

StChristopher's

Family Perception of Care Audit

Progress Report March 2015



Kindly Funded by the Burdett Trust for Nursing



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Progress Report for Burdett Trust for Nursing : March 2015

1. Background to project

Against a background of increasing numbers of frail elderly people, as people tend to live longer with higher health and social care needs, care homes have been playing a larger part in providing care at the end of life. The End of Life Care Strategy (DH 2008) stressed the need for more dignified end of life care for frail elderly people, and put more emphasis on people dying in their place of choice, which for many is not in hospital. St Christopher's Hospice, a large hospice based in Sydenham, South East London, was established to provide care for terminally ill people, but a large part of their vision was to also share their knowledge and encourage research in order to spread best practice to all. In 2008, St Christopher's became the first regional centre for the Gold Standards Framework in Care Homes (GSFCH) programme, and set up the Care Home Project Team in order to deliver the necessary support and training. The GSFCH programme is a quality improvement initiative that aims to advance end of life care in care homes. Implementation of the programme is complete when the care home becomes accredited, which involves submission of a portfolio of evidence and a visit by an external assessor.

The Care Home Project Team aims to support and empower nursing home managers in the five Clinical Commissioning Group (CCG) areas that St Christopher's serves, to develop their end of life care for frail older people living and dying in care homes. Much of the work they carry out is aimed at increasing the confidence and competence of nursing and health care staff within the homes, working alongside them to encourage and empower them to provide quality end of life care. Implementation of the GSFCH Programme within the nursing care homes in these CCGs has provided a structure and enabled the delivery of this. The team work by role-modelling end of life care, attend and facilitate coding meetings, where end of life is discussed for each resident, and attend reflective de-briefing meetings for staff to learn from each resident's death. Many local nursing homes have now completed the GSFCH program, and to maintain this they need to be re-accredited on a three yearly basis. The Care Home Project Team supports them with this process and provides an on-going end of life care sustainability programme. In addition, the team offers clinical support when needed.

The geographical location covers much of South East London and includes Croydon, Lambeth, Southwark, Lewisham and Bromley. It has a population of over one million people of varying cultural and ethnic origins, and varies from inner city urban living through to green belt suburbs. The number of care homes in each CCG varies considerably. For example Southwark have four

nursing homes whilst Croydon has 32. As well as the GSFCH programme, the Care Home Project Team is now offering a separate program for residential care homes called Steps to Success. This is an adapted version of the Department of Health's Route to Success, and is currently being implemented in 24 residential care homes.

Since its establishment, the Care Home Project Team has been monitoring outcomes from the implementation of these end of life care programmes through: place of death for the residents of all the care homes it supports; evidence of advance care plans; evidence of a resuscitation decision; and evidence of the use of an end of life care plan. Year on year, there has been improvement in these outcomes. For example, in relation to the numbers of people dying within their care home at the beginning of the project in 2008 57% of residents died within 19 nursing homes. In 2014 this had increased to 76% across 72 nursing homes. This is a reduction of almost 50% in hospital deaths. Although the accreditation/reaccreditation process provides an insight to how the care homes deliver care, it does not necessarily measure the quality of the care as experienced by the residents and their families and friends. Until the introduction of the Family Perception of Care (FPC) Audit, there had been no specific regular monitoring of the quality of end of life care.

The Family Perception of Care Scale used in the audit was developed by Brazil et al (2004). It captures information about the care provided to residents in their last month of life using a three page questionnaire that utilises a Lickert-type scale. Bereaved relatives use this scale to score how much they agree with each statement. The first statement they are asked to consider is regarding whether the resident was treated with dignity. There are 25 statements, divided into five sections – resident care, family support, communication, rooming and one other section (with questions about GP services along with demographic details). There is also one open question for comments that people may wish to make. In addition, people are asked to rank three of the statements by order of importance for delivering good end of life care. This does not necessarily measure the quality of the care, but does give a good idea of how people want to be treated. The FPC Scale is a validated tool for measuring end of life care in care homes. [Parker and Hodgkinson 2011].

