Care Home at Night, Evening and Weekend - Making Residents’ Choices Happen

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**Summary**  
This project took place in a care home located in a large West Yorkshire city which provides social and nursing care for 40 residents. The project was triggered by a distressing incident when staff felt “powerless” to stop a resident being unnecessarily transferred to hospital, and who subsequently died shortly after admission to the Accident and Emergency department. As a consequence, the nursing team set out to gather the wishes of residents about end of life care and to ensure these wishes would be respected in the event of a resident’s condition deteriorating. With the assistance of a successful application to the Patients First Programme at the Foundation of Nursing Studies (FoNS) and guidance from the Practice Development Facilitator at FoNS, an appreciative inquiry approach was adopted. Using a “Tell Me Your Story” template, three common themes emerged:

- Knowing what a resident wants in terms of future care and ensuring these wishes are clearly documented in a format which will be recognisable and credible to clinicians involved in the resident’s care
- Recognition and anticipation of potential problems and early intervention to prevent crisis events
- Confidence of nursing staff when talking to other people involved in the resident’s care whether family members, other staff, doctors or out of hours providers and a willingness to act as an advocate for the resident where required. It was found that confident staff were able to challenge plans that they felt were not in the resident’s best interest

Changes implemented as a result of the project were a positive acceptance by nursing staff of the importance of Advance Care Planning, ensuring documentation such as Do Not Attempt Resuscitation Orders are in place and early recognition of potential deterioration using the “Stop and Watch” tool and SBAR communication tool. In addition involvement in the project opened up opportunities to share good practice and learning opportunities with a number of other agencies and providers.

**Background**  
**The setting**  
The care home where the project originated is located in a large West Yorkshire city and at the start of the project it was managed by the largest independent provider of long term care in the country with over six hundred homes. The home has 40 beds for residents requiring nursing care
but there are also a small number of residential beds. The nursing workforce is stable and temporary agency staff have not been used for over 10 years. There are qualified nurses on duty 24 hours a day, supported by care staff, nearly all with an NVQ qualification, and ancillary staff.

Within the same city, there were six other care homes managed by the same independent provider, who were also involved in this project. In total, within the seven care homes there were over seven hundred beds providing a whole spectrum of care including residential care, nursing care, dementia care, specialist end of life care and intermediate care. During the time of this project, the company that managed the care homes experienced well publicised financial difficulties which ultimately resulted in the break-up of the company, and homes being taken over by a number of different operators. This resulted in many challenges for the project; these will be described further in the discussion section.

The incident that led to the project
A resident with advanced dementia who had lived at the care home for a number of years appeared “unwell” one morning. She had no close relatives but did have a distant relative who lived some distance away but was rarely in contact. The nurses observed that although there appeared to be no obvious outward signs of infection, constipation, or serious illness, nursing staff who had cared for her for a number of years said that they felt instinctively that something was wrong. On reflection later, the nurses were able to identify that what they had observed were subtle changes in the resident’s facial expression, tone of limbs and level of responsiveness. The concerns expressed by the nursing staff led them to suspect that it was possible that this lady had developed a bronchopneumonia and potentially was in a palliative phase of her life.

As is normal practice, a visit from the local General Practitioner (GP) was requested by the nurse in charge, but this resulted in a visit from the practice Nurse Practitioner. When the Nurse Practitioner visited, she noted a lack of obvious physiological signs such as raised temperature and felt that there were no significant issues to address at that time. However the resident’s condition deteriorated further in the evening and without a definite diagnosis or plan in place from the earlier consultation, the nursing staff felt it was necessary to call for another visit from the GP. Unfortunately due to the time of day, this was provided by the Out of Hours Service, who were unfamiliar with the resident and her condition. When the doctor visited he decided immediately to transfer the patient to hospital despite the nursing staff on duty feeling strongly that this was not the appropriate course of action. They felt that as the resident was nearing the end of her life, she would be better cared for in a quiet and dignified way at the care home. Nevertheless the doctor insisted and booked an ambulance for an acute transfer. Unfortunately, the ambulance did not arrive until some six hours later at two o’clock in the morning, making the supposed need for “acute” care seem difficult to understand. After the incident, nursing staff on duty reported that they had considered challenging the transfer but decided they were powerless given the doctor’s order, the arrival of the ambulance crew and the only known relative’s ambivalence to the situation.

