

# The role of the memory service in helping carers to prepare for end of life: A mixed methods study

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**Objectives:** The objective of the study is to explore current practice and the role taken by UK memory services in helping carers of people with dementia prepare for the end of life.

**Methods:** We used mixed methods including a survey (48 responses/51% response rate) and semistructured interviews (n = 12) with clinicians working in UK memory services accredited by the Memory Services National Accreditation Programme. We used descriptive statistics to report survey findings and thematically analysed interview and survey qualitative data.

**Results:** Surveys: services routinely discussed with carers the progressive nature of dementia (89%), legal arrangements (health: 72%; finances: 74%), advance care planning (63%), and implications of loss of capacity (61%). Fewer services routinely discussed the terminal nature of dementia (41%) and meaning of death (11%) with carers. Most (89%) agreed that these conversations were in line with their role. Interview findings corresponded with survey findings. Themes included diagnosis considered too early to discuss end of life, discussions being inconsistent with a "living well" approach, people with dementia being resistant to conversations, and discussions of spirituality crossing professional boundaries. Services' capacity for follow-up with carers impacted on ability to broach these topics.

**Conclusions:** More in-depth and distressing topics such as end of life and advance care planning require longer follow-up to establish relationships to broach difficult topics. Variability in follow-up practices between services created inequity in the extent to which memory services could address these topics. More research is required to investigate the best method for broaching these topics with carers and the person with mild dementia within different health care contexts.

## KEYWORDS

advance care planning, dementia, family carers, memory services, preparation for end of life, progressive, terminal

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## 1 | BACKGROUND

In 2015, 46.8 million people lived with dementia worldwide.<sup>1</sup> Between 2000 and 2016, annual deaths from dementia more than doubled and dementia rose from the 14th to the 5th highest rank cause of death worldwide.<sup>2</sup> In the UK, 670 000 family and friend “carers” provide the majority of support.<sup>3</sup> Caring can be stressful,<sup>4</sup> and an important determinant of carer well-being is preparation for the end of life of their care recipient. Less prepared carers are at higher risk of complicated grief following death.<sup>4</sup> More than a third of carers of people with dementia report being unprepared for the death.<sup>5</sup>

Carers' preparation for end of life can be enhanced through discussing spirituality and the meaning of death,<sup>4,6</sup> greater knowledge of how dementia progresses,<sup>7,8</sup> understanding the person with dementia's end-of-life preferences,<sup>9</sup> and having legal arrangements in place such as lasting power of attorney.<sup>8,10</sup> Carers value written information to reinforce verbal information from health care professionals.<sup>11,12</sup>

The National Institute for Health and Care Excellence (NICE) guidelines and the European Association for Palliative Care (EAPC) White paper<sup>13,14</sup> encourage clinicians to educate families on the terminal nature and progressive course of dementia and recommend professionals discuss spiritual well-being with families after diagnosis.<sup>14</sup> They highlight advance care planning (ACP) and early discussions about advance statements and lasting power of attorney<sup>13,14</sup> which should occur while the person with dementia has capacity<sup>13</sup> or as soon as diagnosis is made.<sup>14</sup>

Challenges to conducting end-of-life discussions include people with dementia having difficulty envisaging themselves in the future,<sup>15</sup> insufficient time and resources,<sup>16</sup> and staff struggling with terminology and legal frameworks.<sup>17</sup> Clinicians demonstrate more confidence in discussing lasting power of attorney.<sup>17</sup>

Memory services or clinics are secondary care services which assess and diagnose dementia.<sup>13</sup> They may offer continued support,<sup>13</sup> though follow-up varies and they may miss the opportunity to prepare carers for end of life while the person with dementia still has capacity.<sup>18</sup> In the UK, they are often the first contact for accessing information and advice about dementia to people with dementia and their carers. After diagnosis, this information may be accessed via their doctor, social services, or charities such as Alzheimer's Society and Dementia UK. We aimed to examine the role of UK memory services in helping carers of people with dementia prepare for end of life. We focused on carers as the study was one component of a broader programme examining carer predeath grief and preparation for end of life across disease stages. The research questions were as follows:

1. What are memory services currently doing to prepare carers for end of life after a dementia diagnosis?
2. Do clinicians working in memory services agree that these services are an appropriate place to discuss the factors that support preparation for end of life?
3. How do clinicians in memory services perceive the NICE and EAPC guidelines relevant to preparation for end of life?
4. What barriers and facilitators do memory services' clinicians perceive when initiating and having these discussions?