2. Aims of the Family Perception of Care Audit

The Family Perception of Care (FPC) Audit aims to measure satisfaction with the quality of care given to residents dying in the care home during their last month of life. It was intended that the care home staff would use the views of bereaved family members to learn about and develop the end of life care they provide. [See Audit Standard, attached at Appendix I]. The results of the audit are intended to be used within individual homes to help them put together action plans to improve their

end of life care where indicated, as well as to give staff confidence from positive feedback received. In addition, as this is a multi-centre audit with a variety of different sized homes in different locations, it was anticipated that homes could learn from each other, through discussing the results together and various options for end of life care improvements. The target was to recruit at least 42 care homes that have completed the Gold Standard Framework for end of life care in Care Homes (GSFCH) or the Route to Success program.

3. Project implementation process

The staff within the homes that had completed the GSFCH or the Steps to Success program were initially informed about the audit by the St Christopher's Care Home Project Team, and were invited to a meeting in January 2014, at the start of the project, to receive further details for participating. At this meeting they were given appropriate documentation, specific to their home, for use in the audit. Each home has an individual code assigned which is printed on to the questionnaires, so that feedback can be given to the appropriate home as well as to the whole group. The care home staff were encouraged to start to record in a book or folder details of next of kin for each resident. After a resident dies they note the date for sending out the questionnaire – three months after the date of death. A pilot of the audit prior to September 2013 found that there was a higher response rate if the care home rang the next of kin about a month to six weeks after the resident's death, to check how they are and to let them know that the questionnaire would be sent out in about six weeks. The introductory meeting included guidance from a St Christopher's Social Worker about making a bereavement phone call, and further written guidance was included in each home's audit pack.

When the homes send out the questionnaires, they are asked to include the month of death and some kind of identifying code so that there can be individual follow up, in the event that the respondent reports something that seems to need further investigation. The homes also include a stamped envelope addressed back to the Care Home Project Team at St Christopher's. Full Guidelines for participation are attached as Appendix II. The audit aims to measure levels of satisfaction with end of life care provided in the homes, and therefore only deaths that occur within the home (rather than in hospital), and those that were expected, are eligible for inclusion in the audit.

The process of the audit is shown below in Figure One:

