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# The conversation: developing confidence to provide end of life care in Salford nursing homes

Johnson, M, Attree, M, Jones, I, Gamal, E and Garbutt, D

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<b>Authors</b>	Johnson, M, Attree, M, Jones, I, Gamal, E and Garbutt, D
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# The 'Conversation': Developing Confidence to Provide End of Life Care in Salford Nursing Homes

**Martin Johnson, Moira Attree,  
Ian Jones, Ekhlal al Gamal,  
David Garbutt**

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Schools of Nursing,  
Midwifery and Social Work

## **Research Team:**

Professor Martin Johnson, University of Salford School of Nursing, Midwifery and Social Work

(Comments please to [m.johnson2@salford.ac.uk](mailto:m.johnson2@salford.ac.uk))

Dr Moira Attree, Senior Lecturer, University of Manchester School of Nursing, Midwifery and Social Work

Dr Ian Jones, Senior Lecturer, University of Salford School of Nursing, Midwifery and Social Work

Dr Ekhlal al Gamal, Assistant Professor, University of Jordan

David Garbutt, Lecturer in End of Life Care, University of Salford School of Nursing, Midwifery and Social Work

## **Research Advisory Group**

Marie Busuttil, End of Life Care Facilitator, Salford Primary Care Trust

Robin Gene, Commissioner, Salford Primary Care Trust

Dr Stephanie Gomm, Consultant in Palliative Care, Salford Royal Hospitals Foundation NHS Trust

Steve Ingle, Consultant Nurse for Palliative Care, Salford Royal Hospitals Foundation NHS Trust

Bill Strettle, Public and Patient Involvement Co-ordinator, Salford Royal Foundation NHS Trust

Kim Wrigley, End of Life Care Lead, Greater Manchester and Cheshire Cancer Network



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## **Reporting Conventions**

The report draws on observations, interviews and survey data drawn from three care homes (with nursing) in the Salford area. The names of institutions and individuals have been changed to allow some privacy and anonymity. Direct quotes are labelled with a pseudonym and a number, the latter referring to the page of raw transcribed data.

The grant proposals on which funding was based were written by Martin Johnson and Moira Attree. Survey instruments were mainly designed by Moira Attree. Interviews and observations were undertaken equally by Moira Attree, Ian Jones and Martin Johnson. Ekhlas Al Gamal undertook early pilot work and also contributed to the literature review. We are grateful to David Garbutt for additional policy literature.

## Key Messages

- a) Significant resources are needed to engage staff, residents and relatives/carers with the idea of advance care planning
- b) Care home staff are optimistic about involving residents and relatives in planning care at the end of life and some relatives become very involved in care
- c) Clearly registered nurses and other care home workers such as care assistants have different roles, but the overlap between these and the appropriate boundaries would benefit from further work
- d) Talking to residents and relatives about their feelings and wishes for care at the end of life remains especially difficult, but education and training in key skills and knowledge can engender both ability and motivation
- e) Care homes need strong and well-informed leadership in order to implement the Gold Standards Framework
- f) Placing a relative in a care home involves strain and an ability to compromise 'there's no perfect place'
- g) Advance care planning can reduce the distress and the number of inappropriate hospital admissions, but is challenging in the face of staff rotation and out of hours medical staff being unpredictable
- h) The principles of the Gold Standards Framework are widely seen as sensible, but clinical challenges include diagnosing and predicting dying trajectories, especially in heart failure, chronic pulmonary disease and dementia
- i) A particular concern of staff is how to approach nutrition and hydration as frailty and death approach
- j) Communicating about diagnosis and especially prognosis with residents who lack capacity is an increasing problem
- k) Natural justice suggests that resources should be allocated to the general standardisation of a good quality of care at the end of life in ALL care homes whatever their Care Quality Commission rating

# Chapter One: Background, Literature Review and Aims

## Background

The provision of quality care for people at the end of their lives is increasingly a focus and concern for health and social care practice, as well as education and policy makers. Lord Darzi's NHS review (DH 2008) signalled the government's commitment to providing high quality care for all and linked achievement of this vision with the need to develop a high quality workforce.

*"As its first major piece of work the (Dying Matters) Coalition conducted a survey of public attitudes using the National Centre for Social Research (NatCen). The results showed that less than a third (29%) of people had discussed their wishes around dying and only 4% had written advance care plans. Despite this, more than two thirds (68%) of people questioned said that they were comfortable talking about death."* (DH 2010)

The End of Life Care Strategy (DH 2008) emphasises the critical role of knowledge, skill and attitudes in improving end of life care, and that all staff groups involved in providing end of life care require appropriate initial and continuing education/training for their role. However, the National Audit Office End of Life Care Report concluded that *'end of life care training is patchy at best'* (NAO 2008). To date end-of-life care has not had a high profile in health and social care professional educational preparation.

Care of the UK population of dependent older people has been steadily transferred from institutional and hospital based care to primary care and with it has seen the expansion of the independent care home sector (House of Commons 1990, Bartlett et al 1996).

Despite the UK care home population falling in recent years, figures indicate that the number of residents in homes in the independent sector is projected to grow from 419,000 this year to 459,000 over the next decade. Long term care is the largest segment of the UK independent healthcare sector.

Currently in the UK 4% of older people live in long term care and the majority of those live in care homes. This group of patients are increasingly characterised by conditions such as organ failure, dementia, asthma, diabetes or arthritis. They are often frail, increasingly dependent on others and 60% will suffer from more than one long term condition (LTC) (Bowman et al 2004, DH 2005). On average over 50% of care residents will die within 2 years of admission (Katz and Peace 2003, Hockley 2006)

Nationally 5% of people with LTC's account for 42% of all acute bed days and just 2% of patients with chronic conditions account for 30% of unplanned hospital admissions. Chronic disease now accounts for 78% of all spending on health care in the United Kingdom (DH, 2005)

A 2007 study of 627 patients who died in hospital indicated that 44% had chronic life threatening illnesses. In 194 (31%) of these cases individuals could have been cared for in the community and at least 75 (11.9%) could probably have avoided admission. A total of 77 (12%) of patients were admitted from nursing homes and 53 (8.4%) of these could have stayed in the nursing home to die. The mean cost of admission was £3,173 per patient. It was estimated that up to one third of all hospital deaths could have been managed in the community if appropriate services and systems were in place (Abel et al 2009).

The workforce delivering end of life care is large and diverse in professional/disciplinary background, level of preparation, social, cultural and ethnic origin and level of involvement. End of life care is provided in a variety of locations from acute hospitals to primary care and nursing homes, including both generalist and specialist services. In particular it is increasingly provided by staff who lack specialist palliative care preparation. There are approximately one million social care staff in England but only 5% of care home staff have NVQ level 3 (*Skills for Care 2009*). The workforce delivering end of life care is at many different levels, from specialist, through to generalist and basic care provider. Indeed, there is a wide range of worker involvement in the provision of end of life care; from full time to infrequent end of life care provider. In this context it is clear that such a diverse workforce has an extremely wide range of education/training needs, requiring complex education commissioning.

High quality end of life care requires communication and clinical skills that are not explicitly developed and assessed in current initial preparation healthcare professional curricula (NAO 2008). Dickinson et al's (2008) national survey of UK School of Nursing managers presented an optimistic picture, claiming a national average of 44 hours 'teaching' in End of Life and Palliative Care. However, this teaching was in a range of related areas, and whether consistent and programmatic approaches such as the Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities for Care are embedded in the knowledge, skills and competence of all those qualifying is unlikely.

Evidence is emerging that the adoption of end of life care pathways and models: Gold Standards Framework, Liverpool Care Pathway, Preferred Priorities for Care and Advance Care Planning and The North West End of Life Care model can improve end of life care across a range of care settings (Badger *et al.* 2007; Clifford *et al.* 2007; Hockley 2006). Hewison et al (2009) also identified the importance of teamwork in the provision of high quality end of life care. One of the key arguments for interprofessional learning is that students who learn together work together better (Zwarenstein et al 2006); however, very little end of life care education is fully interprofessional (NAO 2008). A key challenge is to spread what has been learnt from good practice in one area across the whole sector. Education and training is an important part of implementing these clinical pathways into all areas of practice across different staff groups.

There is little empirical evidence about the quality, content or outcomes of current end of life care education and training. Neither is there clear evidence identifying what knowledge, skills and competencies are essential to the delivery of high quality end of life care or how these can best be provided. This study reports on aspects of attempts to improve the standard of skills, confidence and competence in end of life care in two nursing homes.

## **End of Life Care in Nursing Homes**

More than half a million older people aged 65 or over live in care homes (nursing and personal care) (Social Care Institute for Excellence 2004). In England and Wales it is estimated that over 80,000 people die in these care settings each year (Department of Health 2008). The provision of appropriate end of life care is recognized to make the process of dying more comfortable and meaningful for a person and their family.

Evidence from the Picker Institute (2008) and Healthcare Commission Patient Surveys since 2002 identified that service users are not involved as much as they would like in care decisions. Lack of involvement can lead to dissatisfaction and reduced quality of care but

one solution is collaborative Care Plans/ Pathways which offer a means of increasing patient involvement in care decisions (Hockley 2006). The Gold Standards Framework (GSF) and Preferred Priorities for Care Plan (PPCP) provide a framework for end of life care provision and expressing care preferences.

Currently, these advance care plans are not implemented widely in care/nursing homes, nor used for patients dying from non-cancer causes, who make up 75% of deaths per annum in England. Indeed the Department of Health (2008) suggest that such plans are implemented in only 7.6 of care homes compared, for example, with 75% of hospices and 75% of other primary care. The demand for end of life care for people dying from non-cancer causes is going to increase as life expectancy increases and more people are suffering chronic conditions and co-morbidities. Responsibility for meeting this need will fall largely to Primary Care in various settings. The NHS End of life Care Programme aims to extend palliative care provision, enabling more patients to live and die in their place of choice.

There are few UK data available regarding the preferred place of care and death among older people. Gott et al (2004) conducted a qualitative study to explore the attitudes of older people towards home as a place of care when dying. The sampling consisted of 32 older people who participated in eight focus group interviews in Sheffield. A further 45 older people participated in semi-structured interviews. The study revealed that most participants indicated that home was, in ideal circumstances, the preferred place of care during dying with home described as having familiarity, autonomy and security. One of the participants stated: *"Well it's your home, it's your home, and you're not among strangers. You can get up when you want to, you're comfortable, you can sit in comfort and watch the television, you can read when you want to, you don't have the discipline at home and that is a big, big Thing"*. However, many respondents had concerns about dying at home such as not having an informal carer, not wanting to be a 'burden' to family and friends, believing that quality care cannot be delivered at home and perceiving 'professional' home care as an 'intrusion'. This study has important implications for policy and practice developments in end of life care. Staff should try to acknowledge the preferences for setting of care during dying and incorporate these 'meanings' of home into care provided in nursing homes by making institutional settings more 'homely'. Although participants in this study were people from one city in the UK, Gott et al (2004) described clearly what strategies were used in eliciting information such as focus groups and semi-structured interviews. They give sufficient details of the steps of analysis, coding and forming themes so that the findings remain connected to the data. This study provides rich information about the attitudes of older people towards home as a place of care when dying.

Although people in care homes die from a range of conditions, many suffer increasing frailty from dementia. Pasma et al (2004) conducted a study of a nursing home with patients with dementia to determine the role and influence of respondents in decision making to start or forgo artificial nutrition and hydration. Data collection methods included participant observation and formal interviews with health care providers in two Dutch nursing homes. The study revealed that the most common participants in the artificial nutrition and hydration decision-making processes were the nursing home physician, the patient's family or legal representative, and the members of the nursing staff who were most involved with the patient. Most patients participated only indirectly in the decision-making process as commonly they were no longer able to communicate their wishes concerning the end of life. Therefore, ongoing communication between the person with dementia, family members and professionals from the early stages of the condition is essential.

Using advance care plans in care homes for people nearing the end of life could increase residents' involvement in care decisions and improve the quality of end of life care. Hockley (2006) showed that engagement with similar decision pathways in care homes which provided these measures could also reduce the number of residents admitted as emergencies to acute NHS hospitals and increase the number achieving their preferred place of end of life care. Achieving residents' preferred care plans could improve patients', relatives' and staff satisfaction with care quality whilst improving care home staff satisfaction could help to increase morale and reduce staff turnover, which is often problematic in care home settings.

