Residents in care homes providing nursing care are becoming increasingly frail and dependent, with 80% having dementia or severe memory problems. Currently, 19% of the UK population die in care homes each year. Care homes (especially care homes providing nursing care) have an important role in the care of dying residents and are now expected to provide good end-of-life care (EoLC). Implementing EoLC tools, such as the Gold Standards Framework (GSF) and the Liverpool Care Pathway for the Dying Patient, can provide a structure upon which to improve the quality of EoLC. However, some care homes, despite completing the GSF programme, find it difficult to implement the measures required to provide optimal EoLC. This article reflects on the author’s experiences over a 2-year period of working alongside such care homes. It describes how she focused on four aspects of EoLC to help support the staff: dignity in care; advance care planning; care of the dying resident using an integrated care plan for the last days of life; and assessment and management of pain and depression using specified tools. Conflicts of interest: none

Key words
Advance care planning
Care homes
Care pathways
Dignity
Gold Standards Framework in Care Homes
Palliative and end-of-life care

Role modelling GSF principles of end-of-life care to care homes

Barbara Kenyon

In 2008, St Christopher’s Hospice, London, became the first regional training centre for the Gold Standards Framework for Care Homes (GSFCH). It has developed a systematic approach to delivering the GSFCH programme and to date has delivered the programme to 165 care homes. Seventy-one of these care homes provide nursing care and are in St Christopher’s Hospice’s immediate locality and under the hospice’s responsibility. 61% of these homes have now achieved GSFCH accreditation. However, there remained the problem of how to help the homes struggling to embed the programme’s recommendations into their practice. This article will reflect on my experiences of supporting five nursing care homes to change their culture and staff practices in order to improve the quality of end-of-life care.

The care of frail older people living and dying in care homes has changed considerably since the introduction of the Community Care Act 1990. This Act encouraged the closure of long-term ‘geriatric’ wards in favour of older people being cared for in the community. Monies from the health budget were given to social services in order to pay for care to be provided either in people’s own homes or, as necessary, in care homes. Before this time, many older people had admitted themselves to a care home, often for companionship. When they became ‘ill’, the majority of residents were transferred to hospital to die (Hockley, 2006). As a result of the Community Care Act 1990, frail older people are staying longer in their own homes. Consequently, by the time they are admitted to care homes, people have become increasingly frail and dependent, with 80% of residents in care homes having dementia or severe memory problems (Alzheimer’s Society, 2013). Currently, 19% of the UK population who die each year do so in care homes (Department of Health (DH), 2012). The End of Life Care Strategy (DH, 2008) recognises the important place that care homes (especially care homes providing nursing care) now have in the care of dying residents. Care homes are expected to provide good end-of-life care (Finucane et al, 2013). End-of-life care tools, such as the Gold Standards Framework (Thomas, 2003; Gold Standards Framework, 2012) and the Liverpool Care Pathway for the Dying Patient (LCP) (Ellershaw and Wilkinson, 2003), have become key structures to help care homes improve the quality of end-of-life care.

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The care home project

In January 2010, I was asked by the Care Home Project Team, St Christopher’s Hospice, to visit specified nursing care homes that had failed to implement fully the GSFCH programme. I was already working at the hospice as a ‘hospice-at-home nurse’ where I supported patients to stay in their own home by delivering palliative care for a number of hours at any one time. I visited each nursing care home for between 4 and 6 hours/week to role model palliative and end-of-life care to nurses and carers. My role was to work alongside staff when caring for the most poorly resident on the day I attended. This way of working provided a practical model that reflected the principles and practices of palliative care for residents and their families.

Over a 2-year period, I visited five nursing care homes. The nursing care home setting was not familiar to me. Consequently, I had no pre-conceived ideas about what my role would entail or how it would evolve. Dewing (2009) suggested that when undertaking practice placements in a nursing home it is important to have an awareness of the existing workplace culture, e.g., how the team functions and the degree of person-centred care practised. For the typical nursing care home of between 50 and 60 residents, there was a staff/resident ratio of one member of staff to five residents. The skill mix was weighted towards carers as opposed to registered nurses, i.e., the average weighting per shift was three trained nurses for 50–60 residents. A number of carers had national vocational qualifications but a proportion was untrained. All the residents were frail and lived with ongoing chronic conditions. The majority were in different stages of dementia and in one home all the residents had dementia.