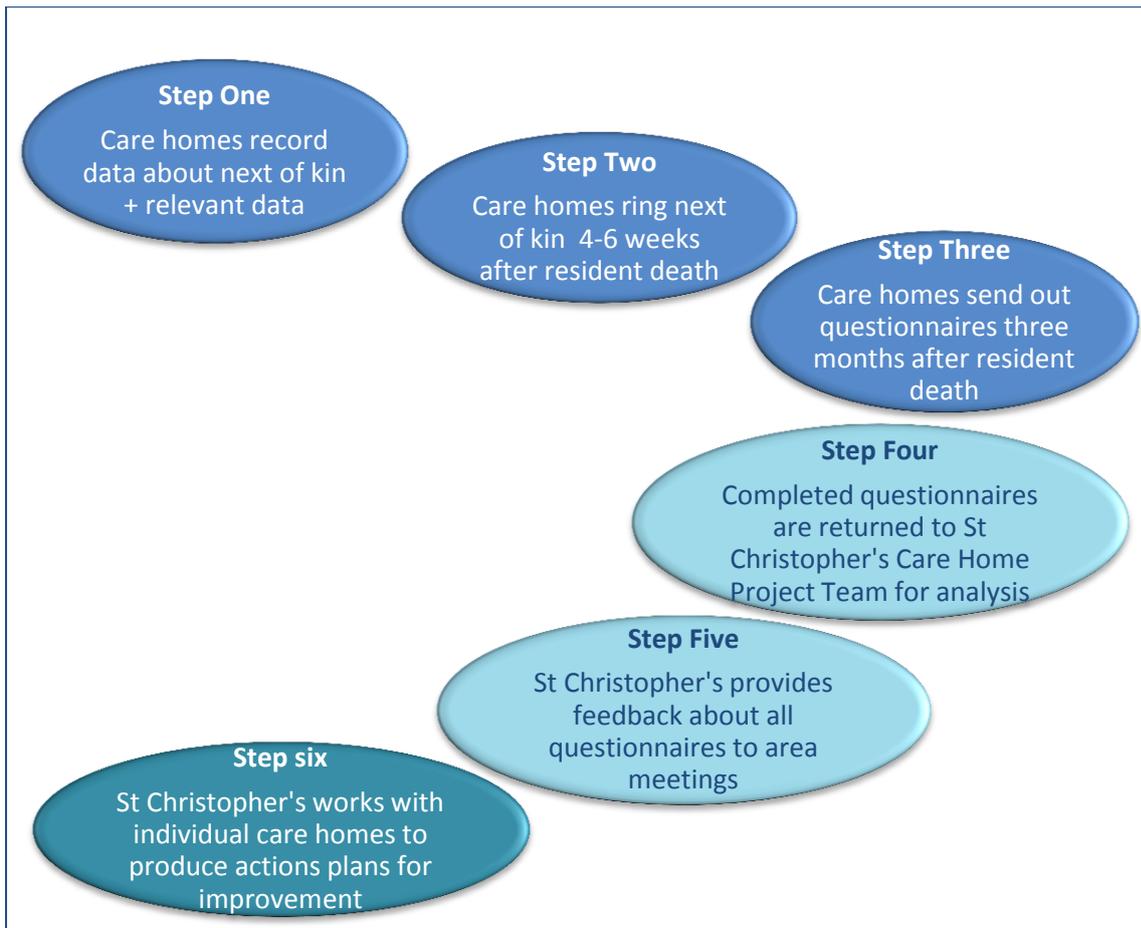


Figure 1: Diagrammatic illustration of the five steps in the audit

4. Challenges / Enabling Factors

Implementation of the audit was not without its challenges. Even where many staff were very enthusiastic about taking part in the audit, practical issues such as staff time needed to set the systems up and allocating the right person to take responsibility for ensuring the audit guidelines were followed meant that the process needed much ongoing support from the audit team at St Christopher's. Where there was criticism of any particular home, a certain amount of diplomacy was needed in delivering that news to the staff, to enable learning and development without any blame or criticism of practices. The relationships that already existed between the Care Home Project Team and the care home staff supplemented the support provided by the audit team, and meant that there was already trust and respect for the advice given by the team. There are definitely factors that can be identified that enabled the audit to become established within the individual homes, such as having had previous experience of taking part in the pilot audit the previous year, and being able to identify one person to coordinate the sending out of questionnaires. The following table (Table 1) sets out the challenges and enabling factors identified by the audit team.

Table 1: Challenges and enabling factors

Challenges	Enablers
Staffing levels/time	Support from St Christopher’s Clinical Nurse Specialists
Embedding the audit process	GSFCH accreditation
Morale in care homes	Having been part of the FPC pilot study
Response rates	Sufficient staff / responsibility allocated
Dealing with “complaint” type responses	Time
Agreeing the Action items to help improve care	One member of staff in the care home, preferably the administrator, taking overall responsibility for the audit
How to deal with issues outside of the control of the care homes	

5. Results from first year of audit

For this project, the results can be divided into those regarding recruitment to the audit and the process of implementing the audit; measuring satisfaction/using carers’ views to learn about their experience of end of life care in the homes; action plans to improve care provided; learning together and improving the confidence of those providing care; and priorities given to end of life care by the bereaved carers.

5.1 Recruitment and Progress with Audit process implementation

All care homes offered the opportunity to participate in this audit agreed to do so. The staff in the care homes were enthusiastic when they heard about the audit, understanding that it would help them develop their end of life care, and willingly committed to taking part. This resulted in the Care Home Project Team recruiting 52 homes into the audit, which was ten more than had been targeted originally: three of those homes did not eventually manage to participate during the year, mainly due to changes in management and other staff turnover.

Of the 49 remaining homes, there were 39 nursing homes and 10 residential care homes, across Bromley, Croydon, Lambeth, Lewisham and Southwark.

There were returned questionnaires from 41 (36 nursing homes and 5 residential homes). Five homes had no eligible deaths during the year, and the other three had no responses from a low number of deaths (one, three and four deaths). Much of the work of the audit team during the first six months was to visit the care homes to help them to establish systems. The homes involved are varied, some very large and others small, some independently owned and others part of corporate groups. Each home has its own systems already in place and finding a way to fit the audit in was more challenging for some than for others. Managing to support 49 homes to be actively involved in the audit is a major achievement for the project. The overall response rate across the participating homes in all five CCGs was 44%, with 224 returned questionnaires from 510 eligible deaths. This is a very good response rate for a postal questionnaire, particularly one which is only sent once, with no reminders, to a bereaved relative. Of those homes with returned questionnaires, the response rates within each individual care home varied from 13% to 100%. The response rate also varied by CCG area: Croydon had a 55% response rate, Bromley 50%, Lewisham 45% and Lambeth & Southwark 21%. Figure Two below shows the actual numbers.