It is evident that family caregivers care a great deal for their relatives and they experience a variety of intense emotions related to their patient's illness. Small, Froggatt and Downs (2007) argue that people with dementia often experience a 'gradual death' leading to relatives having to live and cope with anticipatory grief over a long period (Kiely, Prigerson and Mitchell, 2008). In fact, the diagnosis of dementia creates a sense of family crisis which ultimately disrupts family functioning.

Hennings, Froggatt and Keady (2010) reviewed literature related to current knowledge about family carers' experiences and needs regarding end of life and dying in care homes for people with dementia. The results are presented under three main themes. First of these is 'unfamiliar territory' by which they mean lack of knowledge and experience, lack of communication with professionals and opting for active interventions in an effort to 'do the best' for the dying. They then discuss 'making decisions' (family carers often required to make decisions on their behalf regarding care and treatment toward the end of life). Finally they draw attention to the needs of the grieving carers. They conclude that health care professionals should address these issues when providing support for these carers by improving communication, providing information and support in decision-making. Care home staff should intervene with carers during this stressful period and provide them with support and care.

Lack of communication between carers and health care professionals can be a problem. Studies demonstrate that family members may perceive professionals as lacking preparation and education for their role in guiding and supporting family caregivers in their decision making (Clarence-Smith 2009) and in dealing with carers' worries about discussing the end of life care prematurely (Powers and Watson, 2008). Mitka (2000) noted that nurses play a critical role in providing a palliative and end of life care for patients and families. Moreover he argues that nurses and other healthcare providers should act to facilitate access to other sources of support such as mutual support groups and counselling besides their own efforts to reassure, listen, and be a companion to carers. He makes clear that staff should have training in the necessary communication skills to enable them to work effectively with carers and to support them. This should include how to listen to and communicate in a factual and non-directive way about a resident's condition, the likely prognosis, treatment options and likely outcomes, and how to give bad news in a sensitive way.

Nursing home staff face many ethical issues in providing care to dying residents. Issues include questions regarding advance decisions to decline treatment, respecting the autonomy of residents with dementia who may lack capacity, and decisions about life-sustaining therapies including tube feeding at end of life (Fellows, 1998).

Hertogh et al (2004) conducted a qualitative study of "truth telling and truthfulness in the care for patients with advanced dementia". The purpose of this study was to investigate and analyze the moral tension that exists in the care for nursing home residents. Data were collected by using observation and informal conversations with the nurses who worked in two Dutch nursing homes. Almost all of the nurses stated that the residents 'had a right to (know) the truth'. The findings examine aspects of truth telling such as whether to report the death of a loved one. Hertogh et al's study used two researchers making observations and they describe how the open-ended and tape-recorded interviews were conducted with participants. The observation work and steps of analysis lend credibility to the study, the implications of the study are that nurses should have training and professional support regarding ethical issues when dealing with this group of individuals in order to provide the most appropriate care.

## Education, Training and the GSF

The Gold Standards Framework (GSF) was initially developed by Dr (now Professor) Kerry Thomas building on her postgraduate work whilst a General Practitioner. The aim of the approach is to 'optimise primary palliative care for patients nearing the end of their lives' (Shaw et al, 2010). The approach has experienced widespread uptake with the support of the National Health Service, with over half of GP practices now using the framework and increasing numbers of other services.

According to the GSF training materials the main aspects of the framework are as listed in Table 1.

Table 1. GSF Outline of Key Aspects (adapted from GSF 2009)

- 1. Resources** - Flyer, DVD, preparation pack, facilitator pack and toolkit (see below)
- 2. Training** - Facilitator training, awareness raising, events and up to four workshops
- 3. Ongoing facilitator support** - Induction, support and mentoring for facilitators via email, phone and website
- 4. Evaluation** – After Death Analysis (ADA) for care homes before and after for benchmarking and sustainability
- 5. Accreditation** - Stage 3 of the programme includes self-assessment against accreditation checklist, portfolio of evidence, visit by GSF Care Homes visitor and ADA evaluation. Homes are then awarded a GSFCH certificate and plaque and will be included on a national database of GSF care homes

Internationally as well as in the UK studies have shown that there is a lack of palliative care knowledge and skills among staff in nursing homes (Ersek, Kraybill and Hansberry 2000, Whittaker et al 2006). Mallory (2003) argues that this lack of education has been reflected in the level and quality of end-of-life care provided (Lewis, 2001; Parker-Oliver, 2002). Ersek, Kraybill and Hansberry (2000) reported in their study that there were gaps in knowledge related to symptom management, communication, goals of care, role delineations, time constraints, and emotional attachment. This is supported by Parker-Oliver, Porock, and Zweig (2005) who conducted a systematic review of empirical evidence of end-of-life care in nursing homes in the United States. The researchers concluded that the need for specialised education for long-term care staff is evident.

Education of nursing staff has been shown to increase knowledge, skills and improve patient outcomes (Kenny, 2001).

Among other studies that investigated the level of education among health care providers in nursing homes, Whittaker et al (2006) conducted a quantitative descriptive study in Ireland. The purpose of this study was to investigate the level of palliative care knowledge among 227 qualified staff delivering end-of-life care in nursing home settings. Findings revealed that less than half the sample had obtained formal training in the area of pain assessment/management and less than a quarter had obtained training in non-malignant conditions. 76% of respondents (n = 155) stated that (at that time) they were not aware of the Liverpool Care of the Dying Pathway which was being implemented on a large scale within the UK. Their lack of knowledge, skills and formal training in this area was considered as a barrier to delivering high quality care to residents. Therefore, the need for the development of an educational programme for qualified staff focusing on enhancing palliative care in nursing homes is considered of vital importance. This is supported by Stillman and colleagues (2005) who suggest that implementing such an educational programme, with training, consultation, and an interdisciplinary team approach, increases staff awareness of palliative care issues and improves quality of care. It is therefore essential to define staff's educational needs for palliative care.

Hirakawa, Kuzuya and Uemura in (2009) explored the educational and support needs among one thousand and fifty nine nursing home care staff in Japan. Data were collected through self-reported, structured questionnaires. The results showed that the issues seen as having the most importance in the provision of end-of-life care at their facilities were additional staff, having a physician or nurse available over 24 hours, and staff education. In addition, dementia care, physical care, communication with residents and families, psychological aspects of dying, and pain/symptom control were listed as the five items seen as the most important to address. The main implication of this study was that nurses should provide training and knowledge about providing end of life care in nursing homes to improve the quality of care provided for such people. This is supported by Parks et al (2005) who reported that staff education is central to providing good quality end-of-life care. In view of these facts, in addition to better in-house training in care homes, better input about end of life care is almost certainly needed in undergraduate and postgraduate programmes for nurses and other health professionals. Furthermore, programmes are needed to ensure that all health and social care professionals understand end of life care in nursing homes and offer appropriate interventions.

Few studies have been conducted to evaluate the implementation of an integrated care pathway in nursing homes. Hockley, Dewar and Watson (2005) conducted a qualitative action research study to evaluate the implementation of an 'integrated care pathway (ICP) for the last days of life' (essentially the same as the Liverpool Care Pathway) in eight independent nursing homes. The themes identified included a need for greater 'openness' around death and dying in which key champions and other staff became more confident to speak openly about end-of-life issues. One participant said "*probably the biggest change that I have seen . . . we all talk about it together*". Other themes included 'recognising dying and taking responsibility' in which they recognised that the nurse in a nursing home has a key role in organising the care for residents who are dying. 'Better teamwork' meant that improved teamwork amongst carers and nurses in the nursing homes was important and there were signs that collaborating with GPs had also improved. Hockley et al argue that using palliative care knowledge critically to influence practice made it more likely that problems such as pain, agitation, and 'rattly chest', which were being monitored every four hours, would get reported and that there would be more meaningful communication (with a greater openness and more knowledge about death and dying for both relatives and some

of the residents themselves). This study confirms the usefulness of the 'ICP for the last days of life' as an important tool in facilitating evidence-based quality end-of-life care in nursing homes.

To summarise, the literature reveals a clear need to explore the implementation of less hospital-orientated approaches to end of life care in the context of an ageing but better informed population.

## **Study Aim**

The aim of the study was to evaluate the introduction of advance care planning as a means of improving the quality of care for residents nearing the end of life in care homes. Working in this context, it was inevitable that issues would arise which took us beyond the 'evaluation' of training and are key aspects of the report.

## **Study objectives:**

- Explore the key issues in planning and delivery of end of life care in nursing homes from the perspectives of residents, relatives/families, carers and health care professionals, nurses and managers
- Explore residents', relatives'/families', carers' and health care professionals' views of their role in planning and delivery of end of life care
- Identify areas of care planning & delivery in need of development
- Identify perceptions and attitudes of the above stakeholders towards residents' participation in advance care planning for end of life care
- A further aim is to explore and evaluate the feasibility of using residents and carers as co-researchers in all stages of the research process, including data collection and analysis
- To disseminate good practice outcomes and to enable learning from less good practice

## Chapter Two: Methodology

We adopted a realistic evaluation design (Pawson & Tilley 1997) to address the research aims. Realistic evaluation aims to produce an in-depth analysis of how programmes work in context and are based on the proposition that outcomes are caused by specific 'mechanisms' which occur at a psychological, individual or organisational level, and that these are mediated by 'context' (Pawson & Tilley 1997). The purpose of a realistic evaluation is to establish whether there is a 'putative causal relationship between a programme and its outcomes', that is, where change can be measured following the implementation of the programme. In essence, realistic evaluation evaluates 'what works', 'for whom' and 'in what circumstances', and aims to identify *mechanisms* within the *context* that affect 'outcome'. Realistic evaluation has been used effectively over the last decade in healthcare research to evaluate primary health care (Kennedy et al 2005); palliative care (Tolson et al 2007); acute/ secondary healthcare (Marchal et al 2009); mental health (Byng et al 2005) and healthcare education (Lauder et al 2008 a & b).

Various data sources can be used to provide a comprehensive assessment of a programme and its context, including surveys, interviews, observation and documents (Attree, 2006; Cresswell & Plano-Clark 2007; Tashakkori & Teddlie 2003). Realistic evaluation provides a coherent evaluation framework based on understanding causal mechanisms, which is important in the practice context as programmes need to be fully understood if they are to be effectively implemented and used in practice. Realistic Evaluation analyses the link between intervention, mechanism and outcome which increases explanatory power and improves the usefulness of the findings for decision-makers at various levels e.g. national, regional or organisational, and in other settings (analytical generalisability). Whilst we used this as a guiding methodology, we would not claim rigid adherence to all its elements. Essentially there were two main approaches, a survey and an in depth qualitative study. We regard the former merely as a pilot of instruments because numbers of respondents from two care homes are insufficient to make firm conclusions, and only a handful of respondents were available for the planned post-test. We therefore concentrate in the report on the qualitative findings and use selected survey data to illustrate points.

### Data Collection Methods:

Mixed data collection methods (Cresswell & Plano-Clark 2007; Tashakkori & Teddlie 2003) were used to collect the depth, breadth and level of data required to address the research aims from the various stakeholders' perspectives. Quantitative data were collected from care home staff using two measurement scales combined in one questionnaire before and after the Gold Standards Framework training. Qualitative methods included interviews, focus group and participant observation to explore the context and practice of end of life care planning and delivery in the care homes.

### Pilot Survey of Staff Attitudes, Perceptions and Confidence in End of Life Care

In order for the Gold Standards Framework for end of life care to be implemented in care homes it is essential that the staff involved in its implementation are adequately prepared, are confident in its operation and are committed to its philosophical principles.

The aims of this phase of the study were firstly, to identify to what extent staff were confident in the care of residents at the end of life and secondly to explore their attitudes to the involvement of residents and their relatives in advance care planning. This part of the study was always meant to be 'pilot' in nature, but a little ambitiously we had originally planned to achieve these aims employing a quasi-experimental design, with 'baseline' and 'after' use of the survey instruments to measure any apparent changes in attitudes, perceptions and confidence which might have developed as a result of the Gold Standards Framework Training. In the event, the attrition of Catherine House (one of the 'trainee' nursing homes) from the study meant that insufficient responses would be available for meaningful before and after testing. We developed two scales. The first aimed to identify the respondent's confidence to assess, plan, implement and evaluate crucial elements of end of life care, paying particular attention to the skill of communication within these processes. Staff were able to rate their confidence of a skill on a five point Likert scale ranging from no confidence at one end of the scale to totally confident at the opposite end of the scale (Appendix 1).

The second part of the questionnaire examined the respondent's attitudes towards advance care planning. The respondents were provided with a number of statements relating to advance care planning. Their concurrence with the statements was assessed using a five point Likert scale ranging from strongly agree to strongly disagree. An additional option of not applicable was added in the event that the statement did not relate to an individual's role. Each questionnaire was completed immediately prior to the respondent participating in the Gold Standards framework training programme although some will have had exposure to these ideas elsewhere. In any future study on a larger scale the refined instruments could be used in the more sophisticated way we had intended.

