

# Using advance and emergency care plans during transfer decisions: A grounded theory interview study with care home staff

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## Abstract

**Background:** Advance care planning has been identified as one of few modifiable factors that could reduce hospital transfers from care homes. Several types of documents may be used by patients and clinicians to record these plans. However, little is known about how plans are perceived and used by care home staff at the time of deterioration.

**Aim:** To describe care home staff experiences and perceptions of using written plans during in-the-moment decision-making about potential resident hospital transfers.

**Design:** Qualitative semi-structured interviews analysed using the Straussian approach to grounded theory.

**Setting/participants:** Thirty staff across six care homes (with and without nursing) in the East and West Midlands of England.

**Results:** Staff preferred (in principle) to keep deteriorating residents in the care home but feared that doing so could lead to negative repercussions for them as individuals, especially when there was perceived discordance with family carers' wishes. They felt that clinicians should be responsible for these plans but were happy to take a supporting role. At the time of deterioration, written plans legitimised the decision to care for the resident within the home; however, staff were wary of interpreting broad statements and wanted plans to be detailed, specific, unambiguous, technically 'correct', understood by families and regularly updated.

**Conclusions:** Written plans provide reassurance for care home staff, reducing concerns about personal and professional risk. However, care home staff have limited discretion to interpret plans and transfers may occur if plans are not specific enough for care home staff to use confidently.

## Keywords

Advance care planning, care homes, nursing homes, patient transfer, qualitative

### What is already known about this topic?

- Advance care planning has attracted widespread policy support, including within care homes, as a means of promoting person-centred decision-making.
- A wide range of activities may be referred to (in academic literature and clinical practice) as 'advance care planning'; however, there is a distinction between advance care plans (written by individuals, detailing wishes, priorities and preferences for future care) and emergency healthcare plans (written by professionals, containing clinical recommendations).
- Existing research focuses on experiences of engaging in care planning discussions but much less is known about how these plans are used during *in-the-moment* decision-making when a resident's health deteriorates.

### What this paper adds?

- Although staff consistently described a preference for caring for deteriorating residents in the care home, they felt a sense of unease and vulnerability due to a concern that not transferring a resident might result in adverse consequences for them as an individual.

- Staff valued written plans and recognised their importance in reflecting residents' wishes, but they also highlighted the powerful role of family carers in the development of plans and at the time of deterioration.
- Written plans were seen to legitimise the decision not to transfer residents to hospital, protect staff from adverse consequences and reduce the likelihood of discordance with families.

#### Implications for practice, theory or policy

- The value of advance care planning lies both in the discussion (taking time for sensitive conversations with residents and families) and the written plan itself: there is a need for adequate time and resources to support these discussions, including regular updates.
- Care home staff are wary of interpreting broad statements: plans are more likely to be useful to staff at the time of deterioration if they are detailed, specific, unambiguous, technically 'correct' and reviewed regularly.

## Introduction

Care home residents have complex health and social care needs. They are amongst the 'oldest old' and often have a number of complex co-morbidities, including frailty and dementia, which can affect their quality of life and day-to-day function.<sup>1-4</sup> Illness trajectories in this population can be uncertain and unpredictable<sup>5</sup> and deteriorations may occur gradually or suddenly, as a result of a new condition or an exacerbation of an existing one. Residents' rates of secondary care use are variable and influenced by multiple factors:<sup>6</sup> the majority of hospital use is attributable to less than half of all residents<sup>7</sup> and marked variation in acute emergency care use has been observed between residents from different care homes, even when the demographic and health profiles of residents are similar.<sup>8-10</sup> For some care home residents, a hospital admission may offer limited benefit and pose substantial risk of physical and cognitive complications,<sup>11</sup> with residents experiencing higher in-patient mortality than community dwelling older people.<sup>12</sup>

Although often associated with deteriorating health, advance care planning (ACP) can be done at any stage to ensure that a person receives medical care that aligns with their wishes, goals and preferences.<sup>13</sup> It involves a process of discussion between the individual and their care provider, requiring full involvement of a person with mental capacity to make such decisions for themselves.<sup>13</sup> Advance care planning is considered good practice in end-of-life care.<sup>14-16</sup> It has also been identified as one of few modifiable factors that could reduce hospital transfers from care homes.<sup>12,17</sup> For people living with dementia, it is associated with increased concordance between the care an individual receives and their prior wishes as well as increased satisfaction with care for both the person living with dementia and their family carers.<sup>18</sup> Wishes may be recorded in an Advance Statement or more formal Advance Decision to Refuse Treatment, which is legally binding in the England.