There appeared to be a number of reasons why the nursing care homes were finding it difficult to embed principles of palliative care into their practice. These included limited medical input, ineffective leadership, closed discussion about death and dying, entrenched attitudes and limited communication skills. Also, some of the nursing care homes did not have a culture that supported the development of clinical practice through training. I therefore recognised that it would take time to gain the trust and respect of the staff, and for them to have the confidence, albeit working alongside me, to be able to identify the palliative care needs of their residents.

Dementia is a life-limiting, terminal disease (Coleman, 2012). Albers et al. (2012) suggested that all care for people in long-term facilities should be considered palliative in nature. A palliative care approach that focuses on spiritual, psychological and social care, alongside expert physical care, has the potential to improve residents’ quality of care (Thomas, 2003; Hockley, 2006; DH, 2008). However, I found that the majority of staff, particularly the carers, had little understanding of palliative care, assuming it to be solely concerned with cancer. In all the five nursing care homes, I was initially asked by carers why I was there as they did not consider their residents as having palliative care needs, despite a number of residents being bed bound with end-stage dementia.

It became apparent that although some staff had been sent knowledge into their clinical practice. Nurses, as well as carers, did not appear to be sensitive to changes in a resident’s physical or mental condition. To help address these issues and to provide my role with structure, I focused on four key elements of end-of-life care to help support the staff:

- Dignity in care
- Advance care planning
- Care of the dying resident using an integrated care plan for the last days of life (an adapted version of the LCP specifically designed for nursing care homes)
- Assessment and management of pain and depression using specified tools.

Dignity

Improving the quality of life of frail older people involves focusing on the worth, dignity and individuality of each person (Kitwood, 1997). Maintaining people’s dignity is considered an important aspect of the nursing role in all settings (Royal College of Nursing, 2008; International Council of Nurses, 2012). Dignity is a subjective concept that means different things to different people (Jacelon et al., 2004; Anderberg et al., 2007; Henderson et al., 2009). It is considered an intrinsic characteristic of being human (Chochinov et al., 2002; Jacelon et al., 2004; Anderberg et al., 2007). It has been suggested that dignity for frail older people at the end of life is broadly about: maintaining relationships and a sense of belonging; having control over care; being acknowledged as a human being and having self-respect and feelings of self-worth (Eres, 2003). Frail older people and those with dementia want to be treated as individuals (HolmeroÁ et al. 2007; Volicier, 2007; Moyle and Bowers, 2010) and supported to maintain functional independence and participate in social groups and meaningful activities for as long as possible (Sabat, 2001; HolmeroÁ et al., 2007; Volicier; 2007; Vost-Steller et al., 2013). That helps them retain a sense of purpose and significance and to feel that they belong within a social group (Bridges and Wilkinson, 2011; Vost-Steller et al., 2013). Maintaining frail older people’s sense of dignity also involves listening to what they have to say, respecting their world-views and acknowledging and valuing their memories (Jacelon, 2004; Anderberg et al., 2007; Gallagher et al., 2008; Bridges and Wilkinson, 2011; Vost-Steller et al., 2013).

I found that in all the five nursing care homes, it was the carers who provided the personal care. The carers, therefore, were in the unique position of being able to develop relationships with residents and give them a sense of belonging. However, in three of the five homes, care was very task-orientated as opposed to person-centred (Kitwood, 1997). For example, the impetus to complete the work over-rode the comfort and dignity of residents. Not all residents were given the opportunity to be heard and understood. Some residents made comments such as, ‘The staff are lovely, but with some you have to be careful’. One resident with facial hair was tearful because a carer had asked her if she was growing a beard. Sadly, residents often accepted their existing care because there was no alternative, with one resident saying, ‘It’s okay here, but what choice do I have?’ Barriers to preserving older people’s sense of dignity has been found to include being treated in a child-like and patronising manner; being humiliated and insulted, insensitive communication, lack of holistic
and person-centred care, a culture of task-orientation and rushing and prioritisation of physical care (Jacelon et al, 2004; Anderberg et al, 2007; Gallagher et al, 2008; Royal College of Nursing, 2008; Henderson et al, 2009; Watson, 2013).