A carer accompanied the resident, whose condition had significantly deteriorated by this time. The events which then transpired in the Accident and Emergency department had a lasting effect on the carer who reported how the fragile, confused lady was restrained to allow for blood tests to be taken along with other examinations. The lady died shortly afterwards on a trolley in the department, but with a familiar carer with her.
All staff within the home, but especially the nurses and carers felt very sad, frustrated and angry about the circumstances surrounding the end of life for this resident. Nursing staff had cared for this lady for many years, often being the only ones to buy her birthday and Christmas presents, knowing how to anticipate and care for her needs and comfort her, despite her advanced dementia and consequent behavioural problems. The loss was compounded by an ill-judged, misinformed email from the Accident and Emergency consultant, condemning “care homes” for sending residents to hospital to die. The home manager (project leader) felt that the way to prevent this happening again, was to try to discuss the events with relevant parties such as the Out of Hours provider. However this was met with little success, as the project lead was unable to identify the responsible managers within this service and when discussions were held, there was an apparent lack of recognition by the provider that this was a problem.

Although agreeing with the conclusions of Hammond et al. (2009), that a multi-agency approach is needed to reduce inappropriate admissions, the home manager reluctantly felt she had no power to influence change across organisational boundaries and therefore decided to see what changes could be facilitated within the care home’s own practices and environment to minimise the recurrence of this type of event.

The home manager also agreed with the views of Frogatt et al. (2009b) who believe that education and training on its own will not bring about change in practice in care homes, as effective management skills are also required to embed new systems into the workplace. The home manager looked to identify practical steps that could become part of the care philosophy within the care home. A successful application was submitted to the Patients First Programme at the Foundation of Nursing Studies (FoNS) to provide the support of an external facilitator and a small bursary to facilitate the development and delivery of this project.

Literature review
In the United Kingdom (UK) 500,000 people live in care homes, where the incidence of frailty and comorbidities is increasing. A quarter of resident deaths occur in hospital with at least 40% having no identified medical need to be there (National Audit Office, 2008). An analysis of hospital mortality and readmission rates (Ahearn et al., 2010) confirmed the need to give serious consideration to whether a resident should be transferred to hospital or not. Their findings concluded that nearly 34% of residents admitted to hospital did not survive the admission and a further 51% died within six weeks. In addition, of residents discharged home 41% might be readmitted or die within six weeks.

Although there are a number of studies recording numbers of inappropriate hospital admissions, research into the underlying causes is sparse. Two studies, Hammond et al. (2009) and Read (1999) came to similar conclusions regarding the underlying issues; access to diagnostics, poor communication between primary and secondary care, and excessive cautiousness of clinicians to manage patients in community settings. Clinicians who are not familiar with a resident were also found to order an admission that may have been inappropriate, for example, they may mistake a patient’s problems as acute rather than chronic (Hammond et al., 2009). These issues echo the experience of the home manager and the other care homes taking part in this project.

Nursing staff also reported anecdotally that clinicians (such as GPs) visiting the care home setting often appeared not to recognise as important care home nursing staff assessment of subtle
behavioural change as a sign of deterioration, as no specific physiological change was noted i.e. a raised temperature being present. Although lack of altered physiological response to illness by older adults, such as absence of pyrexia when infection is present, is well documented (Owen and Allen, 1991), in practice nursing staff reported that this was seldom taken into consideration and could lead to a clinician only agreeing to review residents when an infection had already progressed significantly and treatment options within the care setting reduced, for example if the resident was no longer able to tolerate oral medication. This is very similar to the issue that was the focus for this project.

**Aim**
The aim of the project was to gather the experiences and wishes of residents relating to end of life care and enable them to be respected in the event of a resident’s condition deteriorating, thereby reducing inappropriate admissions.