Clinicians may also make recommendations for emergency treatment (sometimes as part of the ACP process)

which may be recorded in documents such as Emergency Healthcare Plans, Do Not Attempt Cardiopulmonary Resuscitation (DNA-CPR) orders (sometimes referred to as DNRs) or Recommended Summary Plans for Emergency Care and Treatment (ReSPECT). These are generally prepared by professionals to guide action in emergency situations and, whilst it is good practice to involve the person to whom recommendations relate, family carers and/or appointed proxy decision-makers may also be involved, especially when the person has reduced or fluctuating capacity.<sup>19</sup>

Although only a minority of frail older people get the opportunity to engage in advance care planning, the majority welcome the opportunity to do so, and many care home residents are willing to discuss end-of-life situations.<sup>20,21</sup> Existing research has suggested that care planning is only the 'first step' in a decision-making process: the mere presence of a written plan does not eliminate the need for decision-making at the time of deterioration.<sup>22-24</sup>

The majority of existing research explores experiences of creating advance care plans, with less known about how plans are perceived, used and interpreted during '*in-the-moment*' decision-making. Care home staff play a crucial role in the day-to-day management of residents' health and well-being and are responsible for responding to suspected deteriorations in residents' health.<sup>25</sup> Therefore it is important to understand how this group of professionals interpret plans during '*in-the-moment*' decision-making.

## Methods

### Research question/aims

'Planning for deterioration' emerged as an important overarching theme in a grounded exploration of staff perspectives on hospital transfers from care homes.<sup>26</sup> The aim of this paper is to explore care home staff experiences and perceptions of using written plans during in-the-moment decision-making about potential resident hospital transfers.

**Table 1.** Care home characteristics, *n* = 6.

Number	Type of service	Type	Provider size	Number of beds	CQC rating	Dementia specialist	Location
1	Nursing	Private for profit	Small chain (5)	35	Good	Yes	East Midlands
2	Residential	Charitable not for profit	Small chain (5)	45	Good	Yes	East Midlands
3	Residential	Private for profit	Independent (1)	15	Good	No	West Midlands
4	Dual registered	Private for profit	Large chain (120)	60	Good	Yes	West Midlands
5	Nursing	Private for profit	Independent (1)	40	Outstanding	No	West Midlands
6	Nursing	Private for profit	Large chain (300)	35	Requires improvement	Yes	West Midlands

### Design

The project was guided by the philosophical paradigm of critical realism<sup>27</sup> which ascribes to a realist ontological position and an interpretivist epistemological position. The interview schedule (Supplemental Box 1) included questions about personal experience of being involved in hospital transfers and a number of vignettes (Supplemental Box 2) which were designed to reflect situations that could occur in care homes. Interviews and vignettes were piloted prior to the commencement of data collection. Data collected during piloting were not included in the final analysis.

### Participants/setting

Staff from care homes with and without nursing in the East and West Midlands of England.

### Sampling and recruitment

Both care home sites and individual participants were purposively sampled. Once permission had been obtained from the care home manager, individual staff were invited to participate by a member of the research team.

### Data collection

Data were collected via face-to-face, semi-structured interviews between May 2018 and February 2019. Interviews took place in a private area of the participant's workplace during their working hours. On two occasions, participants requested that they completed the interview in pairs. In both cases participants were employed in the same role. Each interview was audio recorded and transcribed verbatim. All identifiable data was removed, and each transcript was allocated a transcript number.