Although the majority of carers took pride in providing a better quality of care, reporting their concerns and becoming more open to change as a result of working alongside me, others were more reluctant. For those who were more reluctant, there appeared to be a lack of motivation and commitment. For example, I heard comments from carers that I was holding them up when I was working with them. Lack of stimulating, transformational leadership can result in poor care and unmotivated staff who lack self-esteem about the work they do (Scott-Cawiezell et al, 2004). In order to give person-centred care, nurses and carers require support and education and to feel valued as individuals (Gallagher et al, 2008; Hodgson and Lehning, 2008). It appeared that carers were often unsupported and therefore did not feel valued for the work that they undertook.

In one nursing care home, the benefits of valuing staff were apparent. Here, the manager, nurses and carers worked as a team. Staff had designated roles such as ‘dignity champion’ and ‘palliative care lead’. Carers went beyond their role in their care of residents who were dying and were responsible for a large portion of the implementation of the GSFCH programme. In this nursing care home, even staff without palliative care training displayed a natural empathy when caring for very frail older people. This home had lacked initial confidence in implementing end-of-life care and responded well to my support and encouragement. It now has GSF accreditation because the workforce was motivated and there was good attendance at the training sessions I ran.

To improve dignity for residents I encouraged carers to view residents as whole human beings with physical, psychological, social and spiritual needs. Most of the staff I worked alongside associated spirituality with religion and feared not knowing what to say to residents about spiritual/religious matters. However, spirituality is about an individual’s unique thoughts and beliefs and spiritual care involves taking time to talk to residents, thus getting to know them (Nyatanga, 2005). Staff are often not aware that, in dementia, even though a person cannot remember things from the past, emotional receptivity does not disappear (Hughes et al, 2006). Therefore, sensitive and respectful communication should always persist. I wanted staff to assess how life had given meaning to each of the residents. One of the ways I achieved this was to stress the importance of special keepsakes, such as photographs. We used such keepsakes to engage in conversations with residents about their past and present lives.

I also worked alongside carers, showing them that giving personal care was an important event in the resident’s day and that there were various ways to demonstrate care to residents. For example, offering to massage a resident’s hands and feet with an emollient or styling hair gave residents’ personal attention and improved feelings of self-worth. I noticed that staff began to take time to mobilise some residents and take them to the lounge, which offered stimulation and companionship. Care slowly became less clinical as staff acknowledged that their residents had feelings and that quality, one-to-one interaction could have a calming effect on them.

### Table 1

<table>
<thead>
<tr>
<th>Types of questions that should form the basis of advance care planning discussions with residents in nursing care homes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does anyone have Lasting Power of Attorney for your property and affairs and personal welfare?</td>
</tr>
<tr>
<td>In the event of a gradual decline in your health, is there anything that you are worried about or you dread happening?</td>
</tr>
<tr>
<td>Do you have any particular wishes that you want to achieve before coming to the end of your life? If so, is there anything we can do to help with this?</td>
</tr>
<tr>
<td>Are there any special wishes that you would like us to know about when you are approaching the very end of your life?</td>
</tr>
<tr>
<td>At the very end of your life, where would you like to be cared for?</td>
</tr>
<tr>
<td>Do you have a particular faith or belief system that is important to you? Would you like a minister/other to come and visit?</td>
</tr>
<tr>
<td>Is there anything else, not previously mentioned, that you would like to make known and be written here? For example: more personal touches that would mean a lot to you at the very end of your life; funeral details, e.g. burial/cremation</td>
</tr>
</tbody>
</table>

*Taken from: St Christopher’s Hospice (2012a)*

**Advance care planning**

Advance care planning is the process of commencing discussions about people's possible future health and social care needs and planning ahead in anticipation of deterioration towards the end of life (Henry and Seymour, 2008; Regnard, 2012). It enables the resident to discuss and make known their preferences and priorities for future care, e.g. place of care and death, in the event that they are unable to voice them in the future. It can be difficult for people to look ahead to the time when they become less well. However, making their wishes known affords people more control over decisions relating to their future care needs, especially at the end of life (Chapman, 2008). Residents’ wishes should be documented in advance care plans. These are not legal documents but statements of said wishes and preferences (Chapman, 2008). It is best practice for families to be involved in this process. When undertaking advance care planning discussions, it is important to point out that there may be circumstances, such as if the resident falls and, for example, breaks a limb, where a decision may need to be made to transfer the resident to hospital. However, in such cases, depending on the situation, it may still be possible for care home staff, in conjunction with the GP and district nurses, to manage the situation in the home (St Christopher’s Hospice, 2012a).
Residents’ wishes must be reviewed regularly as wishes may change (Reddall, 2009). Therefore, a resident’s capacity to contribute to best-interest discussions should commence once the resident has settled into the nursing care home, or as appropriate if a resident’s condition warrants it. Table 1 provides examples of questions that should form the basis of advance care planning discussions.