## 2 | METHODS

This was a mixed methods cross-sectional survey and interview study, approved by the University College London Research Ethics Committee (10087/002) with Health Research Authority approval for interviews in the National Health Service (Integrated Research Application System: 220007).

### 2.1 | Surveys

In 2009, the UK Royal College of Psychiatrists established the Memory Services National Accreditation Programme (MSNAP).<sup>19</sup> Approximately a third of UK services are accredited,<sup>20</sup> and we focused on these as they represent current UK best practice. We developed a survey based on a literature review and the NICE and EAPC guidelines,<sup>13,14</sup> delivered through the programme Opinion. Respondents consented online to access the survey. The survey explored the type and format of information provided by the memory service: dementia progression, the terminal nature of dementia, spirituality and meaning of death, mental capacity, end-of-life preferences and legal arrangements, and whether it was provided to patients and/or carers and in what format. We asked if participants thought these discussions were congruent with the memory service's role, sought perceptions of relevant NICE and EAPC guidelines, and barriers and facilitators to these discussions. We piloted the survey with two memory service clinicians.

As of March 2017, 87 of the estimated 300 UK memory services were accredited. We collected survey data from March to July 2017. MSNAP distributed the survey to the 257 subscribers to their service. We anticipated that MSNAP would send it to accredited services only; however, their database included a much broader audience of subscribers including service managers, clinicians, and individuals from any memory service or dementia-related organisation. We invited MSNAP-accredited memory services only; however, it was possible that nonaccredited services could anonymously respond. MSNAP sent the first and second reminder emails 2 and 5 weeks after the initial invitation. Due to poor response to the emailed survey, we reminded memory services via telephone over the subsequent 3 weeks and emailed this again where necessary. These services were identified through the list of MSNAP members on the programme's website.

We included data from all participants regardless of completion. One participant terminated the survey after 16 items (46% complete). Another two services terminated after completing the first page of clinic details before completing any questions relating to the survey topic. We used standard descriptive statistics to present the findings.

### 2.2 | Interviews

We conducted semistructured interviews with clinicians from various disciplines who had contact with people with dementia and carers after a dementia diagnosis in MSNAP-accredited memory services. We did not aim for this sample to be representative but to provide a richer and more in-depth perspective on topics covered in the survey. We aimed to obtain views from rural and metropolitan services and a mix

of disciplines. We felt that four participants from each service would capture most disciplines and a range of approaches and views. We approached one London service which agreed to be involved and five rural services before we were able to confirm participation from two; both located in Kent. Service managers invited staff to participate in an interview, and we limited the number of interviews at each clinic to four. We obtained informed consent from staff and indicated that we would not inform their manager of whether they did or did not agree to be interviewed. We visited the clinic on their meeting day so that most staff were present on the day of interviewing.

We used an interview guide regarding discussions on the progressive nature of dementia and describing it as a terminal condition, discussions about the end-of-life preferences of the person with dementia, including ACP, and around the meaning of death. Interviewers asked clinicians whether they discussed each topic with people with dementia and/or carers, in what contexts those discussions took place, whether they believed discussions were important and congruent with their role, and barriers and facilitators to having those discussions.

Interviews were audio recorded and transcribed verbatim (HG, KM, YK) and thematically analysed using NVivo V11 (QSR International, 2015). HG conducted the primary analysis and established familiarity with data through conducting most of the interviews, assisting with transcribing, and then rereading all interviews. HG used inductive analysis to identify themes regarding discussions to help carers prepare for end of life and barriers and facilitators to having them in the memory service, identifying relevant extracts and creating nodes, then grouping those which were related into broader themes. Within NVivo, the grouping of nodes was categorised under broad themes. Each of these had various levels of nodes and groupings of nodes within these up to six levels (although the fifth and six levels often contained only one or two nodes from one or two participants). Once coding was complete, themes were refined to present the most comprehensive account of the data. KM, who had conducted two interviews, familiarised herself with the remaining transcripts and summarised core themes before reviewing the themes that HG had identified. HG and KM discussed and reflected on all themes and the research question and examined consistency and discrepancies in the findings, which were minimal. A final core set of themes was agreed.