**Objectives**
1. To understand residents’ experiences of good nursing care
2. To gather and understand residents’ wishes regarding future treatment plans
3. To develop a process for using these wishes within a clearly documented format
4. To develop a system of early recognition and intervention to prevent crisis events

**Methods and approaches**
The project leader identified and invited members to form the initial steering group. She requested that each of the six homes send either the home manager or deputy and one or two other staff who would lead the project within their own homes. Home managers were also asked to select people who would be able to attend subsequent meetings to aid continuity in discussions and practice development plans and thereby ensure a stable team/group was established. Within each of the participating homes a separate project group was established to coordinate the project locally. Five formal meetings were held throughout the project with a representative from each home attending on all but two occasions. Support from the Foundation of Nursing Studies (FoNS) was available at one of the meetings and in addition two staff were able to attend (FoNS) workshops in London which gave an opportunity to network and share experiences with other groups engaged in similar practice development projects. The meetings gave an opportunity to share experiences, discuss progress and make any adjustments to the project that were thought to be beneficial.

**Appreciative Inquiry**
Whilst recognising the distress caused by inappropriate admissions the home manager was also aware that things can also go well, indeed some very recent research indicated that despite perceptions, care home residents do have fewer hospital visits than those receiving home care (Bardsley, 2012).

Following support from FoNS, appreciative inquiry was adopted as an approach within the project. Appreciative inquiry is an approach that focuses on what is valuable in what people do and how this can be built on (Cooperider et al., 2003). An appreciative inquiry approach recognises that if something good is happening it is not by chance and therefore, finding out why things go well can be just as beneficial as the analysis of the problem. This approach was quite a revelation to the representatives on the steering group as all reported how disheartening it was to focus on
negative events and that valuing and exploring what they do well encouraged their own participation.

A template called “Tell Me Your Story” (see Appendix 1) was drawn up to facilitate recollection of events where staff felt that they had made a difference to the care of a resident at a difficult time in the resident’s life. Many stories were recounted verbally but thirteen were also written down using the template. They were analysed by sharing the stories with the steering group, with members picking out what were the important issues that made the difference. Keeping in mind the appreciative inquiry approach, effort was made to pick out the positive approaches and behaviours which had made the difference in each scenario. From analysis of these stories, three common themes emerged as making a difference:

- Knowing what a resident wants in terms of future care and ensuring these wishes are clearly documented in a format which will be recognisable and credible to clinicians involved in the resident’s care
- Recognition and anticipation of potential problems and early intervention to prevent crisis events
- Confidence of staff when talking to other people involved in the resident’s care whether family members, other staff, doctors or out of hours providers and a willingness to act as an advocate for the resident where required. Specifically confident staff were able to challenge plans that they felt were not in the resident’s best interest

Following the identification of these themes, the project leader searched for possible approaches to enable these practices to be built upon. Ideally a more collaborative approach would have been preferred but time constraints on steering group members and the fact that they were based at different locations, made this too difficult. However, throughout the process the project leader circulated information to all participants on a regular basis, electronically and via visits to each location. Additionally follow-up meetings were held prior to the final design of proposed new documentation and guidelines were printed to ensure everyone agreed with the strategy.

**Knowing what a resident wants in terms of future care and ensuring these wishes are clearly documented in a format which will be recognisable and credible to clinicians involved in the resident’s care.**

To address the first issue identified, “Knowing what the resident wants” and ensuring correct documentation is in place, the project leader felt a plan to embed a consistent approach to advance care planning seemed the obvious approach. An advance care plan (ACP) is a statement of wishes detailing the resident’s preferred care options, in the event of serious illness (Froggatt et al., 2009a) to ensure the person has the best opportunity to receive the end of life care that they would hope for. ACPs are seen as an important way to avoid crisis acute transfers from care homes and are a quality marker (Department of Health, 2008). However, there remain many challenges in actually ascertaining and implementing residents’ wishes (Froggatt et al., 2009b). From discussions with the steering group the two main barriers to the use of ACPs were identified. Firstly, there was a reluctance to broach the subject with residents by some staff and secondly, there was a lack of consistent documentation to record discussions and decisions, particularly in light of developments such as the Mental Capacity Act (2005).

A number of ACP templates were considered by the steering group:

- Gold Standards Framework (Department of Health, 2008)
• Preferred priorities of care
• Five Wishes, being the most well-known to the group

The project leader, using the above and the Thinking Ahead documentation (Department of Health, 2008) then developed a new template for an ACP. Key features included an introduction about the aim of the documentation, which it was hoped would help staff who were less confident about broaching the subject, by acting as a prompt to key ideas and aims. Issues such as mental capacity to consent to sharing information, appointment of welfare attorneys and presence of advance directives to refuse treatment (legally binding instructions regarding end of life care) made up the first part of the document so that legal issues would be clearly stated.