Advance care planning discussions require the person involved to have the requisite capacity to make their wishes and preferences for future care known (Mental Capacity Act 2005). If the resident lacks mental capacity, such as in cases of dementia, care home staff can discuss preferences and wishes with the family/loved ones and the GP/district nurses in a ‘best-interest’ meeting (Davies and George, 2013). Best-interest discussions relate to the care that it is thought the resident might want at the end of life. St Christopher’s Hospice has produced a document to help care home staff, GPs and district nurses commence discussions with families/loved ones about the care needs towards the end of life of people with dementia (St Christopher’s Hospice, 2012b). The document can help inform best-interest meetings. Best-interest documentation is not legally binding but rather contains information that needs to be made available to future decision-makers about care needs. If at all possible the resident should be involved in such discussions. The ability of people with dementia to communicate and make their wishes known can vary from day to day and throughout the day (Alzheimer’s Society, 2013a,b). Therefore, a resident’s capacity to contribute to best-interest discussions should be assessed at the time of the discussion. Table 2 provides examples of questions that could form the basis of best-interest discussions. It is hard to know whether the way in which families/loved ones respond to advance care planning discussions is influenced by the fact that staff are uncomfortable talking about end-of-life care or because families are already anxious about the future.

In three of the nursing care homes in which I worked, there was no advance care planning documentation in place, despite the homes having undertaken the GSFCH programme which promotes the benefits of planning ahead for care at the end of life. The two other homes did have documentation, but the information gathered was very limited. For example, it only stated where the resident wanted to be cared for at the end of life. No other personal wishes were obtained to make the advance care plan individualised to that resident. I, therefore, held further training sessions but it became very clear that the nurses found broaching end-of-life discussions difficult.

In order to help staff gain confidence in advance care planning discussions, I prepared a completed advance care plan for staff to use as a guide, that was based on the St Christopher’s Hospice advance care planning documentation (St Christopher’s Hospice, 2012a). This helped staff understand the detail that needed to be included. Gradually, staff became more confident about advance care planning and began to look at aspects that needed more in-depth consideration. In one home the process was very successful. The staff were proud when a resident’s wish to die in the home was fulfilled and she died with the light on, listening to an audio recording of ‘Pride and Prejudice’, which the family had brought into the home.

The integrated care pathway for the last days of life for residents in residential care homes

There is a historical culture in nursing care homes of striving to keep people alive (Hockley et al, 2004). In all the five nursing care homes, I noticed a lack of ability among staff to recognise and talk openly about dying. The majority of staff found it very difficult to accept that a resident was dying, as they perceived residents as ‘family’. For example, one carer who appeared upset about a dying resident said to me, ‘I just can’t let her go’. Carers needed to be reassured that it is natural for them to feel upset when a resident to whom they are close is dying. I also found that even when staff felt that a resident was dying, they rarely discussed their perceptions with their colleagues. As a consequence, dying remained clouded in secrecy and was often unanticipated.

I would observe residents at the end of their lives being transferred inappropriately to hospital. This was often because there was no forward planning by staff and GPs. There were incidences when GPs would refuse to prescribe anticipatory end-of-life medication until residents were symptomatic. This highlighted a lack of trust between GPs and the care home nurses. GPs tend to care for only a handful of dying patients each year and consequently lack skill and confidence in recognising the dying process (Hockley et al, 2010). The nurses had got used to GPs making all the decisions, even though the GPs were less familiar.