## 3 | RESULTS

### 3.1 | Survey

We received responses from 48 services (17 replied anonymously). Four services that responded were not one of the 87 accredited services as of March 2017 although they may have been accredited before or after this date (at least two were). Given that a further 17 surveys were anonymously completed, it is possible that other respondents were not accredited. We therefore decided to include all responses. If all anonymous surveys were accredited services, our response rate would be 51% (44/87; ignoring the four described above). For details of participating services, see Table 1. Most participants were female (80%) with a nursing background (87%) (Table 2).

### Key points

- Survey and interview data from UK memory services indicated variation in practice and views about the appropriateness of the memory services broaching topics about dementia progression, prognosis, advance decisions, and end of life.
- Respondents preferred to focus on living well with dementia although did recognise the importance of indicating that dementia was progressive.
- There were mixed views about the appropriateness of telling people with dementia and their family that dementia was terminal.
- Variations in follow-up procedures across services impact on capacity to have follow-up conversations and establish relationships to support end-of-life discussions.

While services varied considerably in the extent to which they follow-up clients postdiagnosis, only 6% of services discharged immediately after diagnosis. Therefore, most clinics offered postdiagnosis support.

#### 3.1.1 | Current practice

We asked clinics to report whether they provided various types of information either directly to the patient or carer, in written format or during postdiagnostic carer groups (see Table 3). When exploring current practice regarding discussions and information provision, we found considerable variability between the topics that support carer preparation. Spirituality and meaning of death were least likely to be discussed.

While the progressive nature of dementia was usually discussed, dementia was less often communicated as a terminal condition. Several participants disputed the classification of dementia as terminal:

*"Dementia is a chronic illness. People do not die of dementia" (Survey 43)*

Most services that ran carer groups reported discussing the given topics within these sessions. The terminal nature of dementia and spiritual conversations were exceptions to this (Table 3).

#### 3.1.2 | Guidelines

Table 4 shows the level of agreement with various NICE guidelines and EAPC recommendations, with higher levels of agreement for NICE guidelines. The only guideline that all participants agreed with was NICE guidance that professionals should discuss lasting power of attorney with families before the person with dementia loses capacity (73% strongly agree).

#### 3.1.3 | Barriers and facilitators

Participants strongly endorsed that these discussions were in line with the role of the memory service (89% responded yes and 11% maybe).

**TABLE 1** Demographic information of responding memory services

Variable	Response—Single Option	N (%)
Country	England	44 (97.8)
	Wales	1 (2.2)
Typical length of follow-up before discharge <sup>a</sup>	Immediate discharge to GP after diagnosis	3 (6.4)
	Less than 3 months	5 (10.6)
	3-6 months	23 (48.9)
	7-12 months	2 (4.3)
	More than 1 year, but people with dementia are typically discharged	7 (14.9)
	Cases are followed up until death	7 (14.9)
Service user population	Urban	17 (37.8)
	Rural	4 (8.9)
	Mixed	24 (53.3)
Length of time since service first launched	1-3 years	1 (2.2)
	4-6 years	13 (28.9)
	7-10 years	16 (35.6)
	More than 10 years	15 (33.3)
Team size	1-10 Staff	14 (31.1)
	11-20 Staff	18 (40.0)
	21-30 Staff	11 (24.4)
	31-40 Staff	2 (4.4)
Variable	Response—multiple options	N (%)
Support offered to carers after a dementia diagnosis <sup>a</sup>	1:1 Sessions	38 (80.9)
	Advice during sessions with both the carer and the person with dementia	46 (97.7)
	Carer support group(s)	30 (63.8)
	Carer education group(s)	33 (70.2)
	Written information	45 (95.7)
Disciplines represented in the team	Nursing	44 (100)
	Medicine	42 (93.3)
	Psychology	41 (91.1)
	Occupational therapy	40 (88.9)
	Social work	16 (35.6)
	Speech and language therapy	7 (15.6)
	Physiotherapy	6 (13.3)
	Other (eg, support workers, dementia navigators etc)	6 (13.3)
	Administration	42 (93.3)

N = 45 unless otherwise indicated.

<sup>a</sup>N = 47.