The second part of the document pertained to treatment and included a prompt to ensure the resident’s GP was aware of the content of this section and also that any necessary supporting documentation such as a Do Not Attempt Resuscitation (DNAR) order was also completed if required. This section also included asking the resident for their views about hospitalisation in the event of deterioration which appeared to be irreversible. Steering group members all reported that although there is currently much emphasis on ensuring DNAR orders are in place, it is actually the lack of clear instructions re escalation of treatment that was a more problematic issue.

The last section encouraged the resident to record the “little things” that might make a huge difference, for example who they wanted to be with them when they were dying, any beliefs or customs they would want to be followed and any plans they had already made like the order of service for their funeral.

An initial batch of ACPs were printed and distributed to the participating homes and to a local hospice. The project leader sought feedback both informally by telephone conversations and more formally through e-mail correspondence from residents, relatives, staff and the practice development group at a local hospice. Feedback was positive but some changes to wording and format were made to account for comments and suggestions made. The final version was printed and circulated. Positive feedback continued with most homes reporting that the document was now part of the admission process for all residents.

Recognition and anticipation of potential problems and early intervention to prevent crisis events.
Several early warning scores such as Modified Early Warning Score (MEWS) (Burch et al., 2008) are available as tools to address the “Failure to Rescue” agenda (National Patient Safety Association, 2007). However they tend to be based on numerical values of physiological measurements such as blood pressure and respirations. These observations are not routinely completed in a long term setting or care home and therefore MEWS is of little use.

Whilst researching for an approach to encourage early recognition of symptoms by the care home staff, the project leader came across the INTERACT II protocols (Ouslander et al., 2009). The system is well known in the United States and is accredited with reducing transfers to acute settings from long term care facilities (Ouslander et al., 2009). One of the tools advocated by INTERACT II is an early warning score called “Stop and Watch”. The “Stop and Watch” tool relies on detection of subtle differences in a resident’s condition such as reduced mobility or loss of
appetite to predict potential problems and allows early interventions to prevent crisis events, and therefore is much more suitable for a care home setting.

With the permission of the author, Joseph Ouslander, the “Stop and Watch” tool was adapted by the project leader to take into account UK terminology and printed up in booklets with tear-off slips on which carers could document their findings and concerns and hand over to senior nursing staff to manage further.

One value of the tool is that it is often the subtle changes in an older person such as slight cognitive impairment which herald the onset of illness rather than a significant physiological change (Owen et al., 1991). Carers are often best placed to notice these changes rather than the nurse in charge of a particular home as they have closer day to day contact with the resident and notice the little changes which can be so meaningful. Early intervention prevents crisis events by either prompt treatment e.g. start antibiotics for a urinary tract infection before sepsis occurs or recognising that this may be a terminal event and ensuring all relevant people are aware and plans are in place e.g. DNAR order and anticipating needs. Research has shown that even if not followed formally, an appreciation of the principles behind the tool can reduce inappropriate admissions to acute settings (Ouslander et al., 2009).

The “Stop and Watch” tool was universally well received by staff, particularly home managers, with some homes reporting that relatives had used the tool as well as staff. In addition, from involvement with FoNS, the project leader was invited to speak at two national conferences; the National Care Home Conference in Birmingham and the Dementia Care Conference in Liverpool. The invitation to attend the Liverpool conference was made by the Dementia Group at Bradford University who were seeking NHS funding at the time to explore the transferability of INTERACT II (Ouslander et al., 2009) tools to the UK setting. The university was successful in obtaining funding and have kept in touch with the project leader, offering an invitation to participate in the Research Advisory Group. The “Stop and Watch” tool garnered much interest from delegates and has subsequently been noted to be used in diverse settings, many of which have no direct contact with the original project but had heard of the tool from colleagues attending the conferences.