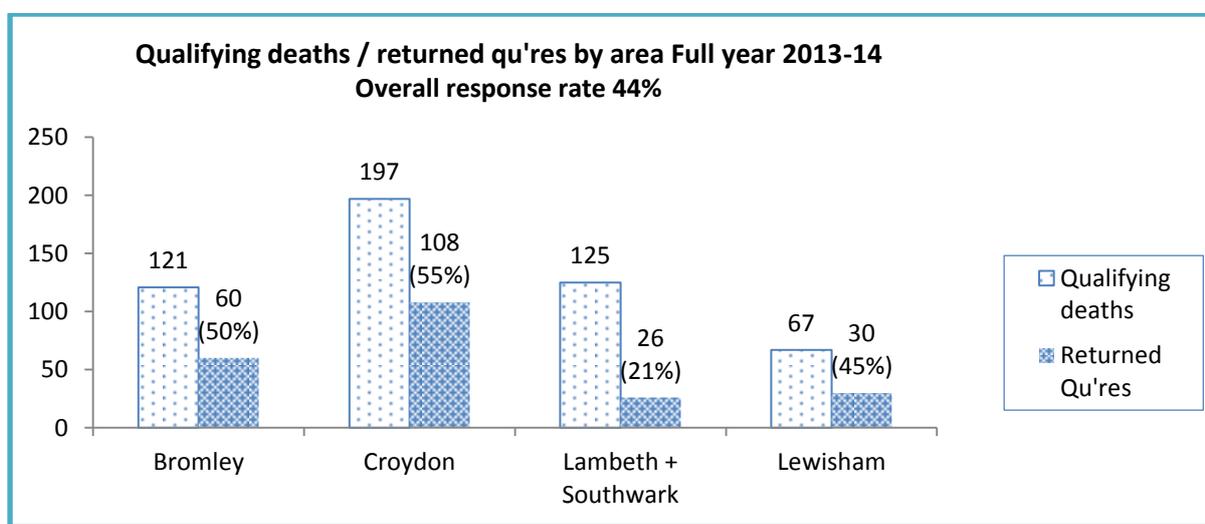


Figure 2: Response Rates across the five CCGs

5.2 Measuring satisfaction + listening to users' views about end of life care

The questionnaires consisted of statements about the care provided, with respondents asked to rate their agreement with the statements from strongly agree to strongly disagree. In addition, one open question asked them to supplement this with any other comments they wanted to make about the care received. Respondents were also asked to rank the

statements they felt were most important for good end of life care: the ranking is shown below in Section 5.5 of this report, along with the results overall for those items. Further information about the responses to each statement is available from the Care Home Project Team if required.

5.2.1 Positive responses:

There was high overall satisfaction with the end of life care given (84% agreed or strongly agreed). Most of the responses were extremely positive, with 80% or more agreement for seven statements across resident care, communication and rooming. Highest agreement was for staff being friendly (93% of respondents agreed or strongly agreed), staff treating the resident with dignity and the room providing privacy (88% agreed or strongly agreed with both); staff being sensitive to the resident's needs and speaking in a way that was easy to grasp (83% agreed/strongly agreed); and staff provided comfort to the resident (82% agreed/strongly agreed).

5.2.2 Less positive responses

Six statements had less than 60% agreement or strong agreement, and these items may require attention by the homes involved. The questions with the lowest agreement as judged by respondents were regarding the GPs having time to discuss issues (44%), and availability of chaplaincy services (48%). The other statements with less agreement were staff asking about rites and rituals (50% agreement), informing about care options (56%), describing what to expect as death approaches (57%) and the GP visiting as much as was necessary (58%).

5.2.3 Comments:

Most of the comments were extremely positive, whilst others highlighted areas that merited further consideration within the homes. Examples of positive comments include:

"I cannot thank the staff at xxx sufficiently for their dedication and care. They were fantastic!!"

"The end of life care was fantastic - we were pleased that our mother was able to remain at xxx and not have to be moved to hospital or hospice. "

"It is very difficult to list only three aspects that were important for excellent end of life care. The latter involves a "package" of nearly all the questions asked and additionally "a little something extra" that makes you feel that your loved one has passed away as peacefully as

possible. XXX home provided the whole package and the "little something extra" and I am forever grateful that my mother was in their care at the end of her life."