**TABLE 2** Survey participants' demographic information (N = 45)

Demographic	Description	N (%)
Gender	Female	36 (80.0)
	Male	8 (17.8)
	Rather not say	1 (2.2)
Job title	Team leader	27 (60.0)
	Service manager	7 (15.6)
	Clinical lead	1 (2.2)
	Other (mainly senior nursing titles)	10 (22.2)
Discipline	Nursing	39 (86.7)
	Occupational therapy	2 (4.4)
	Social work	2 (4.4)
	Medicine	1 (2.2)
	Psychology	1 (2.2)

Several highlighted the importance of having discussions and suggested that families would worry about these issues if not addressed. Some services discussed facilitators to integrating guidelines in their practice, including a knowledgeable and confident memory service team and extra support from the wider community team.

Several participants highlighted barriers. Some explained that they do not discuss the terminal nature of dementia because they encourage people with dementia to live well with the diagnosis. They

suggested that it would then be contradictory to discuss it being terminal. Some participants also discussed pressure from commissioners to focus on assessment and diagnosis, resulting in lack of resource for postdiagnostic follow-up. Several suggested that capacity to have follow-up sessions allows for individualised timing of these discussions:

*"Our team prefer to be guided by individuals and provide information at a time they feel it is needed, as for some carers/patients, it takes time to accept the diagnosis"*  
(Survey 27)

Participants explained how demands placed on memory services exceeded allocated resources:

*"It is so often the case that guidelines are introduced without the services to support the recommendations"*  
(Survey 8)

Suggestions for what would facilitate implementation of the guidelines included more Admiral nurses (dementia specialist registered nurses who have an ongoing professional portfolio within the Admiral Nurse Competency Framework supported by Dementia UK), a larger staff team, and increased staff knowledge of the topics.

**TABLE 3** Topics that contribute to preparation for end of life: discussions and provided information

	In Leaflet Form	Verbally with All Patients	Verbally with All Carers	If Raised by a Patient/Carer	During Carer Support Groups <sup>a</sup>	During Carer Education Groups <sup>b</sup>	No	Other
	N (%)							
The nature of dementia as a progressive illness	40 (87)	40 (87)	41 (89)	16 (34.8)	22 (78.6)	27 (87.1)	0 (0)	5 (10.9)
The nature of dementia as a terminal illness	22 (47.8)	17 (37.0)	19 (41.3)	29 (63.0)	15 (53.6)	16 (51.6)	4 (8.7)	2 (4.3)
Spirituality or interpretations of the meaning of death	8 (17.4)	5 (10.9)	5 (10.9)	29 (63.0)	6 (21.4)	5 (16.1)	13 (28.3)	3 (6.5)
The importance of support for carers from their social network	30 (65.2)	28 (60.9)	36 (78.3)	12 (26.1)	22 (78.6)	27 (87.1)	1 (2.2)	3 (6.5)
The meaning and implications of "loss of mental capacity"	31 (67.4)	27 (58.7)	28 (60.9)	26 (56.5)	18 (64.3)	20 (64.5)	0 (0)	4 (8.7)
Advance care planning discussions about the patient's future wishes	31 (67.4)	31 (67.4)	29 (63.0)	25 (54.3)	19 (67.9)	22 (71.0)	2 (4.3)	5 (10.9)
Legal health and medical care arrangements in anticipation of loss of capacity (eg, health and welfare attorney, advance statements)	38 (82.6)	35 (76.1)	33 (71.7)	22 (47.8)	21 (75.0)	26 (83.9)	1 (2.2)	4 (8.7)
Legal financial arrangements in anticipation of loss of capacity (eg, property/financial affairs attorney)	36 (78.3)	32 (69.6)	34 (73.9)	21 (45.7)	20 (71.4)	25 (80.7)	1 (2.2)	4 (8.7)

N = 46 unless otherwise marked.

<sup>a</sup>Only services reporting running a carer support group are included; therefore, n = 28.

<sup>b</sup>Only services reporting running a carer education group are included; therefore, n = 31.

