (45.7)	51 (37.0)	47 (34.1)	52 (37.7)	51 (37.2)
During family meetings	CH	30 (68.2)	27 (61.4)	30 (68.2)	25 (56.8)	25 (56.8)	24 (54.5)	29 (65.9)	35 (79.5)	25 (56.8)	24 (54.5)
In leaflet form	AN	89 (64.5)	38 (27.5)	24 (17.4)	23 (17.0)	16 (11.6)	51 (37.0)	66 (47.8)	52 (37.7)	74 (53.6)	72 (52.6)
	CH	17 (38.6)	13 (29.5)	13 (29.5)	13 (29.5)	19 (43.2)	9 (20.5)	20 (45.5)	30 (68.2)	17 (38.6)	12 (27.3)
Not provided	AN	-	7 (5.1)	9 (6.5)	8 (5.9)	26 (18.8)	2 (1.4)	1 (0.7)	1 (0.7)	5 (3.6)	8 (5.8)
	CH	-	5 (11.4)	5 (11.4)	5 (11.4)	3 (6.8)	2 (4.5)	1 (2.3)	1 (2.3)	3 (6.8)	5 (11.4)

AN=Admiral Nurse; CH=Care Home; † Missing 3 responses from Admiral Nurses to this question, ‡ Missing 1 response from an Admiral Nurse to this question

Table 4: Respondents' agreement with guidelines as they relate to their service (Admiral Nurses N=125; Care homes N=39)

NICE Guideline/EAPC Recommendation		Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Advance care planning should start as soon as the diagnosis is made†	AN	5 (4.0)	6 (4.8)	12 (9.6)	55 (44.0)	47 (37.6)
	CH	4 (10.3)	0 (0)	5 (12.8)	10 (25.6)	20 (51.3)
Professionals should discuss advance statements and advance decisions to refuse treatment with the person with dementia and their carer, while the patient still has capacity‡	AN	6 (4.8)	1 (0.8)	15 (12.0)	39 (31.2)	64 (51.2)
	CH	5 (12.8)	0 (0)	1 (2.6)	10 (25.6)	23 (59.0)
Professionals should discuss Lasting Power of Attorney with the person with dementia and their carer, while the patient still has capacity‡	AN	6 (4.8)	1 (0.8)	5 (4.0)	35 (28.0)	78 (62.4)
	CH	4 (10.3)	0 (0)	1 (2.6)	10 (25.6)	24 (61.5)
Professionals should discuss Preferred Place of Care plans with the person with dementia and their carer, while the patient still has capacity‡	AN	6 (4.8)	1 (0.8)	12 (9.6)	38 (30.4)	68 (54.4)
	CH	4 (10.3)	0 (0)	0 (0)	12 (30.8)	23 (59.0)
Any advance care plans should be revisited with the patient and family on a regular basis†	AN	6 (4.8)	1 (0.8)	11 (8.8)	41 (32.8)	66 (52.8)
	CH	4 (10.3)	0 (0)	0 (0)	10 (25.6)	25 (64.1)
Professionals should discuss the progressive course of dementia†	AN	6 (4.8)	0 (0)	3 (2.4)	46 (36.8)	70 (56.0)
	CH	4 (10.3)	0 (0)	2 (5.1)	14 (35.9)	19 (48.7)
Professionals should discuss the terminal nature of dementia†	AN	6 (4.8)	1 (0.8)	7 (5.6)	45 (36.0)	66 (52.8)
	CH	4 (10.3)	0 (0)	2 (5.1)	15 (38.5)	18 (46.2)
Professionals should assess religious affiliation and involvement, sources of spiritual support and the spiritual wellbeing of patients and their families†	AN	6 (4.8)	1 (0.8)	18 (14.4)	53 (42.4)	47 (37.6)
	CH	5 (12.8)	0 (0)	1 (2.6)	16 (41.0)	17 (43.6)
Bereavement support should be offered to carers following a dementia diagnosis†	AN	6 (4.8)	3 (2.4)	17 (13.6)	32 (25.6)	67 (53.6)
	CH	5 (12.8)	0 (0)	2 (5.1)	13 (33.3)	19 (48.7)

AN=Admiral Nurse; CH=Care Home, † EAPC recommendation, ‡ NICE recommendation