Issues raised by some comments included communication, particularly being given information about imminent death and what to expect, and problems of understanding strong accents; staffing levels; food and feeding issues; continence issues, end of life staff training needs; medication needs and services from GPs. They illustrate the potential value of the audit where feedback from relatives could be used as a mechanism of learning. Examples of these comments are shown below:

". . . My mum was in the Nursing Home for 15 months and during that time was well looked after. We had a lot of trouble of getting the death certificate and this caused distress to the family. Even though my Mum had excellent care from the home, I think that the service from the Doctor could have been much better. . ."

"The nurse in charge provided exemplary care, but the other members of staff needed more training in end of life care."

". . . My aunt did not cause a fuss in the four weeks she was in the home and all went well until 5-6 days before she died. I realised she was finding it difficult to swallow food. Carers just took the plates away and never mentioned it to staff. I told them but nobody talked about the obvious decline and what to expect . . ."

5.3 Action Plans to improve care:

Following the feedback sessions, each care home developed an Action Plan for improvement, where items had been identified. After the first six months, for many homes their plan centred around embedding the audit process better, and taking steps to improve response rates. Where possible, individual homes are making changes to accommodate comments specific to them, such as ensuring that all staff, including domestic and health care assistants, are aware of residents' needs such as feeding problems or hearing loss, and report back to nursing staff if they notice something amiss. There are some issues that occur across many homes and areas, some of which feel rather out of the control of the homes. In particular, issues around GP visits and their time to discuss issues, along with availability of Chaplaincy services received lower agreement ratings. Provision of information around end of life issues, GP visiting times and access to chaplaincy services were common to many homes' Action Plans. Further information about agreed action items is available from the Care Home Project Team if required.

For those homes that had no issues raised in returned questionnaires and very good response rates we advised examination of the comments that have been made to all audit participants, to share those comments with staff and consider the types of issues that can arise and that may be important to residents and their carers.

5.4: Learning together/improving staff confidence:

The introductory meeting started the process of learning involved in the audit. A talk by one of the St Christopher’s social workers gave useful advice about the benefits of a bereavement follow up telephone call, and started to build participants’ confidence in approaching bereaved carers. This was new to most participants.

Each joint feedback meeting enables care home staff to hear about issues raised and to discuss possible actions – often ideas can be sparked from these meetings. Even homes with no responses can learn from others’ experiences.

5.5 Priorities given to end of life care

In addition to recording their satisfaction with the care provided, respondents were asked to rank the items they felt to be their top three priorities for good quality end of life care, using the statements in the FPC audit. Four statements received the most votes, as follows:

- (1) treating the resident with dignity
- (2) pain being relieved to the greatest extent possible
- (3) providing comfort to the resident and
- (4) being sensitive to the resident’s needs.

The combined rankings for these statements are shown in Figure 3 below.

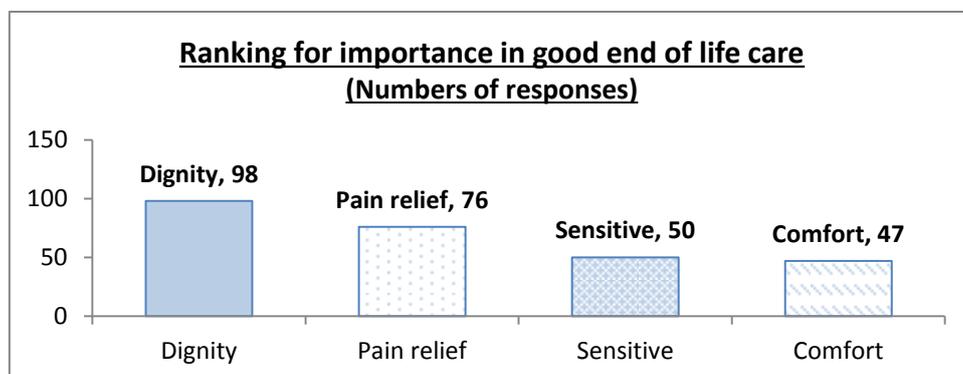


Figure 3: Ranking of importance in good end of life care

5.5.1 Questionnaire results for these priority statements

Three of the statements associated with these top ranked priority items achieved over 80% agreement: staff treated the resident with dignity (88% agreed/strongly agreed); staff were sensitive to the resident’s needs (83% agreed/strongly agreed) and staff provided comfort to the resident (82% agreed/strongly agreed). The item regarding pain relief being achieved to the greatest extent possible achieved 76% agreement. Figure 4 below shows the results for these statements (in percentages) across all care homes in the audit.