### 3.2 | Interviews

We interviewed 12 clinicians, four from each service (Table 5). We analysed 10 transcripts and notes from two interviews (one

participant refused to be recorded, and technical failure prevented another interview being recorded). Interviews were conducted by HG (n = 10) and KM (n = 2). These three services provided postdiagnostic psychoeducation for relatives. One offered a single

**TABLE 4** Participants' agreement with guidelines as they relate to their service

NICE Guideline/EAPC Recommendation	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
	N (%)				
Advance care planning should start as soon as the diagnosis is made (EAPC recommendation)	0 (0)	4 (8.9)	14 (31.1)	11 (24.4)	16 (35.6)
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 (NICE guidelines)	0 (0)	1 (2.2)	2 (4.4)	13 (28.9)	29 (64.4)
Professionals should discuss lasting power of attorney with the person with dementia and their carer, while the patient still has capacity (NICE guideline)	0 (0)	0 (0)	0 (0)	12 (26.7)	33 (73.3)
Professionals should discuss preferred place of care plans with the person with dementia and their carer, while the patient still has capacity (NICE guideline)	0 (0)	0 (0)	3 (6.7)	19 (42.2)	23 (51.1)
Any advance care plans should be revisited with the patient and family on a regular basis (EAPC recommendation)	0 (0)	0 (0)	8 (17.8)	14 (31.1)	23 (51.1)
Professionals should discuss the progressive course of dementia (EAPC recommendation)	0 (0)	0 (0)	3 (6.7)	15 (33.3)	27 (60.0)
Professionals should discuss the terminal nature of dementia (EAPC recommendation)	0 (0)	2 (4.4)	19 (42.2)	9 (20.0)	15 (33.3)
Professionals should assess religious affiliation and involvement, sources of spiritual support, and the spiritual well-being of patients and their families (EAPC recommendation)	0 (0)	2 (4.4)	13 (28.9)	12 (26.7)	18 (40.0)
Bereavement support should be offered to carers following a dementia diagnosis (EAPC recommendation)	0 (0)	2 (4.4)	24 (53.3)	9 (20.0)	10 (22.2)

**TABLE 5** Interview participants' demographic information

Demographic	Description	N
Gender	Female	11
	Male	1
Age <sup>a</sup>	30-39	2
	40-49	7
	50-59	2
Job title	Team leader	1
	Consultant psychiatrist	3
	Admiral nurse	3
	Nurse prescriber	2
	Care coordinator	1
	Occupational therapist	1
	Support worker	1
Time working in the service	Less than 1 year	1
	1-2 years	4
	3-6 years	4
	7-15 years	3

N = 12 unless otherwise stated.

<sup>a</sup>n = 11.

follow-up appointment after diagnosis. Another offered a follow-up phone call after diagnosis. The third could continue to follow-up with families.

We identified four key themes regarding timing, barriers, and practices around discussing these issues within the memory service, and each is described in Table 6. Staff confidence or lack of confidence was also identified as a key factor, but for brevity, we have not described this theme as it is well documented in the literature.<sup>16,21,22</sup>

## 4 | DISCUSSION

We aimed to explore current memory service practice in helping carers prepare for end of life. Most clinicians agreed that discussions of these topics were appropriate for their role. However, there was considerable variability in practice. Informing people with dementia and family about the progressive nature of dementia and providing written information about legal issues were routine, as was emphasising to carers the importance of accessing support from their social network. However, discussing the implications of loss of capacity, ACP and legal arrangements only occurred in two-thirds of services, 37% of services would tell the person with dementia that it was terminal, and only 11% discussed spirituality or the meaning of death. When these conversations occurred, clinicians usually provided written information, consistent with MSNAP audit.<sup>19</sup> We found stronger endorsement for NICE than EAPC guidelines which may be expected given the latter are not mandatory and are relatively new.

Clinicians prioritised encouraging people to live well with dementia over discussing end of life. They referred to the National Dementia Strategy, Living Well with Dementia<sup>23</sup> and that end-of-life discussions contradicted this approach. However, one of the strategy's outcomes is for people with dementia to be confident that their end-of-life wishes will be respected.<sup>23</sup> A study of diagnostic practices in UK memory services also found that doctors tended to focus on positive aspects and downplay the progressive nature and prognosis of dementia.<sup>24</sup>

Clinicians distinguished between defining dementia as progressive and terminal. They often had to repeat to family that dementia was

progressive, raising the question as to how well the person with dementia and family interpret and understand the information provided. This may explain why carers of those with advanced dementia do not recall being told dementia was progressive or terminal at diagnosis.<sup>25</sup> The NICE guidelines currently recommend naming a member of staff to lead the implementation of care plans with each family.<sup>13</sup> It may be helpful to develop a model of progressive disclosure for clinicians to implement over follow-up appointments<sup>11,12,26</sup>; however, this is limited if services do not offer follow-up.