## **Scale Development**

We used expert panel methods (DeVellis 2003) to develop two scales for measuring staff perceptions and confidence in end of life care. The scales were short, self-completed Likert Scales. A systematic, structured scale development process was used (Worthington & Whittaker 2006; Rattray & Jones 2007), commencing with generation and review of potential themes/items for inclusion and ending with expert review and small pilot study of the scales. Consensus methods (DeVellis 2003) were used to reach agreement on items to be included in the scales.

Two scales were developed and combined in a questionnaire to assess staff perceptions and confidence on end of life care planning and delivery (see appendix 1).

1. Staff Perceptions of care planning at the end of life
2. Confidence Log

## **Staff Perceptions Scale**

A Staff Perceptions of Care Planning at the End of Life scale was developed from the literature, research aims and questions, as well as the GSF programme aims. The scale explored staff perceptions of care planning at the end of life. The 17 statements related to:- resident and family involvement in care planning; end of life care planning and healthcare professionals' role in care planning. The 5 point Likert scale ranged from *Strongly Agree* and *Agree*, through *depends* (neutral) to *Disagree* and *Strongly Disagree*. 8 of the 17

items were reverse scored. Space was provided at the end of the scale for participants to add their view or comment. The staff perception scale generated ordinal level data that was analysed using descriptive statistics.

## Confidence Log

A Confidence Log (Thornbury 1999) was developed to enable participants to rate their own confidence on:- the GSF tools, end of life care planning and communicating with residents, relatives and colleagues. The Confidence Log was a 2 page, 27 item, self-rating scale, designed to assess the level of confidence on a five point Likert scale. The scale ranged from *Totally Confident*, through *Very Confident*, *Somewhat Confident* to *Little Confidence* and *No Confidence*. The Confidence Logs were constructed by the researchers to focus on the concept of interest from the literature, research aims and questions, as well as the GSF programme aims. The Confidence Log was designed using the principles of questionnaire design outlined by Oppenheim (1992), scale development by Trochim (2002a) and DeVellis (2003), as well as recommendations by Thornbury (1999). The 27 items were grouped into five sections relating to:

- the GSF tools (4 items)
- end of life care planning (5 items)
- communicating with residents about end of life care (7 items)
- assessing residents' end of life care needs (4 items)
- communicating with colleagues about end of life care (7 items).

Space was provided at the end of the Log for participants to add their comments. The Confidence Log generated ordinal level data; differences between groups, mainly registered and unregistered staff were compared using descriptive statistics.

## Expert Review

The Staff perceptions scale and Confidence Logs were subjected to Expert Review (DeVellis 2003; Worthington & Whittaker 2006; Rattray & Jones 2007) by five NHS personnel who had an end of life care remit, to assess the content validity, comprehensibility and clarity (Oppenheim 1992; Trochim 2002a). They agreed that the scales were generally clear and unambiguous, and that the items were appropriate and relevant to the study aims and GSF training. Minor amendments to clarify terminology, non-response and 'not known' were made as a result of feedback from expert panel review and pilot study participants.

## Procedure

Participants were asked to complete both scales on Day 1 of their GSF training. Our plan to undertake a post-test nine months after completion of the training was frustrated by insufficient numbers for statistical comparisons. Short written instructions on how to complete the scales were given at the top of the first page; the course facilitator and researcher were on hand to clarify scale completion instructions, if required. Those willing

to participate were given a 5-digit identification code to ensure anonymity and to facilitate comparison.

## **Survey sample and respondents**

The respondents were recruited from two care homes where managers had expressed a wish to introduce the Gold Standards Framework. The homes were also able to demonstrate certain quality standards with the possession of a (then) Commission for Social Care Inspection (CSCI) 2 star award. A convenience sample of carers and registered nurses were recruited to participate in the study. As the study aimed to be inclusive and provide an overview of current practice we did not introduce any selection criteria. All those who wished to participate, regardless of clinical grade, completed the questionnaires.

A total of 35 people completed the attitude questionnaire, 23 from home 1 (Birchwood) and 12 from home 2 (Catherine House). Note that Birchwood was also a site for the qualitative study, but Catherine House was not because losing a grade in the (then) CSCI inspection had led to the Primary Care Trust asking us to suspend this care home from the study. Despite this we believe it is reasonable to use the anonymous 'pilot' data from this care home for that purpose. 22 of these respondents were care assistants and 10 were registered nurses. There were an additional 3 questionnaires where the status of the respondent is unknown. A total of 34 people completed the confidence log. Some questions were left unanswered by respondents, therefore the percentages presented are calculated based on the number of respondents that have answered individual questions as opposed to the total sample size.

## **Qualitative Data Collection Methods and Analysis**

We undertook fieldwork of various kinds during the project. We used participant observation of methods of training and the delivery of workshops both at the Regional Study Days and more locally, both in Primary Care Trust premises and in the care homes themselves. This approach has been used successfully by many health service researchers in this field of work (Lawton 2000, Hockley 2006) and allowed study of the context of both the training the current processes of care planning and delivery. In these activities we wrote field-notes which include ad hoc or 'informal' interviews with respondents.

In addition we undertook individual or small group interviews and focus groups with staff, relatives and residents in order to develop an understanding of current approaches, values and attitudes to care planning at the end of life. These enabled us to explore the context of care, mechanisms affecting care delivery, and what all key stakeholders such as residents, relatives and staff felt about planning for end of life care.

Many respondents in the qualitative study and the pilot survey were different. In the case of the larger Birchwood care home which was just entering the GSF training process, quite a number of interview respondents would also have had the opportunity to complete the baseline questionnaire. Having been the focus of our early pre-study orientation residents, staff and relatives from the more experienced, but smaller, Acton Court care home became involved in more depth after the unfortunate withdrawal of Catherine House from the main study.

Field-notes and interviews were transcribed and anonymised. The research team met several times to compare and contrast analytic themes, agreeing on core elements which should appear on this report. These were also discussed at an advisory group meeting and tested in several seminars and conference presentations. Whilst we were guided generally by the context, mechanisms and outcomes model we have been mindful of the importance of data being paramount to the analysis, so we have presented a good number of field-notes and interview quotes in support of the discussion.

Table 2: The qualitative data formal interview sample

	Acton Court	Birchwood
Residents	2	7
Relatives	1	5
HCA and Senior HCA	6	8
Registered Nurses	5	7
Manager	1	1
Total respondents	15	28

Formal semi-structured interviews with one or more staff were formally arranged, but occasionally took place opportunistically as people became available. We made a point of visiting after 9pm to capture the opinions of night staff. Interviews were recorded digitally and for the most part transcribed professionally by Outsec™ who provided a very quick and reliable service.

## Limitations

Although the number and variety of respondents was encouraging, this remains a study of two nursing homes in a predominantly working class city location, however the depth of insight possible with this approach strengthens the study outcomes. Managers in both homes were very committed to improvements in end of life care, and it remains very important indeed to understand stakeholders' experiences of end of life care in less motivated settings, which are probably in the majority.

# Chapter Three: 'The Conversation'

## The Nursing Home Context

Initially we undertook 'pilot' work in Acton Court, a small Nursing/Care Home which had been using the Gold Standards Framework for two years and was becoming experienced. Our main study was to have been conducted in two bigger nursing/care homes which were at the point of being 'trained' in the Gold Standards Framework Processes for the first time, following them over time to see how their confidence and other aspects developed. Sadly, one of these homes lost grades on the Social Services Quality Inspection, so the Primary Care Trust advised us to suspend detailed study there. Although such issues are common enough and would warrant investigation, we concede that a further invasion of their privacy at this delicate time would have been unhelpful on this occasion.

In the event then, Acton Court became a focus for more in-depth study and formed a useful comparison with Birchwood which was at a much earlier stage of development in 'GSF' End of Life Care Training.

## The Workforce

There is no doubt that the supply of motivated, experienced staff to nursing homes in the UK is precarious.

	Acton Court	Birchwood
Residents	25	69
RN Staff	7	12
Care Staff	15	38
Ancillary Staff	3	17
Total staff	25	67

Table 3: Staff and residents at the two nursing homes studied in depth

Home Manager John felt that working at Birchwood which was part of 'Triangle', a very large nursing home provider (over 700 homes), meant that management and recruitment processes were clear and helpful. Attracting staff presented challenges, however:

*I sit in management meetings and say openly that these are my problems and if you want my home to be amazing then I want more money for the carers so I can recruit from a broader group, and the same for the nurses. (John, RN 96)*

Discussing the commonly experienced problem in this sector of 'high turnover' John felt that his workforce was comparatively stable at this home, a view echoed by Denise for the smaller Acton Court:

*No, not here. Not now. Not with this thing that we've got at the moment. But sometimes I feel that some people come into care without really caring. Especially at Christmas. But they don't realise what it involves. We have girls that come for interview, and we show*

*them round and things, but when you actually come to physically do it, then they can't physically do it, so I think you've got be... you've got to be caring to do it. (HCA Denise, 34)*

A number of staff commented that rising unemployment seemed to lead to some unsuitable applicants coming along, but that usually they soon left. Some didn't seem to realise the involvement with intimate care and helping people with otherwise socially taboo areas of life such as elimination. Given that this sector is expanding and the population is ageing, it is reasonable to assume that many of those who currently are student nurses may expect to work in settings like these for some part of their career. Acton Court was on the local University circuit and sometimes had nursing students for a few weeks. We asked whether students seemed to adapt to the care home atmosphere:

*Some do, and some don't.....I remember one that we had, and one of the ladies was asking for a drink, and the drink was actually on a tray in front of her, and she just walked out the door and left it to the other carers, but I think if you're going to be a nurse, you've got to be a good nurse, she could have gone over, and just handed the drink. That's the way I feel, you know. (Denise, HCA 34)*

## **Education and Training**

The preparation of care homes in Salford for the adoption of the Gold Standards Framework was very much supported by the Salford Primary Care Trust, the Greater Manchester and Cheshire Cancer Network and the Northwest Regional Strategic Health Authority. In particular, training in the use of the Frameworks and the associated care pathways was provided both on Regional Study Days, on Health Service Premises in workshops and in a tailored package of seminars/workshops in the care homes themselves. However, the uptake of this training was limited to homes already achieving a good standard of general care as judged by the Care Quality Commission, and of these, to those homes who were prepared to register. There is cost for the registration process to enable supervision, audit of progress and final certification (which the majority of care homes are finding themselves) but clearly the greatest cost to care providers was the release of staff to attend study periods and workshops.

Since the Government launched its End of Life Care Strategy it has given substantial sums of money for the development of this area of provision. In particular the money was to be used by Primary Care Trusts (PCTs) to enable people to have better quality end of life care and an improved choice of place of death. In 2009-2010 most of the provided £88 million was allocated to PCTs who seem to have varied greatly in their preparedness to use the money for this purpose. According to the Department of Health those PCTs who have invested appropriately are those which were already engaged quite well in improving services at the end of life (DH 2010). Fortunately, Salford PCT allocated resources not only to the National Health Service Sector, but also to the support of private and charity owned care homes and other providers.

In particular the PCT, together with Salford Royal Foundation NHS Trust and the Northwest Strategic Health Authority, provided expertise in education and training in key areas of end of life care for care homes which engaged with the Gold Standards Framework. Once so engaged, care home staff could expect to attend regional study days, local education and training days on Salford NHS premises or at the local hospice and support seminars and group meetings actually on site in the homes themselves. The success of these was mainly due to the flexibility of the main facilitators and end of life

care co-ordinators in responding to local needs, such as repetition of sessions for the small numbers who, by reason of workload, were able to attend.

The training was largely arranged around the key elements of:

- Communication skills
- Assessment of personal needs and preferences
- Advance care planning
- Symptom control
- End of life care tools such as the Gold Standards Framework, Preferred priorities for Care and Liverpool Care Pathway
- Exploration of attitudes to death

Local experts and staff who had used the tools and approaches in earlier phases of training would often assist in the training which added realism. For example one speaker from a home successfully using the end of life care tools claimed that *'it's not all black and white'*. She had seen one resident be put on and taken off the Liverpool Care Pathway three or four times. She also pointed out the complexity of defining roles. For example for 'residential' patients managing the care of the dying process was, according to the Care Quality Commission, the district nurses' role whilst for 'nursing' residents the care home nursing staff should be taking more responsibility.