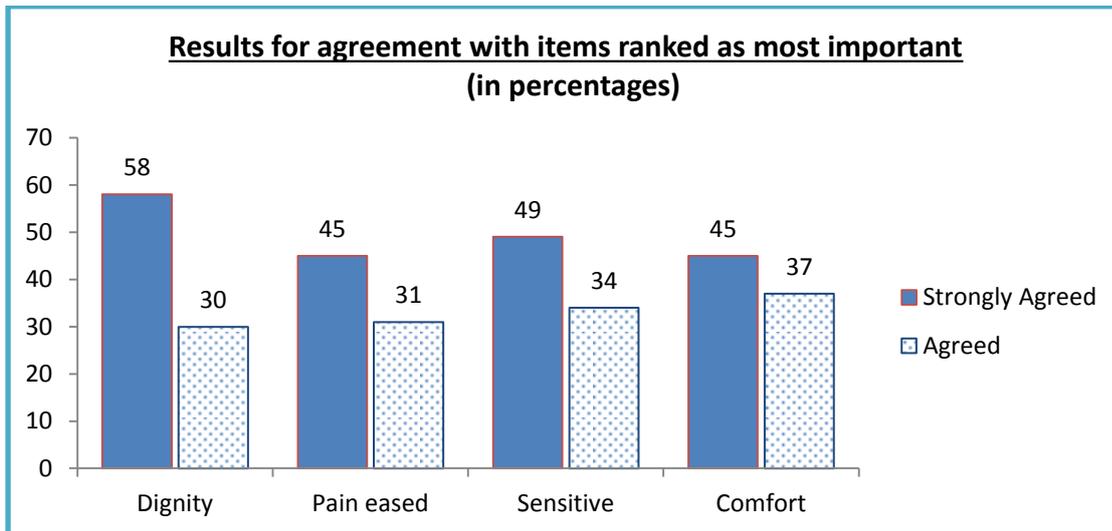


Figure 4: Overall results for the four items ranked as most important for good end of life care

Given the focus of the Burdett Trust on delivering dignity, it is particularly pleasing to note the high satisfaction rate regarding residents being treated with dignity: with 88% of respondents agreeing or strongly agreeing that their loved one had been treated with dignity. The full responses to this statement are shown in Figure 5 below.