Clinicians often felt that the time of diagnosis was too early for these discussions and that people had a lot of information to absorb; however, uncertainty as to when is the best time to do this is well documented.<sup>17</sup> Developing relationships and holding ongoing discussions to broach these sensitive topics<sup>27</sup> may not be possible as different services offer variable amounts of follow-up, creating inequity in service provision.

There was consensus that discussions about spirituality and the meaning of death were not part of the memory service's role. However, given carers have suggested the need for these discussions,<sup>4,6</sup> we should continue research to identify by who and when these discussions should be broached.

Barriers to discussing the terminal nature of dementia and advance care planning are found internationally.<sup>9,28,29</sup> Research to date has focused on education and advance care planning with family carers during advanced stages of dementia<sup>30,31</sup> rather than during mild dementia and involving the person with dementia. One US pilot intervention targeted people with mild dementia and involved a reminiscence activity to examine what it has meant to live well followed by ACP discussion on what it would mean to live well in the future. While some benefits were found, many people were not interested in participating as they did not consider they had memory problems or wanted to undertake a study relating to memory.<sup>32</sup> Poppe et al<sup>21</sup> recommend that if advance discussions are to occur shortly after diagnosis, they need to be initiated by health care professionals in mental health teams and memory services who have this as a core part of their work and receive training and clinical supervision for this role.

### 4.1 | Limitations

By restricting our sample to MSNAP-accredited services, our findings are not representative of all clinics, but gaps amongst these services are likely to exist in other services too. One limitation is that some respondents were from services not accredited at the time of the survey. However, we recruited 75% of the sample during the period of telephone follow-up, in which we only contacted accredited services. Given that half of MSNAP-accredited services responded, there may be a nonresponse bias; however, the staff numbers and discipline mix reported by respondents is consistent with MSNAP services nationally.<sup>33</sup> Services that did not respond may have been too busy or not have considered the topic relevant to them. They may have reported lower capacity and importance of having these discussions. Respondents may have overestimated the extent to which staff in their services provided information to their clients.