Given the staffing difficulties the training took several months to complete, and certainly not all staff got to many or all of the sessions. Individual sessions could be short and disrupted by crises and especially, given that in two of the homes the training room was a residents' sitting room, residents would occasionally enter.

Clearly this fluidity led to a likelihood that knowledge of the processes and detail was varied throughout the staff, but in all cases there was strong commitment from the senior staff to attend and to 'train' staff less fortunate in attending the sessions by 'cascading' the main points through meetings and supervision. Indeed Health Care Assistant Karen felt that since she couldn't attend all of the 'series' she was not selected for any, and learned mainly from handover reports. At Acton Court the training was mostly undertaken in the basement which acted as a seminar room, store, office and refuge for staff.

However, one experienced HCA of 12 years was enabled to attend all the sessions, even the ones in other locations, so it seemed clear that every effort was being made. Assistant Tanya said:

*I actually really enjoyed it to be honest. I thought it was the best thing that could have come to me. It's quite an eye opener. (76)*

At a later stage the sessions usually included an exploration of the staff members' feelings about death, including their own. Of course this was potentially quite challenging but in our experience of several observations of the training it was well handled. When we asked Tanya to expand on how this had been for her she suggested:

*To be honest, I don't really worry about it anymore. I think it's probably part of life now. So I don't actually... I can't explain it really. I'm actually quite calm about it, with all the things that you can actually sort out beforehand, and then it's not left to anyone else in particular. (Tanya, HCA, 76)*

Tanya went on to say that the training and the development of better care at the end of life reassured her about being in that situation herself one day.

### ***“There’s no such thing as a perfect place”***

Residents find themselves being cared for in a nursing/residential home for all sorts of reasons and choosing which one is not easy. Kathleen had found herself responsible for moving her mother in law (Grace) from a residential care setting to a home with ‘nursing’ because she had begun to display signs of aggression. *‘She would lash out’* and in fact had *‘trashed the office’* so was becoming unmanageable in that setting which had a low staff to resident ratio and no-one with mental health training or experience.

*Well we were given a list by the social worker and it was a case of hit and miss. You know, who’s got a place who’s not got a place. There are not very many in your area.* (Kathleen, Daughter, B65)

Kathleen explained that the home had to be within a five or ten-mile radius and that ideally her Mum’s room would be on the ground floor so she could interact with others and yet be kept in view. Grace, now blind, had been widowed many years before, so was used to her own company, yet liked to have people popping in and out as if at home in a busy neighbourhood. Previously, at the peak of her vulnerability at home she had been burgled, so a key feature of placing her in care was to maintain her safety.

Selma was visiting her husband Ian who had a long and difficult history of bipolar disorder, but who had become increasingly aggressive as a dementia process began. She was given good advice:

*...one of his nurses, who I’ll be eternally grateful to, he said to me ‘don’t make appointments’ at any of the homes ‘just go and that’s when you’ll get the right idea’ and he said to me ‘don’t be impressed if it’s all neat and tidy’ he said ‘because sometimes they’re not necessarily a good home, sometimes they can be scruffy but they’re loved and they’re taken care of’ and I remembered that.* (Selma, B82)

Resident Dot, in her 70s and in the home because she couldn’t get about, seemed happy with her lot. Her many relatives would come to see her and she had confidence in the staff:

*They are good to you and the food’s good and everything....I’ve got no troubles with anything, I’m just happy.* (Dot, Resident, 140)

Expectations vary however, and Sally had looked hard for a suitable home for her Mum:

*I think when you go and visit any Care Home it’s not just about what does it look like, it’s how it feels as well. I’m a great believer in how things feel around the Care Home. And I know the Care Home that I did like and I chose first – there weren’t a lot of vacancies. So that’s how my Mum came to be here.* (Sally, Relative, B32)

So she placed her in Birchwood, a relatively large home with two floors, one for residents most of whom had progressive dementia, and one for less dependent residents, but many of whom still lacked capacity for the kind of social interaction of which they had once been capable. This presented a challenge for residents who still gained much from conversation and social activities. We spoke to Kenneth, in his eyes a ‘young fella’ of 85

who was adamant that he would be leaving this home soon for one where he could communicate with more of the residents:

*There's more life there, if you know what I mean....They go out for days.*

Clearly, in some homes and for residents with their full faculties finding people to talk to and engage in 'normal' activities with can be very hard. For those with diminished capacity however, there was little choice. We asked Selma if she had anything to add:

*Not really because I know that they do their best and I'm confident in that. Like I said to you before Moira, there's no such thing as a perfect place. (Selma, Relative, B87)*

## Chapter Four: Care Planning for End of Life Care

### In and out of hospital

67% of people who die in Salford die in the local hospital. This figure includes a significant number who have been transferred from a nursing home during some kind of health crisis which, if it were possible to recognise the probability of death, might have enabled the resident to die more peacefully in familiar surroundings and with people they know.

Registered Nurse Lorna from Birchwood which was just adopting the GSF approach told us how things used to be when residents were ill, that is, how her superiors might have questioned her judgement and that of her colleagues:

Lorna: *We get response, well why didn't you send him to hospital, why didn't you do something... Yes so...*

Int: *That's what's expected.*

Lorna: *That's what we... yes. So we used to send them to hospital. We didn't, some people used to say they'd like to die here but the relatives would say, no just leave here but you're thinking, if I leave I will be in trouble so we just used to send them to hospital. (Lorna, RN, Birchwood, B59)*

Acton Court Manager Helen felt that working in a GSF certified home allowed her some control in situations like this provided the individual and their relatives' views were clear. One resident had terminal cancer which, it was thought, might erode an important blood vessel:

*....it is actually deteriorating, however we don't know what's happening internally so I got in touch with MacMillan .... because this gentleman's relative doesn't want (him) being admitted to hospital. It's like a crisis really. .... They advised what to do in an emergency. So it's all set up really, I've got the drugs in the fridge should he be bed bound. So if he does haemorrhage and to calm him down and I've also got the buzzer alarm.... And so all that is set up ready. It might never happen but if it does I hope no one dials nine, nine, nine only for him to die en-route with something like that. (Manager Helen, 2)*

Even when agreed, the policy not to admit didn't always work. Helen related an incident where the nurse on night duty had faced two residents having relatively unexpected deteriorations in one night:

*We had two ladies dying, and even though it was written not to be admitted to hospital the nurse on nights panicked because it looked bad: two patients dying, and he unfortunately sent for an ambulance for one of the ladies, and the family were mortified, absolutely mortified .... and because the family had been like lived just here, especially close to the hospital you know, (they said to the hospital) 'We want our mum sending back, we want our mum sent back.' And the ambulance driver brought her back (here) where she died. (Helen, Manager, 4)*

Helen talked about the difficulty of addressing this decision with the nurse concerned, but there is no doubt that staff are often anxious not to be seen to be in charge when more than an 'expected' number of residents die or become very ill. Later we discuss the 'Shipman Factor' which for some GPs has limited their preparedness to prescribe

morphine and derivatives except in the most clear cut cases of last days of life, but it must not be forgotten that there have been a number of high profile cases of nursing staff attempting to and actually murdering people in their care (Heffernan 2008). Even when not using drugs which might shorten life they fear accusation by relatives or others of failing to take reasonable steps to preserve life.

It is also clear that with unexplained deterioration there is often little option but to admit residents to hospital for investigation. Ursula was aged 89 and, whilst being very forgetful in the short term and unable to manage at home, was far from the 'terminal' phase of her dementia process. In fieldwork we chatted to her at length about her life and relatives, which remained full in her memory. She was able to walk with a frame and, whilst regularly getting chest infections usually recovered well and got back to managing her personal hygiene with just a little help. She passed her time reading and listening to her radio. She had a quiet personable nature and became a key informant as we made a point of following her progress over quite a few months. Although frail and having had some kind of minor 'stroke', so potentially near to the end of her life, she spoke optimistically of going out with the staff from time to time and sitting in the garden, something she had loved. On the other hand the staff said that she was realistic about her future:

*Ursula used to say it a lot. She'd say, 'I'm not scared of dying. I'm not bothered if I die.' You'd say, 'Oh, Ursula, don't talk like that, you're not going yet' and you'd get a laugh out of her. They're not really... I don't know. Some of them, they're ready, aren't they, to go anyway? I try and change the subject and cheer them up a bit. .... I don't know. I think they get to that point when they're not well and they're just, they've had enough. (Margaret, Senior HCA, 51)*

A few weeks later on a visit to interview staff Acton Court Senior Health Care Support Worker Denise (31) recounted how Ursula had been taken into City Hospital having had a fall and had died there.

INT *Now Ursula, did she need to be on the (Liverpool Care) Pathway, or did it all just sort of happen?*

RES *No, she went into hospital, hopefully they put her on the Pathway at the hospital, but obviously we didn't get the feedback, we just got the phone call saying unfortunately Ursula had passed away.*

People in Ursula's situation will remain complicated. Though frail she was classed as 'residential' so the Gold Standards Framework would be less likely to apply, that is no one condition was obviously likely to threaten her life in the coming weeks. Although she had expressed her sentiments about not fearing death, the staff on duty could do little else when she fell and broke her hip but admit her to hospital. Although life-threatening, with good fortune and effective management even the very old can recover.

The evaluation of the Gold Standards Framework study led by Liverpool John Moores University makes the point that after admission from a nursing home the average length of time spent in hospital by people with dementia before death was about 14 days (McClelland et al. 2008). Of course death may not be inevitable and we know that for some people it might even be their preferred place of death, based on their past experience of other relatives and friends, who we know have until now mostly died in the hospital setting.

## Multi-disciplinary working

Whether residents are admitted to hospital or not in particular circumstances and whether or not they are designated as 'weeks to live' so that the relevant drugs and equipment for the End Life Care Pathway can be acquired, depends very much on the view of the General Practitioner (GP). Many nursing homes, and these two in particular, often have over a dozen GPs relating to their residents from when they were at home, so consistency of attitude and knowledge in relation to good end of life care can be difficult to achieve. Staff complained that some GPs would not visit a resident who, in virtue of currently being in a home now lived 'off the patch' (Training Day Fieldnote 6.11.08).

As Acton Court Staff Nurse Raj explained, residents were assessed on a monthly basis in respect of their 'trajectory', that is to say their likelihood of approaching death within years (A), months (B), weeks (C) or days (D). Once they were assessed as 'C' the system for obtaining the Liverpool Care Pathway drugs in preparedness for stage 'D' involved communication with the GP surgery, often by Fax machine on the appropriate form.

The manager Helen explained that a good deal of her time was taken up explaining to GPs that having the drugs available, especially in anticipation of deterioration at a weekend could be vital for the comfort of dying residents. Achieving this in one case proved a particular challenge. Aged 83, Sam was in the home for terminal care suffering from end stage heart failure and was on the Liverpool Care Pathway, but in the remitting and relapsing nature of the condition predicting death within days is virtually impossible. In fact Sam had been 'end stage' for many weeks, but convincing the GP that having the drugs available might make his last days more comfortable was problematic. Helen had repeatedly asked for the medications:

*But I think, you know, the more we get in with the doctors now...you fax and fax and fax...Dear doctor....Dear doctor... for months and months for Sam's drugs. And one doctor that I asked for a lady just absolutely thought I was definitely on it (morphine) and I've still not got the drugs for this lady and she was horrified that I'd asked for drugs. So you know, some of them are great and some are still a bit reluctant. (Helen, Manager, 10)*

Aware that 'out of hours' decisions were perhaps the most challenging of all, we visited nursing homes to meet night staff to gain their perspective. At Acton Court the night nurse was reassuring that with good communication and developed relationships the GP's out of hours service could be usefully contacted, although sometimes this would be to complete the formalities of certifying death:

*I never have difficulty... only... of course the doctor will have priorities, or there is... whatever, there is a collapse, they will be right away, they'll come... they will respond right away. Only because I know they are busy in the week and especially (when) they expect a death on 'the pathway' and the client has already died, they will come a little bit late. Of course other nursing homes, they will go there, they will prioritise, of course they only will come for confirmation. (Dalisay, RN, 40)*

At Birchwood the staff were talking about their experiences before the introduction of the GSF, and one of the managers, John, recounted his difficulties with a well-known pharmacy and some GPs. His example was that an ordered prescription had arrived with things missing – in his view a clerical error at the Pharmacy. The ensuing dispute about whose error this was or whether the drugs had been misappropriated led to a particular resident failing to get the medicines she needed.