Table 2: Examples of questions that could form the basis of a best-interest discussion relating to the end of life

- Does anyone have Lasting Power of Attorney for the resident’s property and affairs and personal welfare?
- Were there any particular wishes that your relative/friend/resident wanted to try to achieve before coming to the end of their life? If so, is there anything we can do to help with this?
- Do you know of any specific worries that your relative/friend/resident talked about if their health started to decline towards the end of life?
- Do you have any specific thoughts about where your relative/friend might want to be cared for at the very end of life?
- Do they have a particular faith or belief system that has been important to them? Would they like a minister/other to visit towards the very end of life?
- Is there anything else not yet mentioned that is important for us to know? For example: more personal touches that would mean a lot to you/your relative at the very end of their life; funeral details; e.g. burial/cremation

Taken from: St Christopher’s Hospice (2012b)
with the residents than the care home staff. Therefore, I supported
the nurses to discuss their thoughts about residents and to engage
in end-of-life care discussions with both the GPs and residents and
their families/loved ones.

It has been found that nursing care homes that implement
an end-of-life tool such as the LCP are more likely to achieve
a positive death experience for their residents (Seymour et al, 2011). I therefore helped introduce a version of the LCP that has
been adapted specifically for care homes, in order to enhance the
planning, delivery and recording of care in the last days of life. This
adapted LCP is available to download (http://www.stchristophers.
org.uk/sites/default/files/education/education/steps_stepthree_ICP_july2012.
pdf). The criteria for commencing a resident on the pathway are
listed in Table 3. It must always be remembered that despite
being commenced on the pathway, some residents improve
unexpectedly, in which case it may then be appropriate to
discontinue the pathway and provide care as usual. Like the LCP,
the integrated care pathway promotes the importance of comfort
measures, anticipatory prescribing, discontinuation of inappropriate
interventions, psychological, social and spiritual care, support for
both resident and family, as well as care after death. Examples of its
goals of care are listed in Table 4.

There was apprehension among staff about the pathway, especially in light of recent media reports that patients are
being commenced on the LCP inappropriately, leading to
discontinuation of hydration/nutrition and premature death (Davis
and Guyer, 2013; Riley, 2013). There was also concern about when
to commence the integrated care pathway, despite clear guidelines
in the documentation (see Table 3). I found that it was difficult to
get protected time to teach staff regarding the proper use of the
integrated care pathway. Therefore, I decided to discuss it with staff

### Table 3

**Criteria for commencing a resident on the pathway**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing rapid day-to-day deterioration</td>
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<tr>
<td>Becoming semi-conscious, with lapses into unconsciousness</td>
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<tr>
<td>Refusing or unable to take food, fluids or oral medication</td>
<td></td>
</tr>
<tr>
<td>Irreversible weight loss</td>
<td></td>
</tr>
<tr>
<td>Profound weakness</td>
<td></td>
</tr>
<tr>
<td>Changes in breathing pattern</td>
<td></td>
</tr>
</tbody>
</table>

*Taken from: http://www.stchristophers.org.uk/sites/default/files/education/education/steps_stepthree_ICP_july2012.pdf*

### Table 4

**Goals of care for residents who are dying**

- The resident is pain and symptom free, e.g. he/she verbalises comfort when conscious or shows no signs of being in pain on movement when unconscious
- The resident is not agitated or distressed, e.g. he/she does not display signs of delirium, terminal anguish, restlessness (e.g. thrashing, plucking, twitching). N.B. All potential causes of agitation have been ruled out such as retention of urine or constipation
- Breathing is calm and does not sound wet/rattly
- Mouth is clean (e.g. mouth is not dirty, no presence of thrush). Mouth care using pink sponges/gauze soaked in cold water should be performed at least 2 hourly or the resident helped to take sips of water if still able to swallow
- Resident has passed urine and/or is comfortable (if resident is restless due to full bladder; the district nurse should be called to assess for a catheter)
- The resident is comfortable and in a safe environment (e.g. resident’s position has been changed regularly when too weak to turn independently; pressure-relieving aids are in situ such as a special mattress)
- The resident is observed for signs of approaching death, e.g. mottling/purple skin indicating peripheral shutdown and a thin and thready pulse. Such signs can help care home staff prepare family/loved ones that death is approaching
- All medication is given safely and accurately (e.g. if syringe driver is in progress, it is checked regularly)
- Appropriate religious/spiritual support has been given (e.g. visit by priest, music playing, religious texts read, poetry, sitting with resident, especially if family not present)
- Family/loved ones have been prepared for the resident’s imminent death and the signs and symptoms that may be present, such as a ratty chest. It has been explained to them that food and drink are no longer vital. Their needs are accommodated, e.g. being given regular refreshments
- Family/loved ones are given appropriate support and advice after the resident’s death

*Taken from: http://www.stchristophers.org.uk/sites/default/files/education/education/steps_stepthree_ICP_july2012.pdf*

When the opportunity arose, I would just sit with a dying resident and encourage a carer to sit with me. Many carers became more confident in end-of-life care as a result of their increased knowledge. I observed them showing families how to give mouth care to their loved one. Others began to realise that...
just being with the resident and offering warmth and friendship were of enormous value to dying residents and their families/loved ones.