**TABLE 6** Qualitative interview themes and illustrative quotes

Theme	Description	Illustrative Quotes
Diagnosis as too early	<p>Discussions to help carers to prepare for end of life were often not considered appropriate at the time of diagnosis. Participants explained that families needed time to process a diagnosis before these conversations. However, there was recognition of the barrier that the typical focus of memory services today is to diagnose, initiate treatment, and discharge to primary care. Developing a relationship with families helped make conversations feel more natural and appropriately timed.</p> <p>Some participants recognised how changes in capacity of the person with dementia were an issue if discussions are delayed. A common exception to this was lasting power of attorney and dementia as a progressive condition. Participants explained that it was important to establish lasting power of attorney when the person with dementia still had capacity. The need for honesty when delivering a diagnosis was often cited as the reason for describing the progressive nature of dementia. However, participants needed to repeat this message.</p> <p>Participants thought this was likely due to the high level of stress experienced by families at diagnosis. This was why postdiagnostic follow-up was considered important for delivering new messages and helping families understand and retain important information. Admiral nurses and carer groups were considered a valuable resource for promoting these discussions. Primary care was considered unlikely to have the resource or specialist knowledge to do this.</p>	<p>"I think that a lot of it is around the trust that ... they build up with me and what they feel comfortable to talk to me about" (Interview 3)</p> <p>"You're constantly reminding people ... that's the normal progression, because you've got this diagnosis. People tend to forget that" (Interview 11)</p>
Living well with dementia	<p>Clinicians often suggested that they could not talk about the terminal nature of dementia and end of life care while encouraging a person to live well with the diagnosis.</p> <p>They encourage clients to have a good life with dementia but that this meant they could not discuss a good death.</p> <p>Within this theme, clinicians draw a distinction between discussions regarding the progressive and the terminal nature of dementia. While families were routinely informed of the progressive nature of dementia, only one participant indicated that they have described dementia as terminal. The progression of dementia could be incorporated in a strength based and "living well" approach by explaining that progression is often very slow. However, using the word terminal suggested death as imminent and may take away people's sense of control.</p> <p>Several participants did not recognise dementia as a terminal condition as people may die from other causes. Some clinicians had not considered dementia as terminal before.</p> <p>A second subtheme was the strategy to maintain positivity until the person with dementia or family became cognisant of disease progression. Once decline became evident, participants felt this could be a trigger and a sign of readiness to discuss progression and end of life.</p>	<p>"Where they have just received the diagnosis, to focus on the end, I think that is wrong, that destroys hope and that destroys the will to get the best out of their lives still ... I think the emphasis in the ... diagnostic process has to be on support, on management, on having the best quality of life" (Interview 1)</p> <p>"When I talk about diagnosis I don't talk about death. When I talk about diagnosis I talk about the things that we can help them to do in life. It might seem ... slightly hypocritical potentially to start talking about well what about having a good death?" (Interview 10)</p> <p>"I think that puts the fear of God into most people, using 'terminal'. That makes it kind of a bit more imminent and out of one's control ... I try to encourage people to think about what they can do now, um, and how they can exert control" (Interview 2)</p> <p>"It's not that I've thought about it properly. I haven't decided not to use the word terminal. I just don't. It's not part of the culture of talking about dementia that you use the word terminal." (Interview 10)</p> <p>"This is very thought provoking, why don't I think of dementia as terminal?" (Interview 9)</p> <p>"In terms of end of life care, now I think this would again be discussed when there is more an issue of increasing frailty, declining mental and physical health, so at that time when end of life is more of an issue" (Interview 1)</p>
Resistance from the person with dementia	<p>A considerable barrier to discussing end of life related to a perceived resistance from people with dementia, despite family and carers being keen to have these discussions.</p> <p>Participants described strategies for addressing the disparate interest in these conversations between people with dementia and family. These included reiterating that discussions could not progress without the person with dementia's consent, having postdiagnostic group sessions where the person with dementia and families were separated, and providing information in writing for people to take away and consider when ready. However, this often remained a conflict.</p>	<p>"There's plenty of people who don't talk much about (end of life preferences) because that's an indicator that they are going to be dying soon, or if the family try to prompt them to sort a plan, it is 'oh you want me out of the way' sort of thing" (Interview 11)</p> <p>"To start talking about advance care planning when there appears to be disproportionate interest between carers and umm patients ... can make people feel uncomfortable" (Interview 10)</p>

(Continues)

TABLE 6 (Continued)

Theme	Description	Illustrative Quotes
Crossing boundaries	The final theme was that discussing spirituality and the meaning of death with families was crossing a professional boundary and viewed as imposing personal views. This concurred with the view that discussions of death and spirituality were taboo topics, particularly amongst older people.	"To my mind that would be completely wrong ... I don't want to be seen to be proselytising ... one has to be really careful that they are not conveying one's own religious or spiritual views". (Interview 1) "I think a lot of people are scared of talking about faith, spirituality... just like a lot of people are scared of talking about sex and sexuality, particularly in the over 65s". (Interview 11)

The data could be corroborated by obtaining the perspective of people with dementia and their carers.

While most services (94%) provided some postdiagnosis follow-up, we are unable to determine whether discussions occurred during the initial diagnosis or at a follow-up appointment. Based on qualitative interview findings, clinicians were more likely to broach these topics postdiagnosis. While we introduced the study as concerned with information to carers, we also sought views about information to patients. It is difficult to distinguish whether clinicians were referring to carers or patients. Findings indicate that the information routinely provided to patients and carers did not differ substantially; however, qualitative findings suggested greater barriers to conversations with patients than with family.

Thematic analysis was undertaken before interpretation of quantitative data to reduce risk of confirmation bias. A second researcher also independently identified themes before comparing them with those that had emerged from the primary researcher's analysis. However, it would have been preferable for both researchers to fully code all data to examine consistency in themes identified.

## 5 | CONCLUSION

Services agreed with addressing dementia as progressive and the need to establish lasting power of attorney early in the diagnostic process. More in-depth and distressing topics such as end of life and advance care planning require longer term follow-up to establish relationships to raise difficult topics. More research is required to investigate the best method for broaching these topics with carers and the person with mild dementia within different health care contexts. Variability in follow-up practices between services created inequity in the extent to which memory services could address these topics.

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