*I can understand that protocols need to be in place for missing drugs, it's fine, I've no problem with having the police come round to search this place and go through everybody's bags if need be, but get on with it quickly and let's not make a drama of it, you know. The bottom line is, we need it.... Because what I've found with the GPs here, and (Large Pharmacy Chain), is they're more interested in process rather than people and I've no time for that, the process is always secondary to the person for me, and I think that a bit of growth is needed. (John, RN Manager, 104)*

John was resolving the problem by using the 'safeguarding' procedure. He felt it was potentially an underused and useful tool to exact accountability from GPs and the health service bureaucracy when it could be shown that residents had suffered because 'procedure' was more important than 'people'. John felt that some GPs seemed to assume that staff working in the care home sector were of lower status than their contemporaries in more acute settings, and valued their opinion less as a result.

## **Support from NHS Services**

Although both homes had 'nursing beds' there remained an interface with the NHS nursing services such as Community and MacMillan Nursing Services. Often pressure ulcers would be seen and advised on regularly by the specialist wound care nurse, and in the early stages of development of the Gold Standards Framework approach to end of life care MacMillan or other Community Nurses would initiate the administration of the relevant drugs, often by syringe driver.

*To be honest with you, when we were doing this course I already involved one resident, you know, so we used this Gold Standard but the district nurse was coming and then she injected and she medicated the lady. (Ghazala, RN, 164)*

It seemed, however, that these external nursing services expected that this role would in due course become one managed on a day to day basis by the registered nurses in the home, with the NHS staff being involved only in an advisory capacity. This relationship arises from a common understanding that the residents' needs are uppermost, but is potentially problematic because of the differential sources of funding for each service. Each of these care homes with NHS 'nursing beds' attracts some funding for this work so it could be perceived that they should become self-sufficient in 'nursing'. The nursing homes are run for owner profit, so the boundary between NHS funded work in and out of the home is a delicate one depending on good will. Studies of community nursing work in the nursing home sector (Goodman et al. 2005) have shown that this 'boundary' can limit the amount and quality of NHS Community nursing services from which residents in nursing homes would be entitled to benefit if they were in their own homes.

## **Nursing and Health Care Assistant/Support Worker Roles**

There is no doubt that Health Care Support Workers, or 'Nursing Assistants' are the bedrock of the nursing home sector. They are the major part of the workforce and any resident's experience of care is heavily dependent on their personal qualities, skills and commitment. They clearly form an important part of the multi-disciplinary team despite their invisibility in some of the literature which would describe this team as consisting of 'professionals'.

Health Care Assistants (HCAs) noted that residents spent most of their time with them, so most of the opportunity to talk about their situation fell to this grade of staff. One in particular said:

*They call us nurses anyway so I don't think they know the difference. (Demi, HCA122)*

Many interviews with HCAs suggested a feeling of some exclusion from the end of life decision processes. Senior HCA Noreen (177) explained:

*We don't really get told about medications or anything, but if a resident says 'oh I'm in pain' we'll tell the nurses and they'll give them pain relief and things like that.*

Although hinting at being a little excluded she continued that she felt consulted in matters to do with residents and their families because she knew them so well and it was the nurses' role with the doctors to plan the care itself. When we asked if she had enough information about residents Demi had also felt a little excluded when, for example, she had been sent along to hospital with a resident who had deteriorated:

*Yes. Because sometimes we are sent to the hospital with the resident. You don't know anything. They just say "Okay Demi, you take her to the hospital" ..... They (at the hospital) ask me "Is she allergic to anything?" and I am like, I can't answer. I look so daft. (Demi, HCA, 122)*

It would not be fair to state that exclusion from information was systematic, but the care home division of labour does lead to the nurses having most routine access to and control of assessment and planning information. However, the GSF approach does include meetings and discussion of residents' needs at the end of life with as many staff as possible.

## **Using the GSF**

Helen at Acton Court told us how she had got started with the GSF and integrated Care (Liverpool Care) Pathway approach:

*I actually got all the research of the Liverpool Pathway myself so I knew about it. And I've said I'd love to actually do it here. And then the PCT's End of Life Care Facilitator rang and I nearly bit his hand off. Yes, yes, yes! And obviously we had to pay a fee to do it, you know because of the training and everything and that was it really. (Helen, Manager, 2)*

Manager of Birchwood John told us how he had decided to allow his staff to join the GSF programme:

*It was through meeting one of the GSF coordinators, I think it was Hazel originally, and she'd spoken to a few home managers, and I think at the time our home was ready to take on the GSF because we'd done quite a lot of work on the changing culture within the home. I was a new manager as well at that time, so I was quite eager to take a new project on, a new project for the home. (John, Manager, 94)*

Clearly the introduction of new ways of working needs to be championed by the manager of the home. In both cases they had independently seen a need for improved decision making and care planning at the end of life for residents to have their needs and wishes

met more effectively. Of course in each case the home owners had to be happy to adopt the change too, especially as there are cost, training and other resource implications. Acton Court was one of two homes owned by a former nurse, whilst Birchwood was part of a large group of several hundred homes UK wide.

Helen explained how a meeting is held about once a month to code residents on the A to D continuum, which helps to prompt a more detailed discussion with residents and or their families about how things should progress as health deteriorates. Once residents are coded 'C' something like a chest infection might be the trigger for a deterioration which:

*It's either resolved or it's not resolved. So that's when the drugs are sat waiting and then when they are dying you know we have to make sure that's where they want to stay; (typically) they don't want to be sent into hospital. I'm really, really fortunate here because my register, the majority of relatives want to have the residents stay here: they don't want (them) to be sent into hospital to die. (Helen, Manager, 2)*

Part of the study involved the pilot of instruments to measure confidence in, perceptions of and attitudes to the new frameworks. All respondents were from the two care homes at the start of their programme to adopt the Gold Standards Framework. Since exposure to these developments was variable depending on previous experiences, when asked if they understood the GSF for end of life care their responses were relatively uniformly spread between no confidence and very confident (Chart 1). Unsurprisingly, when comparing the two groups of staff (Chart 2) the HCAs were more likely to possess no confidence compared to the qualified staff (HCAs 36.4% v RN 10%) and conversely the nurses were more likely to state that they were very confident (HCA 18.2% v RN 30%). (NB the percentages on the horizontal (x) axes indicate strength of response)

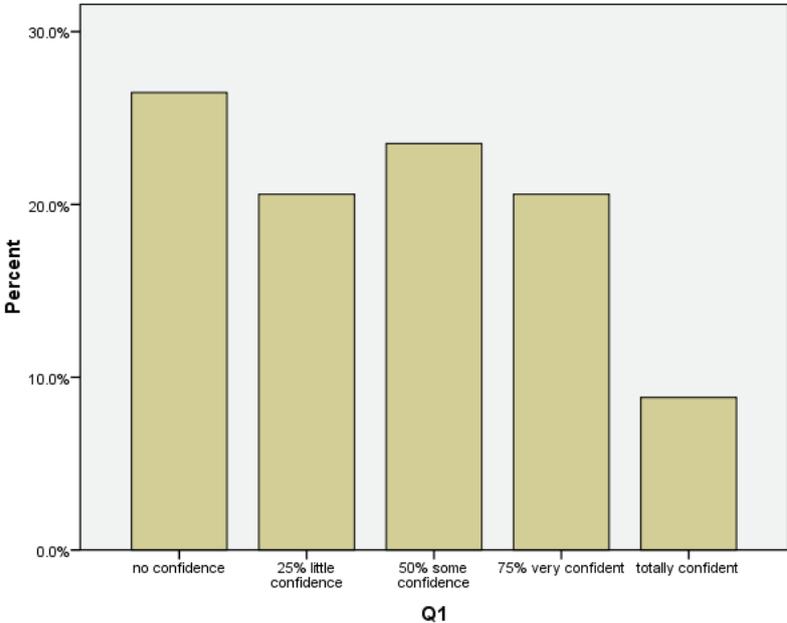


Chart 1: Baseline care home staff confidence in their understanding of Gold Standards Framework (N = 32)

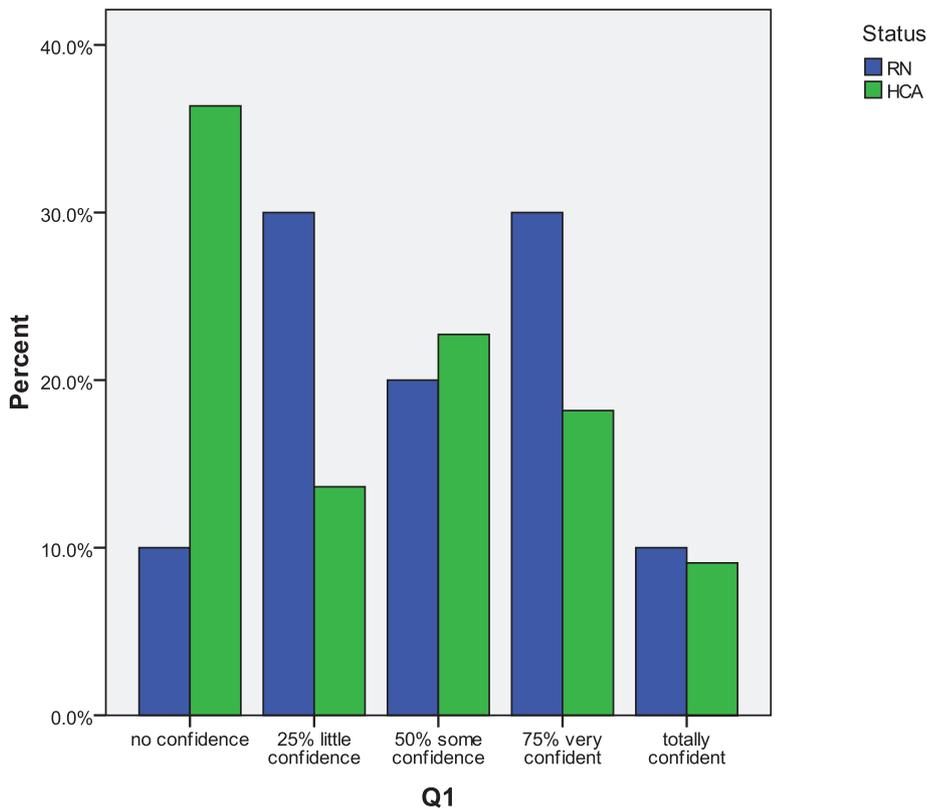


Chart 2: Baseline comparison of Registered Nurse and Health Care Assistant Confidence in their understanding of the Gold Standards Framework (RNs N = 10, HCAs N = 22)

## Diagnosing dying and using the Liverpool Care Pathway

Much of the practical planning in using the GSF is based on an attempt to diagnose or predict the dying state. In some forms of end stage malignant disease the ‘trajectory’ of death is said to be more predictable, less ‘relapsing’, but in the long term conditions endured by many nursing home residents such as dementia, heart failure, chronic airways disease and stroke, this dying ‘trajectory’ is much more difficult to estimate. The purpose of the monthly review meetings (or more often if needed) is to try to classify residents so that plans for anticipated death can be made. These might include discussions with relatives about preferences for or against the nursing home, or elsewhere, as the preferred place of death. The plans would also include notification of the GP and Pharmacy that suitable ‘end of life’ symptom management and pain relief are needed.

The official Liverpool Care Pathway (LCP) criteria were based on the best evidence at the time but are clearly open to a good deal of interpretation and only apply in the context of a definitive diagnosis of a ‘terminal’ condition (Ellershaw and Wilkinson 2003):

- The patient is bedbound
- Only able to take sips of fluids
- Semi-comatose

- No longer able to take tablets

As we have suggested, many conditions are ‘terminal’, but at different and rather unpredictable rates. The actual estimation is somewhat intuitive, so nurses and care staff learn from experience and pick up signs.

Prior to the substantive training package, when asked to assess their confidence in using the Liverpool Care Pathway over half of the group (51.5%) stated that they had no confidence in their understanding of the pathway. Only 6.1% of respondents felt totally confident. Once again this figure was unevenly distributed between the two groups with 76.2% of the HCA having no confidence compared to only 10% of the nurses. However the nurses were not completely confident in their understanding of the care pathway with 70% of nurses answering that they possess either little or only some confidence.