Assessment and management of pain and depression

Pain and depression are common symptoms in frail older people, both of which are under-recognised and mismanaged (Mellor et al, 2008; Ballard et al, 2011). Both pain and depression are difficult to assess, especially if residents have moderate to advanced dementia. Within the nursing care homes pain did not appear to be taken seriously. Consequently, pain was often not being treated adequately in residents with, for example, arthritis, neuropathies and/or pressure ulcers. Some homes were not assessing residents. Despite pain-assessment forms being suggested by the GSFCH programme (for people who are able to report their pain as well as those who are not, e.g. as a result of dementia), they were not being used. A typical comment from carers was, ‘Well, she always has pain, she moans everyday’. There was little insight regarding the nursing role of taking responsibility and being in a position to help resolve problems.

People with dementia are often unable to report their pain, which makes a self-report pain-assessment tool redundant. I therefore helped to introduce the DOLOPLUS-2 assessment scale (Lefebvre-Chapiro, 2001). The DOLOPLUS-2 scale requires two or three members of staff to observe the resident for signs of pain. Pain is assessed in relation to somatic, psychomotor and psychosocial reactions, and scored over 10 domains (Table 5). The tool focuses on changes in behaviour and functioning involving sleep, appetite, activity, mobility, facial and body language, alongside changes in communication and social life. Commencing a pain chart on admission to the care home will provide a baseline for each resident. Effective management of pain can lead to significant improvement in symptoms of agitation and/or aggression in residents with dementia (Corbett et al, 2012). It must not be assumed that agitated residents just require a review of their antipsychotic medication. It is first important to consider that agitation may be a distressed reaction to a stimulus such as pain. I found that carers were able to use the DOLOPLUS-2 pain assessment very effectively during the provision of personal care, as this tends to be the time when residents manifest more pain. Staff were pleased when they saw that providing pain relief half an hour before dressing changes or giving personal care helped the resident’s pain levels.

Depression in frail older people can present as difficulty concentrating, irritability and deterioration in function and understanding. Its cause is usually multifactorial (Mellor et al, 2008). However, I found that it was a common misconception among carers to think that depression was the result of the person being moved into a care home rather than physiological reasons. I wanted to raise awareness among carers about the causes and symptoms of depression. As with the assessment of pain, assessing for depression in people with advanced dementia can be aided by using an assessment tool. Consequently, I introduced into the homes the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al, 1988).

The CSDD assesses signs and symptoms of depression specifically in people with dementia (Table 6). The assessment relates to possible symptoms of depression over the previous week. As patients with dementia may find it difficult to report symptoms, information is obtained from both the person with dementia as well as the carers/nurses who know the resident well. Many of the items on the CSDD can be assessed and scored after direct observation of the patient. The scale takes approximately 20 minutes to administer. As with the pain scale, by completing the CSDD, the staff have more tangible evidence on which to base discussion about their concerns with GPs.

Both the tools were a new initiative. Therefore, nurses needed support to complete the assessments and keep them under review. Two out of five of the homes have reported using the tools with success.

Table 5

The 10 domains of pain assessment of the DOLOPLUS-2 scale, with examples of scored measures

1. Somatic complaints: the resident expresses pain by word, gesture, crying or moaning
2. Protective body postures adopted at rest: unusual body positions intended to avoid or relieve pain
3. Protection of sore areas: the resident protects one or several areas of his/her body by a defensive attitude or gesture
4. Expression: whether the facial expression appears to express pain (e.g. grimaces, drawn, atonic) and the gaze is fixed, empty, absent, or the presence of tears
5. Sleep pattern: whether the sleep pattern is normal or the resident has difficulty going to sleep, wakes frequently (restlessness), is suffering from insomnia which affects waking times
6. Washing/dressing: pain during washing and/or dressing, alone or with assistance
7. Mobility: evaluation of pain on movement, change of position, transfer, walking alone or with assistance
8. Communication (verbal or non-verbal): whether communication is unchanged, the resident has become withdrawn, is more demanding of attention or refuses to communicate
9. Social life: whether the resident participates as normal in daily activities such as during meal times and entertainment or only participates in activities when asked to do so, sometimes refuses to participate or refuses to participate in activities
10. Problems of behaviour: whether the resident displays normal behaviour or is becoming more aggressive, agitated, confused, indifferent or is showing signs of regression or asking for euthanasia