### Data analysis

Data were analysed in three steps, using the constant comparative method,<sup>28</sup> in line with the Straussian approach to grounded theory.<sup>29</sup> Firstly, each section of each transcript was coded according to the phenomenon

or concept that was being discussed, thus identifying a number of 'open codes'. Secondly, an exploration of relationships between codes produced 'axial' codes, before 'selective codes' – core categories to which all data related – were identified. Coding was initially carried out by hand before using NVivo 12. Data collection and analysis occurred concurrently and analysis was an inductive process. The first author (FH) carried out all interviews and initially coded transcripts; the remaining authors (CW, NA) independently reviewed five transcripts. Themes were continually reviewed, validated and refined throughout data analysis until theoretical saturation was achieved.

### Ethical issues

Ethical approval was obtained from the University of Leicester's Research Ethics Committee for Medicine and Biological Sciences (reference: 15304). Participation was voluntary and written informed consent was obtained from all participants.

### Results

All members of staff who were approached agreed to participate. In total, 28 interviews were held with 30 members of care home staff across six care homes. Information about each of the care home sites is displayed in Table 1.

Participants included seven managers, three deputy managers, seven registered nurses, seven senior carers and six carers. Twenty-eight (93%) of the participants were female. All managers worked exclusively during the day-time. Of the remaining 23 participants, six exclusively worked night shifts and one worked a mixed pattern of days and nights. The average length of interview was 38 minutes, ranging from 18 to 75 minutes. Further demographic information about participants is presented in Table 2.

### 'What if it is not enough?': Exploring influences on staff decision-making

Staff consistently described a preference (in principle) for keeping deteriorating residents in the care home and acknowledged the burdens associated with hospital

**Table 2.** Distribution of participants and their job roles across care homes, n = 30.

Site	Total number of participants	Primary job role within the care home				
		Manager	Deputy manager	Registered nurse	Senior carer	Carer
1	5	1	1	1	1	1
2	7	1	1	*	3	2
3	4	2	*	*	*	2
4	7	1	1	3	2	0
5	3	1	0	1	1	0
6	4	1	0	2	*	1
Total (N):	30	7	3	7	7	6

\*indicates the job role did not exist in this home.

transfers, particularly for residents living with dementia or nearing the ‘end-of-life’. A frequent concern was that residents would not receive the support they needed in busy and unfamiliar hospital environments.

*‘People who live in a care home, especially with dementia, it’s not good for them to go to hospital. . . If they go to hospital it’s a completely different environment. . . So it’s better for them to stay here.’*

(Senior Carer, Care Home 4)

*‘If we have someone who is end-of-life and they are going to die. . . they get special attention. Well, in the hospital you won’t get special attention because they are so busy and they want to cure people.’*

(Manager, Care Home 5)

However, staff felt a sense of unease when applying this principle to individual residents. They worried that residents’ needs could not be met within the care home during a period of illness and that *not* transferring a resident to hospital might be perceived as failure to fulfil a ‘duty of care’. Besides an intrinsic desire to ‘do the right thing’, this was linked to the need to justify decisions to families, senior colleagues, managers, and potentially to external regulators in legal or disciplinary procedures. This led to a sense of personal and professional vulnerability in the face of a deteriorating resident.

*‘What happens if I keep them in place and keep them clean and comfortable, what if it is not enough?’*

(Nurse, Care Home 6)

*‘The decisions we make can have long term implications. . . Sometimes our colleagues will look at it from a broader perspective. It’s not nice to go through [disciplinary procedures], sometimes with suspensions. I have bills to pay and a family to feed.’*

(Deputy Manager, Care Home 4)

Staff described experiences of residents being transferred to hospital due to pressure from family carers, even when staff felt a transfer was not appropriate. Family carers had a powerful role in decision-making. Staff voiced concerns that acting in ways that did not align with family carers’ wishes might lead family carers to make complaints (either to the care home manager, or to professional and regulatory bodies) which could have potentially severe and long term implications for them as an individual.

*‘There are occasions at the very least where relatives are demanding for their loved ones to go in the hospital even when it is not needed. . . I need to be honest, we have had situations where we have had to send somebody into hospital just because the family asked for it.’*

(Manager, Care Home 1)

*‘We have got one daughter here who thinks she has a duty to her dad. . . she would rather see him in hospital, and he will die in hospital. . . There is nothing we can do, although we don’t think it is the right place to be.’*

(Manager, Care Home 6)

**‘Having the paperwork in place’:  
The importance of a written plan for deterioration**

Staff often referred to having ‘the paperwork’ or ‘a plan’ in place. Although they used varying names for this (including ‘advance care plan’ and ‘emergency care plan’) these terms were generally used to refer to documents prepared by healthcare professionals (rather than by patients).