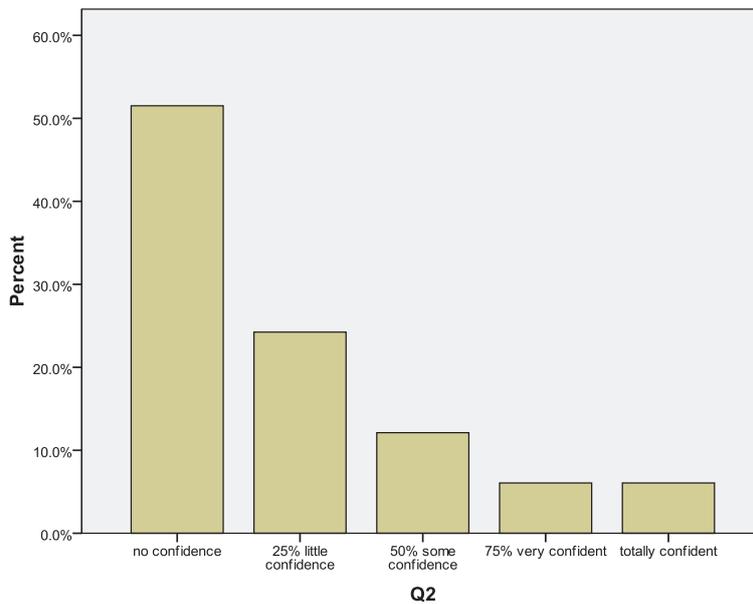


Chart 3: Baseline care home staff confidence in their understanding of the Liverpool Care Pathway (N = 32)

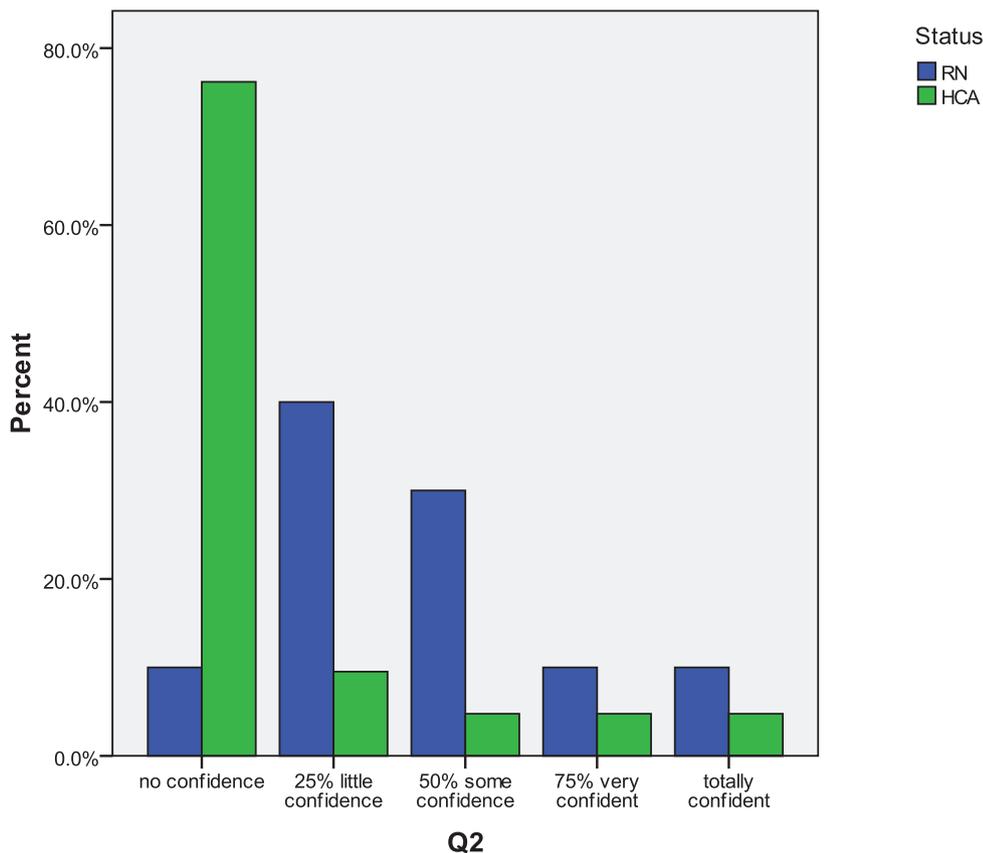


Chart 4: Baseline comparison of Registered Nurse and Health Care Assistant Confidence in their understanding of the Liverpool Care Pathway (RNs N = 10, HCAs N = 22)

Ghazala (RN, 164) explained carefully how a progressive deterioration might occur over a few days or weeks. For example with one resident with dementia, her daughter would come daily and help with food and drinks, which gradually her Mum stopped taking saying 'I don't want it, I don't want it'. Despite this she kept her mobility for some time, walking about, but declining medicines.

In such a situation medical and to some extent nursing training would encourage a belief that a hospital assessment would be the right thing, since the process might potentially be reversible, such as a chest or urinary infection. In this case, however, the daughter was adamant that her Mum would not want to be in hospital in this state, in fact she said: 'My Mum's fed up now' so once she was unable to get out of bed it was accepted that this was a dying state, not a treatable illness. But even in this situation when on the Liverpool Care Pathway nothing is certain. Another RN, Abida, (171) put it like this:

*But this lady is... the radiation of life, one day she's down other day she is pick up and like this is going. It's about one week already now.*

The phenomenon of 'bounceback' is commonly experienced in nursing homes when someone whose death is expected with virtual certainty appears to rally and defies realistic planning for death. Dave spoke of how his Mum's repeated admission to hospital with bladder infections had become tiresome in the context of advanced Alzheimer's disease, yet one could understand staff wanting to deal with an ostensibly treatable condition.

Dave however, was well aware of his Mum's experiences of caring for her own mother with advanced dementia which had led her to say: *'If that ever happens to me, put me down'*. Dave had thought deeply about these questions and was well aware of the difficulty of having hard and fast rules of what to do in each circumstance, but retaining a focus on quality of life if possible.

Manager Helen pointed out how sometimes you know people are near the end whether or not they meet the LCP criteria:

*One lady that died was a lung cancer and I wanted to do...I wanted the drugs and he (GP) came out to see her but she didn't meet any of the criteria. You know, she was talking, she was sat up but you know on intuition: you just know don't you? And after being a nurse for some time you do get to know and I went, 'No, I really want pathway drugs for this lady'.* (Helen, Manager, 8)

Perhaps rightly the GP was cautious, but came the day after and prescribed Diamorphine. He could see what Helen could see and that the weekend would be difficult for the lady without the prescription.

We had met 86 year old Annie Jones in the day room chatting about her early life. Although her two sisters had worked in the offices and her brother who was a 'tattler' couldn't understand her enthusiasm for the mill itself. Reluctantly her brother took her along and *'as soon as I got in I liked it, yes!'* (Annie, Resident, 76). Annie had been a weaver and found it noisy and dangerous, but fun, making lots of friends. Seemingly well at this point, and certainly with a very good memory for historic events, Annie had come into the home for a 'holiday'. In reality she was expected to deteriorate in due course and sadly, but a few weeks later, her inoperable deep pelvic tumour had led to her being gravely ill. She was now enduring malignant erosion by the cancer of her perineal region, an ulcer had suddenly invaded her rectum and led to pain and constant leakage of faecal material through a large fistula.

As much as we are more honest about their situation with people these days, it seemed merciful that Annie didn't fully comprehend her situation. She was now on the Liverpool Care Pathway and was under sedation to relieve pain and terminal distress. Rather like her namesake (Annie) in the study of a hospice by Julia Lawton (2000), the consequences for other residents of the foul-smelling exudate were such that Annie had been moved to an upstairs side room, where fans and air fresheners could be deployed to minimise (but not remove) this aspect. One of the nurses explained how this genuinely terminal phase was much more predictable:

*... I was told she would die today, you see, because I can see, I have loads of experience, loads of discolouration starting from the feet, going up, because of no more oxygen, oxygen saturation, it was that night, I always check her every hour, thirty minutes, just going up, I noticed there was discolouration, oxygen already from lower extremities, and when it was 8.00 o'clock in the morning, already up to here, up to the thighs, I told the next nurse she will go, she will go today, hopefully, and 11.00 o'clock she died.* (Dalisy, RN, 40)

It can be seen that, understandably, Dalisy was expressing hope that Annie would die earlier than later, despite anxieties in the context of the LCP that it is sometimes used to legitimise the ending of life when it may not be clinically necessary (Devlin 2009).

## Awareness of Dying and 'The Conversation'

Awareness of dying is a fundamental concept in the early work by sociologists coming to grips with the experience of terminal care (Glaser and Strauss 1965). At a time when in Western hospital culture patients with difficult or terminal conditions were routinely prevented formally from knowing their diagnosis and prognosis, they identified in the state of 'closed awareness' that some patients certainly did not know these things to which the staff were privy. In suspicion awareness other patients had worked out that they probably had a terminal diagnosis, but staff might not confirm it. Mutual pretence allowed both parties to know the truth, but protected both from having to discuss it. Talking about the future is a professionally challenging aspect of the work of caring for the dying which they called 'sentimental work', a concept not unlike 'emotional labour'. In the relatively rare situation of open awareness patients and staff exchanged information about the situation.

Together with the openness of the 'hospice movement' in general the influence of Glaser and Strauss in opening up awareness in 'Western' medicine is very great. Nevertheless, speaking directly about death as such remains relatively rare in the nursing homes. Rather, euphemisms are used, not with intent to deceive, but to 'soften' the emotional impact of the information. Manager John explained how 'poorly' was used to portray a deterioration which might result in a resident's death:

*If there's any change, somebody becomes unwell, we always have to contact the family anyway and say 'Oh you're mum's poorly, you're father's poorly', whatever, and at that point as well we'll talk about the GSF. (John, Manager, 101)*

Where practical staff would try to be honest with residents about their situation, but this was problematic in those losing capacity from dementia, such as Ursula for example:

*Yeah, with the Dementia patients, with that side of things I don't think she knew what was going on from one minute to the next most days. She would have her good days which you could sit and talk to her. We were very honest with her.*

*... But being honest with you, there was only so much she would understand and she would forget it twenty minutes later and she'd be asking us this every day. It was a bit frustrating, not on our part but must be frustrating for her; asking the same question and being told the same thing all the time. (Karen, HCA, 26)*

HCA Danielle (116) confirmed this:

*Yeah, it is tricky, but some of them do, yeah ... they have their up days and their down days just like everybody does ... they have some moments of complete clarity where they suddenly realise exactly what is going on, but then other times they're not so sure.*

This moving in and out of awareness, especially of being near to the end of life, and variable capacity to make decisions clearly has implications for advance care planning, in that a decision made one day might not have a permanent currency.

Residents with long-term conditions other than dementia will often be more aware of their situation. We have mentioned Sam who had end stage heart failure and was clear about his wish to remain in the home and to face death there. The staff nurse informed us that on admission Sam had been expected to have about four 'weeks to live'. In the event he was

there eight months later, and living with this uncertainty and enduring great fear and discomfort from day to day for so long was a great burden:

Int: *That's right. Now can you tell me a bit more about Sam? He was a difficult case, wasn't he?*

Karen: *Sam?*

Int: *Yeah, that's right. He would be sort of went up and down quite a bit. He'd be very ill and then he would bounce back a bit and eventually it caught up with him but he seemed to know a lot about the future, didn't he?*

Karen: *Yeah. He was very with it. ... Didn't have any dementia or anything like that so he knew what was going on and you could tell sometimes because he did feel quite depressed. He knew he was here and that was going to happen to him eventually and that would get him down. There would be days where he wouldn't eat, lost interest to eat and we'd just have to sit and persuade him. Tell him he's got his family round him. That's something to look forward to because he did used to cheer up when his family came to see him.*

Int: *But he was going to die here without being taken into hospital, wasn't he?*

Karen: Yes.

Heart failure in such cases tests the 'criteria' beyond their capability at present. They are crude and a guide at best. Although on most days Sam was bedbound and sometimes semi-comatose, when he would be capable only of sips of water and no food, on other days he would 'bounce back' and be well away from meeting the LCP 'final days' criteria. Yet even on good days his most distressing symptoms were breathlessness, inability to swallow safely, and extreme anxiety about the discomforts of dying. He was being given oxygen, for example, not in order to prolong his life but to relieve the agony of breathlessness. It was clear that the staff spent a great deal of time with Sam doing their best to deal with his physical symptoms and especially talking to him about what may happen, having 'the conversation'. The home manager, Helen, led this process by example, but it was never easy, indeed it exemplifies why in some contexts this type of emotional labour is avoided. It's very challenging.