Source: Lefebvre-Chapiro (2001)
### Table 6

Possible indicators of depression in people with dementia as assessed by the Cornwell Scale for Depression in Dementia

<table>
<thead>
<tr>
<th>Mood-related signs</th>
<th>Behavioural disturbance</th>
<th>Cyclic functions</th>
<th>Ideational disturbance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety (e.g. anxious expression, ruminations, worrying)</td>
<td>Agitation (e.g. restlessness, handwringing, hairpulling, lip biting)</td>
<td>Diurnal variation of mood (e.g. symptoms worse in the morning, variation of mood in the evening)</td>
<td>Suicide (e.g. feels life is not worth living, has suicidal wishes or makes suicide attempt)</td>
</tr>
<tr>
<td>Sadness (e.g. sad expression, sad voice, tearfulness)</td>
<td>Retardation (e.g. slow movements, slow speech, slow reactions)</td>
<td>Difficulty falling asleep (e.g. problems falling asleep at night)</td>
<td>Self-depreciation (e.g. self-blame, poor self-esteem, feelings of failure)</td>
</tr>
<tr>
<td>Lack of reactivity to pleasant events (e.g. inability to enjoy, lack of interest in, pleasant events or interactions with family/friends)</td>
<td>Multiple physical complaints (e.g. indigestion, constipation, diarrhoea, stomach cramps, belching, joint pain, backaches, muscle aches, frequent urination, sweating, headaches, heart palpitations, hyperventilation, N.B. These signs and symptoms should be in excess of what is normal for the person and not be side-effects of medications or related to a gastrointestinal condition)</td>
<td>Multiple awakenings during sleep (e.g. waking up in the middle of the night not related to going to the bathroom and then going back to sleep)</td>
<td>Pessimism (e.g. anticipates the worst)</td>
</tr>
<tr>
<td>Irritability (e.g. easily annoyed, short tempered)</td>
<td>Anxiety (e.g. anxious expression, ruminations, worrying)</td>
<td>Early morning awakenings (e.g. earlier than usual pattern)</td>
<td>Mood congruent delusions (e.g. delusions of poverty, illness, or loss, perceives illness as punishment)</td>
</tr>
</tbody>
</table>

*Source: Alexopoulos et al (1988)*

### Discussion

Bringing about change in terms of palliative and end-of-life care in nursing care homes is difficult as care home staff traditionally focus on rehabilitation and receive minimal or no training in the care of people at the end of life (Watson et al, 2006; Hockley et al, 2010). End-of-life care tools, such as the GSFCH programme and an end-of-life care pathway, provide an important structure to care home organisations (Hockley et al, 2010). There is evidence that nurses and carers working in nursing care homes want to give good end-of-life care. Since the initiation of the GSFCH in 2004, over 2000 care homes in the UK have undertaken the GSFCH programme (Gold Standards Framework, 2012). However, not all care homes implementing the GSFCH programme have an external facilitator to help them through the process and even those that do fail to implement the programme. Research currently being carried out at St Christopher’s Hospice has found that organised, facilitated support from a dedicated care home project team, has a significant effect on nursing care homes gaining GSFCH accreditation.

Over a 2-year period, I worked with five nursing care homes that were struggling to implement the GSFCH programme, role modelling palliative care skills. I feel that in many aspects the project was successful. For example, by role modelling the integrated care pathway, staff were motivated and empowered to recognise the signs and symptoms of dying. They were also able to acknowledge the importance of assessing and managing residents’ symptoms regularly. Discussing future care needs, using the advance care plan document as a guide, helped staff understand the required depth of discussions to ascertain residents’ wishes and preferences at the end of life. The healthcare needs concerning assessment and control of symptoms in care homes, and where frail older people die, has traditionally been the domain of doctors. However, with support and use of different tools, increasingly nursing care home staff are able to take more responsibility (Hockley et al, 2004; Hockley, 2006). In this project, by implementing the DOLOPLUS-2 and CSDD assessment tools, many carers felt more empowered to report symptoms of pain and depression. The nurses also came to recognise the value of their contributions to end-of-life care discussions.