*‘And obviously a lot of the paperwork comes into play – you’ve got Do Not Resuscitate forms to consider, our care plans to consider and the emergency care plans that the doctors give.’*

(Deputy Manager, Care Home 2)

*'The ReSPECT form is when we say "Do Not Resuscitate", you know? While the advance care plan is more to find out what they like, in the last days, do you want your family to sit with you all the time? Do you like music?'*

*(Carer, Care Home 5)*

Staff believed that completing 'the paperwork' was primarily the responsibility of the person's doctor but they felt comfortable to support these conversations. Care home managers saw this as a skilled task that not all staff could perform, and some described offering informal support to develop the skills and confidence of new colleagues.

*'It would be a doctor's decision to put the DNRs in, not ours. But we are having the first part of the discussion. We are explaining it - prioritising comfort, even at the expense of sustaining life. We talk that through before the doctor comes in.'*

*(Manager, Care Home 3)*

Once in place, staff perceived these documents to signify that a clinical decision had been made 'in advance' of a deterioration. The language used suggested that staff perceived them to be directive documents that provided a 'clear pathway' (Manager, Care Home 4) to be followed.

*'We have a lot of residents where the decision has been made prior to them being unwell, they have a care plan in place that states they need to be kept here and be kept comfortable.'*

*(Deputy Manager, Care Home 1)*

*'Each individual should have a care plan and that would tell you when they should be admitted and not to be admitted to hospital.'*

*(Senior Carer, Care Home 2)*

Whilst staff recognised that these documents should reflect the individual's own preferences, it was recognised that they would also reflect the views of professionals and family carers, particularly when a resident had reduced or fluctuating capacity.

*'We wouldn't want everyone to have a DNR. . . . Some of the residents say no and that's fine. . . . And somebody might have the first stages of dementia but they can understand, in that moment. . . . We've got four residents who wouldn't understand, so we have to get the relatives to talk to the doctor.'*

*(Manager, Care Home 3)*

### ***'I am covered': Legitimising the decision not to transfer***

Staff believed that both the process and output of planning for deterioration was valuable. The discussion

(process) allowed residents, family carers and staff to anticipate the resident's needs prior to a deterioration occurring and to prepare for the end-of-life. The documentation (output) was valued as an agreed upon plan to guide 'in-the-moment' decision-making. For staff, the value was linked to their experiences of decision-making at the time of deterioration (as described above). It was perceived to reduce the potential for distress and conflict amongst care staff, residents and family carers at the time of deterioration, and to reduce feelings of personal vulnerability, legitimising the decision *not* to transfer a resident to hospital and reassuring staff that they were both doing the 'right thing' and, importantly, 'covered'.

*'We have a care plan - wishes for end-of-life. . . . If I have the paperwork in place. . . then it's OK. Because for me, I am already covered.'*

*(Nurse, Care Home 6)*

*'We all do the advance care plans for everyone. . . we try to get the family on board as quickly as possible on board because they can make it very difficult for you'*

*(Manager, Care Home 5)*

### ***'Signed, sealed, dotted, delivered and reviewed': Creating a plan that avoids the 'default' option***

Staff described situations in which residents were transferred to hospital despite a plan recommending against admission. If there was any perceived inadequacy or ambiguity in 'the paperwork', for example if documents were general, vague or 'wishy washy', a transfer would tend to follow.