We spoke to 83 year old resident Gladys who had come into Acton Court because she had few local relatives and had suffered a disabling left-sided stroke (she was left handed). Now that Gladys had found she also had an inoperable lung cancer she made it clear that two nights previously she and her son (aged 59) had had a long conversation with manager Helen about what should happen next. She seemed remarkably stoic, perhaps because she felt that she had no worrying symptoms yet from the cancer. She kept herself busy watching TV and reading Catherine Cookson novels which she observed, though enjoyable, *'all end the same way don't they?'*

For the research team, asking residents about their feelings in this respect was also something of a challenge. Originally from the Southwest of England Gladys had pointed out that she was somewhat estranged from her seven brothers and sisters. We asked *'Have you made any friends here?'* to which she replied *'Yes, she was cremated yesterday'*. Gladys explained that having got over a bowel cancer with major surgery her 63 year-old friend had then had a heart attack and never recovered. She seemed to say

that an amount of uncertainty about when and where one might die was a good thing: *'It's a good job we don't know what's going to happen'*. (Gladys, Resident, 91)

Clearly, although a good deal has been achieved in talking about the likelihood of death in some conditions, there is little certainty about the future for people when gravely ill with heart failure or end stage dementia. This makes both discussion of the resident's future and the application of criteria for 'end of life pathways' problematic both for nursing home staff, GPs and the people who are facing death.

The discussion above draws heavily on the experience of Helen and Colleagues at Acton Court, where they had experience of using the GSF and the LCP. When we piloted our survey with staff in the two 'baseline' care homes (Birchwood and Catherine House) respondents were asked how confident they were to take part in a discussion with residents and families about end of life care. A third (33.3%) had some confidence with the remainder of responses being equally distributed across the range. The nurses were more confident with 50% stating they have some confidence and a further 30% stating they are totally confident. The health care assistants were less confident with 22.7% not having any confidence but with a further 22.7% having some confidence and a further 13.6% being totally confident.

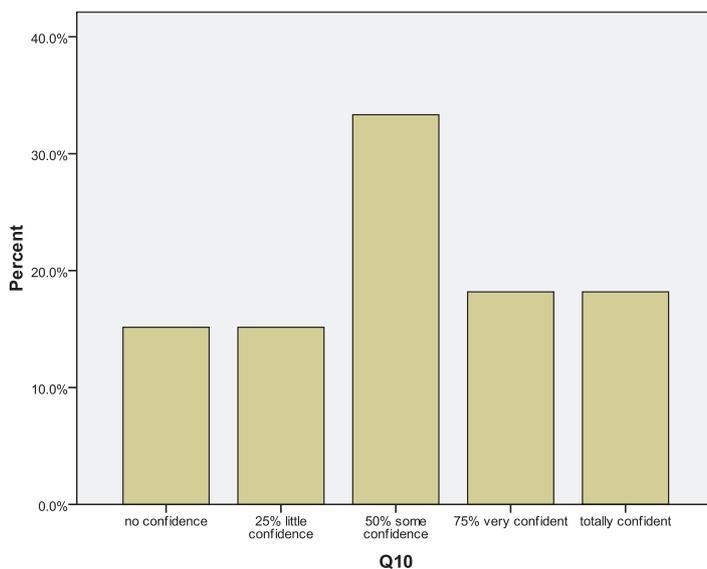


Chart 5: Baseline care home staff confidence in their ability to take part in discussions of end of life care with residents and their family (N = 32)

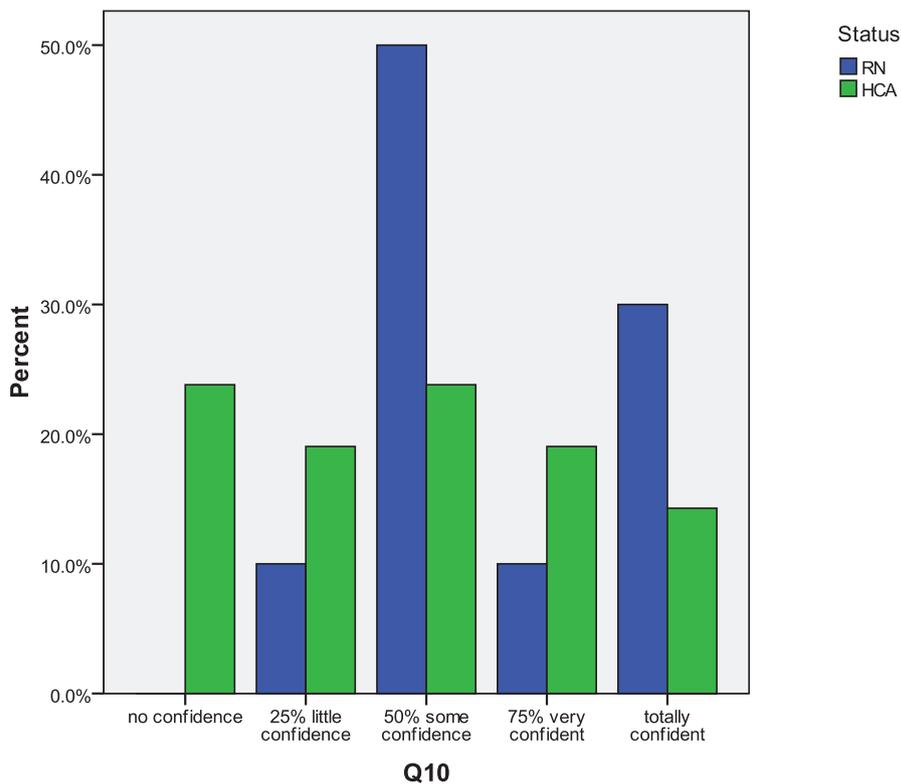


Chart 6: Baseline comparison of Registered Nurse and Health Care Assistant Confidence in their ability to take part in discussions of end of life care with residents and their family (RNs N = 10, HCAs N = 22)

### Dying itself

Generally speaking, nurses and care assistants are familiar with death. Much practical nursing education still takes place in hospital practice which we know to be a common, if imperfect, place to die. Most experienced care workers have looked after people in the dying phase. On the other hand, for many but not all relatives the death of a loved one is a new, or at least rare experience.

Borrowing from the hospice movement, the Gold Standards Framework sets out to allow people to ‘live until they die’ and both nursing homes had this philosophy firmly in view. Although they had yet to adopt the GSF approach across the home, the manager of Birchwood felt that the company were very supportive of the approach, as was the manager of Acton Court, the owner of which had just the two homes.

Resident’s Daughter Sue was resigned to her Mum dying in the nursing home, but recognised that the dying process was unpredictable and possibly lengthy:

*My younger daughter just thinks because I keep saying, ‘Oh I don’t think my mum’s going to be here that long’. (She replies) ‘Mum you’ve been saying that for two years now and she’s still here’. (Sue, Daughter, B 52)*

In the context of this uncertainty she suggested that this ‘living till you die’ approach meant retaining the simple things as long as possible:

*To me it's just the absolutely basic needs because that's all my Mum's got now in her life, it's having cuppa tea when she wants, making sure the pad is changed and that she's not in a wet pad all day and... feeding if she's... because with that we're feeding her I don't know how it works. I don't know if they can keep like, if she was in, at home I'd probably give her yoghurt, not that she won't eat that. A glass of milk, if not that something else. (Sue, Daughter, B 52)*

HCA Denise had 12 years experience at Acton Court and had even begun her nurse training, but left to have a child. She explained how some residents chose not to eat almost as a feature of their 'decision to die':

*I mean one lady we had here, to me, was a prime example. She'd been with us quite a while, sitting in the end chair, her name was Olive... and this particular day, she just said to me I really don't feel well, I really don't feel well. I said it doesn't matter Olive, come on, I'll take you to bed. So we put her into bed, gave her a drink, came in the next morning, and she loved Weetabix...*

*... that's what she had for breakfast. So I've gone to give her the Weetabix, and she had a couple of spoonfuls, and then she just looked at me and said 'No, No more.' And that was her. Didn't eat or drink, for a couple of days, and that was it. (Denise, HCA, 29)*

Nutrition is a contentious aspect of the dying process, not least because losing the ability, or refusing to eat or drink is a key criterion of being graded as on the Liverpool Care Pathway. No-one wants the dying to feel hungry, or thirsty, and yet using technology such as nasogastric (NG) or percutaneous enterogastrostomy (PEG) tubes or 'persuading' the frail to eat is now increasingly regarded as the wrong thing to do. It is now 30 years since a Swedish team led by Norberg argued that forcing patients with end stage dementia to eat and drink was often not in their interests (Norberg et al. 1980). Whilst understanding this approach, HCA Lorna identifies that in the case of individuals, whether to give food and especially drinks 'on the pathway' is not so clear cut:

*It (The Liverpool Care Pathway) is helping but the thing we're not sure about is, and again, when you're doing, stop giving this food, nothing to eat. We're not sure at what stage now to stop giving food because that lady who passed away, we (were) giving her drinks, she was still drinking until the district nurse came and said, 'No, No, No don't give anything', and I said, 'Why? She's still drinking'. I was thinking we can give until she... (Lorna, HCA, B62)*

Strictly speaking the Liverpool Care Pathway would only be in use if the person was 'semi-comatose', but the latter defies easy interpretation in day-to-day practice. The advice of the district nurse here was no doubt given in good faith, traditionally people at this end stage were coerced to take fluids and food (Norberg et al, 1980), so it is easy to see how collaborative working can require time and negotiation for consensus to be reached on the best way forward for each individual. Such time is scarce.

Son Dave spent a good deal of time at Birchwood helping with his Mum who had Alzheimer's disease, and other residents. A little unusually he had thought about his Mum's future:

*...my feeling is that the condition that my mum is in, I couldn't write down a plan that says under the following circumstances, the following things should be done, because it's really*

*a question of what's the best quality of life, you know that she can't survive the condition and therefore, it's what's the best quality of life..... You got the same sort of thing, what upsets people is when someone is ... their relative is whisked off to hospital, because they know how distressing that is and they know that there was no choice ... they have no say in it and they have no say in it because nothing was written down. (Dave, Resident's Son, B101)*

Dave acknowledged that sometimes residents with severe dementia might present a challenge to staff when they suffered from potentially remediable conditions. Overall, however, he felt that the quality of life in this situation was more important than perhaps extending life for a few weeks or months.

Kathleen explained that her feelings about her Mother-in-Law's situation were coloured by her experiences of seeing her own father die uncomfortably. She remembered saying to the nurses at the time she felt guilt at expressing her feelings:

*I know when my Dad was dying, I sat there with him all through the night, and I'd say "Oh please God, take him, just don't let him have to go through another day" and then I'd go home and think, "That must sound awful to people." But to me that wasn't my Dad there anymore. That person had gone ... (Kathleen, Daughter in Law, B78)*

Having accepted the inevitability of death, relatives Dave and Kathleen clearly wanted to reduce the suffering, both their relatives' and their own, to a minimum. Nurses too try to have this aim, but it must be balanced with a responsibility to avoid complications. On the one hand there is great stigma to allowing a 'patient' to develop a pressure ulcer from not being turned from side to side sufficiently, usually 2-hourly. As we can see, Denise felt this dilemma acutely in caring for a lonely older lady approaching death:

*This lady was with us for about 2 years, and nobody (relatives) ever came. At Christmas time the staff used to buy her bits and pieces, just social... anyway she was dying, and all the staff take time to sit, we all sit for an hour or so to make sure, especially with no relatives, and I remember it was summer, it was beautiful, it was really warm, and I was sat with her, and one of the them came up and said 'have you got any breaks, because we want to turn her', and I said 'I don't think she'll turn, not at this stage, no'. Because what damage could be done? It's not going to matter, it really isn't. It's not worth disturbing her, there was no point, because she was just going to slip away. (Denise, HCA, 33).*

Such judgments are fine ones. Compared to other complications, such as urinary or chest infections which might be less easily attributed to 'poor nursing' nurses greatly fear the discovery of pressure ulcers which might have arisen on 'their watch'.

## **Discussion and Implications for Practice, Education and Research**

In Ivan Illich's brilliant challenge to the medicalisation of death he argues:

*"Today, the man (sic) best protected against setting the stage for his (sic) own dying is the sick person in a critical condition. Society, acting through the medical system, decides when and after what indignities and mutilations he (sic) shall die. The medicalization of society has brought the epoch of natural death to an end." (Illich, 1976 p 207)*

It is clear that admission to hospital is appropriate for some medical and surgical 'emergencies' late in life, anything else would be ageist and unfair. What residents, and where they lack capacity, their advocates such as relatives, professionals and other care workers must try to bear in mind, is the likelihood of at least months and hopefully years of life worth living if such admission takes place. The Gold Standards Framework is an attempt to allow human life to end naturally, as peacefully and free of distressing symptoms as possible in a location and surrounded by people well known to the dying person and their family. If this cannot be the person's own home, and many would find this difficult, increasingly in the UK and elsewhere this may be a nursing or residential care setting. This report draws out some key challenges which became evident during an evaluation of the GSF Education Programme as it was experienced by nursing home staff and residents in two nursing homes.