I was less successful in bringing about change for those residents who were not imminently dying but who still had palliative care needs. The residents in the nursing care homes were highly dependent with chronic conditions and various co-morbidities. In my opinion, the current staffing levels of one carer to five residents (unchanged since those set down by the Community Care Act 1990) are not enough to cope with the increased dependency of residents (Bowman et al, 2004). It was sometimes difficult for nurses and carers to look after residents with so many co-morbidities. The care home staff welcomed my role modelling but my time in each nursing care home was limited, i.e. only 4–6 hours per week. The staff felt it was a significant loss when my placement ended as they had benefited from my support and advice.

When role modelling best practice it is important not to denigrate staff for their current suboptimal practices, while...
at the same time highlighting aspects of care that require changing. During this project I found that the majority of staff were keen to learn and welcomed the role modelling method, as it made them feel valued and supported. Providing support to care homes by role modelling best practice has been shown to increase the number of advance care planning conversations, the implementation of end-of-life care pathways, and reduce the number of inappropriate hospital deaths of frail older residents with dementia (Finucane et al, 2013). However, good end-of-life care and reduction in hospital deaths is also dependent on stable management within care homes and the culture of care homes being orientated to end-of-life care (Finucane et al, 2013).

**Recommendations**

- Palliative care principles need to be acknowledged by nursing care homes staff as the foundation of their work.
- There needs to be an increased number of nurses in nursing care homes to care competently for the increasingly dependent residents being admitted.
- There needs to be more access to healthcare education to improve nurses’ knowledge in meeting residents’ complex care needs.
- There needs to be more external support from GPs and other community specialists, i.e. mental health professionals.
- All new staff to a nursing care home should attend a palliative care induction day.
- Palliative care specialists need to role model skills in nursing care homes in order to help staff undertake advance care planning discussions, complete assessment tools correctly and manage symptoms.

**Conclusion**

This article has highlighted my experiences of being involved in a 2-year project role modelling palliative care skills to staff in five nursing care homes following a failure of the homes to embed the GSFCH programme. The four main areas that I concentrated on were: dignified care, advance care planning, care of dying people using an integrated care pathway and the assessment of pain and depression. In most cases the attitude and practices of staff did change but, where there was a lack of motivational leadership specific to end-of-life care, it was difficult to bring about change. More GP support and improved transformational leadership is recommended, alongside more appropriate staffing levels to care for the increased number of residents suffering chronic conditions alongside multiple co-morbidities.

I would like to acknowledge Jo Hockley in the writing of this paper and both Jo Hockley and Kathy Morris for their mentorship during the project.

**References**


The use of assessment tools specifically designed for frail older people and those with dementia can increase the recognition of common end-of-life symptoms. The use of assessment tools specifically designed for frail older people and those with dementia can help implement an end-of-life tool such as an end-of-life care pathway or the Gold Standards Framework, can help achieve a positive death experience for residents. The use of assessment tools specifically designed for frail older people and those with dementia can increase the recognition of common end-of-life symptoms.

**Key Points**

- Nursing care home residents are becoming increasingly frail and dependent, with many also having dementia. Currently, 15% of the UK population die in care homes each year.
- Nursing care homes can find it difficult to practice the principles of palliative and end-of-life care because of limited medical input, ineffective leadership, closed discussion about death and dying, entrenched attitudes, lack of education and training and limited communication skills.
- A palliative care approach focusing on physical, spiritual, psychological and social care can improve the quality of life of care home residents at the end of life.
- Preserving the dignity of frail older people at the end of life is broadly about relationships and a sense of belonging; control over care; being acknowledged as a human being; and self-respect and feelings of self-worth.
- Advance care planning is the process of commencing discussions about people's possible future health and social care needs and planning ahead in anticipation of a resident's deteriorating condition towards the end of life.
- It has been found that nursing care homes that implement an end-of-life tool such as an end-of-life care pathway or the Gold Standards Framework, can help achieve a positive death experience for residents.

**References**


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