The importance of recognition and anticipation of problems was recently highlighted when a resident was referred to one of the participating homes by the local acute hospital for rehabilitation following a fall. Staff quickly realised that this lady was actually nearing the end of her life and were able to effectively coordinate between the resident, family, rehabilitation team, and GP to ensure all her needs were met during this time. After her death feedback from her family showed deep appreciation of the skilled and compassionate interventions of staff.

Confidence of staff when talking to other people involved in the resident’s care whether family members, other staff, doctors, out of hours providers and a willingness to act as an advocate for the resident where required.

The INTERACT II protocol also provided a solution for care home staff to improving communication skills and confidence in staff via the SBAR communication tool (Situation, Background, Assessment, Recommendation)(NHS Institute for Innovation and Improvement, 2011). This tool aims to provide a structured approach to communicating information about patients between professionals, to ensure the relevant information is handed over with significant
issues easily identified and emphasised. The tool has also been advocated by the NHS Institute for Innovation and Improvement (2011) as a way of improving patient safety. Again, with the permission of the authors, some changes were made to the original template to adjust this to a care home setting. The SBAR tool proved to be less well received than the ACP and “Stop and Watch” tool. Although participants in the project understood the principle of having all relevant information to hand as well as a clear understanding of the desired outcome, many felt that it was too cumbersome to collect information together on a form prior to calling, for example, a doctor. Interestingly this feeling was echoed by Ouslander et al. (2009). However, it was agreed by the steering group that an example of SBAR would be held near telephones in nurses’ stations as an aide memoire.

Discussion
Unfortunately as the project was progressing it came to light that the parent company of the group of homes would cease to operate and homes would transfer to different management operators. The limited time left together on the project necessitated a change of approach to ensure the progress made was sustained. The steering group decided to produce a resource folder to be kept in each home. In addition to the ACP, “Stop and Watch” and SBAR tools, supporting information such as information about the Mental Capacity Act and Lasting Power of Attorneys, was also included. An example of the new regional DNAR form was included at the suggestion of group members, as were prompts about language which may be helpful in initiating end of life care conversations.

The folders were brightly coloured and distinctive and supported by some aide memoires such as lanyards with “Stop and Watch” prompt cards. A launch day was planned by the project leader and well attended, with at least one representative from each participating homes and included home managers, nurses and senior carers. The day included reflection on the project; time to discuss experiences about how staff felt care had improved and an opportunity to review all the tools e.g. ACPs and “Stop and Watch”; and an opportunity to ask questions and to clarify how the tools should be used. Although sad in many ways as it would be the last meeting that the main project care homes would attend together before departing to other operators, the project leader felt confident that as they had all worked together for many years, that although the project could not conclude as originally intended, the participants would still engage and promote the process within their own settings.

Although it was disappointing that the project could not run quite as planned, informal feedback has been that the tools and experience of being involved in the project has had a lasting effect on practice within the different settings. Additionally, the project lead particularly valued the introduction to appreciative inquiry and has subsequently used this approach to explore many different issues within the care home setting.

The initial intention was to evaluate the effectiveness of the programme by monitoring levels of crisis/inappropriate hospital transfers, since the introduction of the tools. This would have been done by using the reflective tool available on INTERACT II website which reviews events leading up to an admission to conclude if the event was potentially avoidable. The change in the management operations of all the participating homes made this impossible to achieve.
Conclusion
This project aimed to gather the experiences and wishes of residents relating to end of life care and enable them to be respected in the event of a resident’s condition deteriorating, thereby reducing inappropriate admissions to the accident and emergency department. An appreciative inquiry approach was used to collect examples of good practice which could be built upon.

Involvement in the project gave a sense of achievement in understanding what went well in end of life care and supported the use of a variety of approaches to embed this in practice rather than the traditional method of just unpicking events that had not gone well. Whilst major organisational changes impacted on the outcomes of the project, all the care homes involved continue to report informally that acute transfers remain very low, demonstrating that although it would be ideal to have a joined up multi-agency approach to this issue, care homes themselves can nevertheless make a difference. Therefore, all the team members would commend care homes to participate in projects such as Patients First Programme, not only to develop practice but also to celebrate what they already achieve.

References

Last accessed 02.04.2012.


Appendix 1: Tell me your story

I made a difference, when:

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Why did things go well?

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What can we learn to make sure things go well in future:

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