*'The [transfer] I can think of was where there was a little break in communication. The care plan didn't actually state "not for hospital admission". . . . It was a technicality where the doctor hadn't quite written it for the paramedics to be happy. Some will be a 1 to 20 guide of exactly what to do and others are a little bit wishy washy, which is what happened there.'*

*(Deputy Manager, Care Home 2)*

Staff felt that a 'good' plan (one that they would be confident to follow at the time of deterioration) should provide detailed, specific and unambiguous guidance, and must be reviewed regularly and understood by families. Staff were wary of interpreting plans that did not explicitly cover the specific clinical situation at hand. Staff also highlighted that, even when clear plans were in place, families sometimes changed their minds when faced with the reality of an acute deterioration. In these situations, the family's view would tend to hold sway, even in the presence of

a written plan. As such, planning did not remove all the challenges at the time of deterioration.

*'[Planning] is crucial. As long as it's been made and it's signed, sealed, dotted and delivered and reviewed – and that's the important thing because people's situations can change.'*

(Manager, Care Home 2)

*'The ReSPECT form. . . was written by the daughter "not for hospital admission". But the patient's condition was severe, so we called 999 and the paramedics said, "no it's not for hospital admission". We contacted the daughter. . . she said "if my mum is going to die due to this infection I am going to sue the home". It means she wanted active treatment to save her life.'*

(Nurse, Care Home 4)

## Discussion

Although staff consistently described a preference for caring for deteriorating residents in the care home, they felt a sense of unease and vulnerability when applying this to individual residents. Staff were concerned that the decision to *not* transfer a resident to hospital could result in a number of consequences for them as an individual, including personal consequences (feeling they had not done the 'right thing'), professional consequences (facing disciplinary actions), and social consequences (in the form of damaged relationships with residents and family carers).

The process of creating a plan enabled staff to understand residents and family wishes in advance, reducing the potential for conflict at the time of deterioration. The written document provided direction during in-the-moment decision-making, legitimising the decision *not* to transfer a resident to hospital and reducing the perceived risks to individual staff. However, when a written plan was perceived to be inadequate, or did not exist, transferring a resident to hospital could become the default response.

### Strengths and limitations

The strengths of this study include our use of a purposive sample of care homes and participants, semi-structured interviews to allow new findings and topics of conversation to emerge, and vignettes so that participants could discuss the subject in a less personalised way. Data were collected as part of a wider project that sought to understand care home staff decision-making regarding hospital transfers and may have been richer if questions had focussed solely on the use of written plans at the time of deterioration. This study only explored the views of care home staff and not the range of other participants in the

decision-making process, who may have different perspectives. There is also scope for desirability bias in these results (with staff reporting the more positive aspects of their own professional behaviour).

### What this study adds

This study provides new insights into the ways care home staff perceive, use and interpret written plans during acute deteriorations in residents' health. Staff valued these written plans but acknowledged the powerful role of family carers, both in the creation of plans and during in-the-moment decision-making. This power appeared to be rooted in a belief that family carers might make complaints if staff decisions did not align with their wishes, with the perceived prospect of potentially severe and long-term implications for staff. Therefore, although advance care planning is intended to support person-centred care and decision-making for residents, written plans also provide protection for care home staff by legitimising the decision *not* to transfer a resident to hospital. In doing so, written plans can reduce hospital transfers that may be initiated due to concerns about consequences to individual members of staff, rather than being driven by the expectation of improved health or well-being for residents.

This study highlights the tensions, conflicts and vulnerability felt by care staff when faced with a deteriorating resident. Whilst previous studies have highlighted medico-legal issues as a concern for professionals within transfer decisions,<sup>25</sup> this study extends this observation to issues of wider professional liability and a sense of a personal, moral duty of care, in which staff express concern about having 'done enough' for the resident. Findings reflect studies that have suggested that the creation of a written plan is only one step in a broader process of decision-making.<sup>22–24</sup>

From the perspective of care staff, plans should be clearly worded, specific, unambiguous, reviewed regularly and understood by families in order for them to be effective. The difficulties of making specific plans for care home residents, due to their less predictable illness trajectories, has been highlighted,<sup>5</sup> yet care home staff feel that they need this specificity and have limited discretion to interpret plans that are written in more general terms. The challenge, then, lies in preparing plans that are both '*specific enough*' to be used by staff with limited discretion to interpret broad statements, but '*general enough*' to reflect the often less predictable illness trajectories of care home residents. Further research is needed to understand how to achieve this balance.

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### Supplemental material

Supplemental material for this article is available online.

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