First is the provision of strong clinical leadership and motivation necessary to take responsibility for the dying process in such settings. This needs to be supported by General Practitioners, specialist palliative care nurses and consultants who can and will visit the nursing home, and where appropriate specialist community nursing and pharmacy services. These factors do not regularly come together. Acton Court and Birchwood are regarded by the Care Quality Commission and the Primary Care Trust Managers as being well above average, which is why they were supported to seek GSF registration. Only a small fraction of the 53 Nursing and Residential Care Settings in Salford have taken up the Gold Standards Framework approach and not all of these have succeeded. We must wonder what care at the end of life is like in the homes not so well regarded.

Second, even in settings which work well with advance planning for end of life care, ensuring consistency of approach by 'out of hours' GP services and even the nursing staff in the home is difficult. All too often residents with, for example, late stage dementia find themselves in hospital. In such cases staff and outsiders have defaulted to the sequestration of death (Lawton 2000), or at least people at high risk of death, into hospital care. Admission to a hospice is very unlikely and especially in this group of patients. This may be partly explained by a culture in which hospital care is seen as safer and less likely to attract criticism from relatives or peers, but also a place in which the provision of equipment, specialist expertise and knowledge are seen to be concentrated when 'out of hours' nursing homes may rely on inexperienced and temporary or bank staff.

Third and perhaps of greatest challenge is the difficulty of diagnosing, predicting and planning for death itself. The tools and criteria provided by pathways and frameworks are suitable steps forward, but despite its fallibility in cases of 'bounce-back' nothing outranks the experience and intuition of strong clinical leaders. Glaser and Strauss (1965) identified the state of 'closed awareness' in which some patients certainly did not know what the staff and their relatives knew. In 'suspicion awareness' patients had worked out that they probably had a terminal diagnosis, but staff might not confirm it. 'Mutual pretence' allowed both parties to know the truth, but protected both from having to discuss it. Talking about the future is a professionally challenging aspect of the work of caring for the dying which Glaser and Strauss called 'sentimental work', a concept not unlike 'emotional labour' Smith (1992). In the relatively rare situation of open awareness patients and staff exchanged information about the situation.

We identified three key areas which need to develop in order to provide high quality end of life care:

- care planning

- communication and
- collaboration and coordination

The GSF programme includes tools and techniques which can be used to improve all these key areas. Care planning is essential and requires holistic and on-going assessment, followed by advance care planning for all residents. GSF assessment tools and care pathways should be used as standard practice to improve care planning and documentation. Care planning by care home staff should also include proactive, early involvement of GPs, primary care staff and relatives. Shaw et al (2010) whose study is co-authored by members of the GSF implementation team, a conflict of interest they duly acknowledge, reviewed 15 studies which had in one way or another evaluated the GSF framework in use. They concluded that the framework has considerable potential to improve end of life care but further work is necessary to support uptake, which is certainly true in nursing homes.

Communication is crucial; *'Having the conversation'* emerged as the core theme in this study. End of life care includes the need to involve, discuss with and listen to those approaching end of life or their closest carers; talking openly about end of life care needs and preferences requires knowledge, skill and confidence. Staff providing end of life care need to have the necessary attributes to deliver high quality end-of-life care (DH, 2009); currently high quality education and training are not routinely provided to non-specialist staff providing this care to residents in care homes. The provision of appropriate knowledge and skills needs to be addressed in both preregistration and post registration healthcare professional preparation and also provided to care home care support workers.

Collaboration and coordination are essential for improved team working both within the care home and between other care providers e.g. GPs, out of hours; primary care and specialist palliative care staff. Communication is crucial to this process; using GSF tools and pathways can facilitate communication in end of life care (McClelland et al, 2008). Lack of communication and understanding of changes in the provision of end of life care in care homes were barriers to improving the quality of end of life care in care homes. Providing interprofessional end of life care education could address communication, collaboration and coordination issues at the same time as developing healthcare professional's knowledge and skills.

Appropriate resources and training are required to ensure that high quality end of life is provided to everyone irrespective of the care setting. Education is a crucial aspect affecting the provision of high quality care; however, education alone will not be sufficient to change practice. Working practices, systems and culture also need to change so they support the principles of person centred end of life care.

## **Afternote**

The fact that end of life care has become a government policy priority is clear. What remains elusive is a clear understanding of how we can maintain and improve the quality of care that sadly many of us will need in later life in nursing and residential care homes. It was clear to the research team that this is a rich area for investigation and improvement. With more time and more than our 'pilot' budget we would have explored both the field and our data in greater depth. In the event we devoted greatly more time and energy to the project than the new financial accountability and managerialism in universities will allow. It will be important to undertake studies in homes where care quality is thought to be less than optimal, preferably action research studies in which we move beyond observation and description to involvement and change for the better. We will do our best to secure support to this end.

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## Appendix 1

Code	
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# Staff Confidence and Perceptions of Care Planning at the End of Life

We are nurse researchers carrying out a study into care planning for the end of life. It has been approved by the University of Salford Research Ethics and Governance Committee and Care Home Managers. You may be assured that all the information you give will be **COMPLETELY CONFIDENTIAL**.

Please be as honest as you can in answering the questions as there are no **RIGHT** or **WRONG** answers.

### SECTION 1

The following statements are descriptions of the possible effects of Care Planning at the end of Life.

Please read each statement carefully and decide whether you **AGREE** or **DISAGREE with** that statement. In all cases the statement relates to the process of **PLANNING CARE AT THE END OF LIFE**

If you **HAVE STRONG AGREEMENT OR DISAGREEMENT** with the statement, please tick the **STRONGLY AGREE** or **STRONGLY DISAGREE** column.

If you really cannot decide, then tick the **DEPENDS** column, although whenever possible we would prefer you to tick one of the **AGREE OR DISAGREE** columns if you can, since we are interested in an overall impression. If the statements do not apply to your role then please tick **NOT APPLICABLE**

		Strongly agree	Agree	Depends	Disagree	Strongly disagree	Not applicable	Office use only
	<b>Example: Florence Nightingale was an important leader</b>	✓						
P01	Residents/ patients want to be involved in care planning							
P02	Residents/ patients should not be involved in care planning							r
P03	Families want residents to be involved in care planning							
P04	Families do not want to be involved in care planning							r
P05	Care planning takes more time than we have							r
P06	Care planning allows residents to express their preferences for care							

		Strongly agree	Agree	Depends	Disagree	Strongly disagree	Not applicable	Office use only
P07	Care planning increases resident involvement in their care							
P08	Care planning does not result in individualised care for residents							r
P09	Care planning improves communications between residents and care home staff							
P10	Care planning could harm communications between residents and their family							r
P11	Care planning will improve care quality							
P12	Care planning will upset residents unnecessarily							r
P13	Care planning can clarify residents' care preferences							
P14	Care planning ensures that residents wishes are considered							
P15	Health care professionals know what care is best for residents							r
P16	Health care professionals do not always know what residents want							
P17	Health professionals cannot plan what care is best for residents/ patients alone							r

**Is there anything you would like to say about involving residents in End of Life Care Planning? If so, please add your view here.....**

**THANK YOU.** That is the end of Section 1.

## **SECTION 2**

The following 20 questions relate to levels of confidence in your knowledge and ability to plan care at the end of life using various tools and approaches. Please try to estimate your current level of confidence in relation to each item.

		<b>100% Totally confident</b>	<b>75% Very confident</b>	<b>50% Somewhat confident</b>	<b>25% Little Confidence</b>	<b>0% No confidence</b>	Office use only
	<b>How confident are you that you understand:</b>						
C01	The Gold Standards Framework (GSF) in Care Homes?						
C02	The Liverpool Care Pathway for the Dying?						
C03	Preferred Priorities for Care?						
C04	Advance Care Plan e.g. GSF Advance Care Plan?						
	<b>How confident are you that you can:</b>						
C05	Identify residents needing end of life care using Gold Standard Framework coding A,B,C and D?						
C06	Assess residents needs, symptoms and preferences ?						
C07	Plan end of life care around residents' needs and preferences?						
C08	Provide/ deliver end of life care to a high standard?						
C09	Help to monitor and report end of life care?						
	<b>How confident are you that you can communicate with residents about end of life care preferences:</b>						
C10	Take part in the discussion with residents and family?						
C11	Collect the information needed to plan care?						
C12	Handle difficult questions or refer them to senior staff?						
C13	Handle the emotions that may follow						

		<b>100% Totally confident</b>	<b>75% Very confident</b>	<b>50% Somewhat confident</b>	<b>25% Little Confidence</b>	<b>0% No confidence</b>	Office use only
	discussions about end of life?						
C14	Recognise that residents' have concerns about their future?						
C15	Support the resident to explore their' concerns?						
C16	Respond to residents' concerns?						
	<b>How confident are you that you can support residents to explore their':</b>						
C17	Understanding of what is happening to them?						
C18	Concerns about their care?						
C19	Preferences for their current care?						
C20	Preferences for their preferred place for end of life care						
	<b>How confident are you that you can:</b>						
C21	Talk with colleagues about residents' end of life care plans?						
C22	Talk with family members about residents' end of life care plans?						
C23	Talk to health professionals outside the care home about residents' end of life care plans?						
C24	Communicate with the 'Out of Hours' Services?						
C25	Challenge colleagues who do not follow residents' care plan?						
C26	Challenge health professionals from outside the care home who do not follow the residents' care plan?						
C27	Seek help from a Care Home or PCT End of Life Care Lead?						

**THANK YOU.** That is the end of Section 2.



## **Appendix 2: Dissemination to date**

### **Presented 11 papers on methods and outcomes as follows:**

Jones, I., Attree, M. Johnson, M. (2009) Evaluating Gold Standards Framework Implementation in Salford Nursing Homes. Royal College of Nursing, Nursing Older People Conference, April, University of Salford

Attree, M., Johnson, M., Jones, I. (2009) Where are we up to?: A Review of End of Life Care in the Curriculum. Nurse Education Tomorrow Conference, Cambridge, September

Jones, I., Attree, M. Johnson, M. (2009) Evaluating Gold Standards Framework Implementation in Salford Nursing Homes. National Care Homes Research and Development Network, University of Manchester, June 09

Johnson, M., Attree, M. (2010) Evaluating the impact of education on the practice of End-of-Life care planning and delivery in care homes in the UK NETNEP, 3<sup>rd</sup> Elsevier International Nursing Education Conference, Sydney, Australia. (Johnson was funded from other sources, the project made a contribution to Attree's expenses)

Johnson, M., Attree, M. (2010) Evaluating the impact of education on the practice of End-of-Life care planning and delivery in care homes in the UK. RCN Research Society Conference, the Sage, Gateshead, UK

Attree, M., Johnson, M. (2010) Methodological Pearls and Pitfalls: using Realistic Evaluation to evaluate the impact of end-of-life care education on practice in care homes in the UK. RCN Research Society Conference, the Sage, Gateshead, UK

Attree, M., Johnson, M. Jones, I., (2010) Evaluating Gold Standards Framework Implementation in Salford Nursing Homes, University of Manchester School of Nursing and Social Work, March 2010

Attree, M., Johnson, M. Jones, I., (2010) Realistic evaluation to evaluate the impact of end of life care education on practice in care homes. Nurse Education Tomorrow Conference, Cambridge University, September 2010

Johnson, M., Attree, M., Jones, I., and Al Gamal, E., (2010) The end of life care continuum: being practical and facing up to challenges for the curriculum. Nurse Education Tomorrow Conference, Cambridge University, September 2010

Jones, I., Attree, M. Johnson, M. (2011) Evaluating Gold Standards Framework Implementation in Salford Nursing Homes. April, First Erasmus funded HUROPPEL (Human Rights, Older people and End of Life Care) Conference, University of Salford

Johnson, M., Attree, M., Jones, I., and Al Gamal, E.,(2011) 'The conversation': awareness and diagnosis of dying in nursing homes. RCN Research Society Conference, Harrogate, May.

### **Meetings:**

Meetings with staff at the nursing homes

Meetings with relatives at the nursing homes



**University of Salford**  
A Greater Manchester University



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**Contact: Nursing & Midwifery Research Centre**

**Jill Potter**

**Tel: +44 (0)161 295 2751**

**E-mail: [nmresearch@salford.ac.uk](mailto:nmresearch@salford.ac.uk)**

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