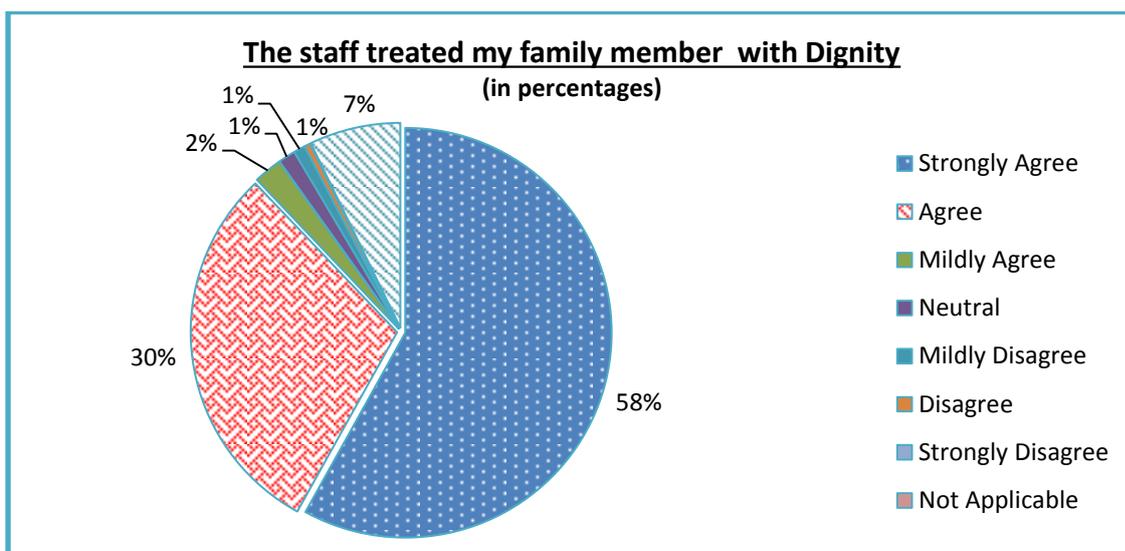


Figure 5: Responses for the staff treated my family member with dignity

6. Conclusions / Future Plans

Change takes time. Having recruited more than the original number of homes to participate, the initial focus was on providing support for putting in systems for the audit in each of the participating homes. This took much time and organisation. However, the response rates for the full year at 44% overall show that the processes, where implemented efficiently, do lead to good participation.

Feedback received from the returned questionnaires has been reported to the homes in groups as well as individually. Issues have been discussed between care homes and within care homes by the St Christopher's Care Home Project Team, which has enabled learning about the areas that need to be developed within some homes in order to improve the end of life care they provide. Home managers have received information that can help them lead and bring about change in their homes, and family members have had the opportunity to share their experiences. Their experiences have helped the care home staff to develop the care they offer and to improve end of life provision.

The homes have been supported to produce reflective action plans in order to address those areas where respondents indicated less satisfaction, and St Christopher's Care Home Project Team continue to provide expert advice and support to help these processes.

In addition, the positive nature of the majority of the returned questionnaires and the delightful comments made by some respondents has also been used to improve staff morale in what can often be a rather thankless environment, and in a world in which care homes receive much negative publicity. Participating in this audit helped the care home staff to become more confident and skilful in the care they provide for residents at the end of life. Further information regarding evaluation and monitoring of this project, showing the homes' views of participating in the audit is attached at Appendix III.

St Christopher's is grateful to the Burdett Trust for Nursing for funding this innovative project, and that appreciation is echoed by the homes participating in the audit. The project team would also like to thank the homes who have taken part, for their time, energy and resources. The end result will be a better quality of care provided to those dying in care homes. In particular, it is interesting to note that the most important item for good end of life care is regularly identified as treating the resident with dignity, and also reassuring to see how often that is achieved within the care homes.

The Care Home Project Team has been fortunate to receive one year's further funding from the Burdett Trust for Nursing to continue with the audit. The plan is to expand the numbers of care homes participating and to improve response rates further. A further 19 homes are being invited to an introductory session at the end of March, and it is hoped that they will all participate for the next

year. Commissioners within the CCGs involved are being consulted around taking the audit forward in future years, as they have shown considerable interest in assessing the quality of care in this way. St Christopher's staff are closely involved with end of life care plans for all the CCGs covered by this audit. This presents a natural opportunity for feeding back our results and any concerns we may have over broader issues regarding end of life care.

Further work is also needed to understand better the value of learning through such an audit process, and the Care Home Project Team is planning to develop a research proposal to achieve this.

Finally, the Team aims to share results of the audit and description of how the audit was set up and operates, in order to spread the good news about the valuable work being carried out by care homes, and to highlight the areas that need more help. They will be producing a Poster presentation for the European Association of Palliative Care Research Conference in Copenhagen in May 2015, details of which will also be published in a summer edition of Palliative Medicine. Further articles are planned for publication in other interested journals.

Vohra JU, Brazil K, Hanna S, Abelson J: Family Perceptions of End-of-Life Care in long-term care facilities. *Journal of Palliative Care* 2004; 20(4): 297-302.

Parker D. and Hodgkinson B.: A comparison of palliative care outcome measures used to assess the quality of palliative care provided in long-term care facilities: a systematic review. *Palliative Medicine* 2011; 25(1): 5-20.



StChristopher's

St Christopher's
51-59 Lawrie Park Road
London SE26 6DZ Switchboard: 020 8768 4500

Registered Charity 210667

Appendices:

- I Audit Standard
- II Guidelines for audit implementation
- III Project evaluation/monitoring

Appendix I : Standard: End of Life Care

Care Group: Family members of residents who die in local care homes.

Standard Statement:

The care home will use the views of bereaved family members to learn about and develop the end of life care they provide.

Structure:

1. Correct, fully completed and up to date documentation of family members' contact details.
2. After a bereavement one family member of each resident who died in the care home will be posted a Family Perception of Care Scale questionnaire.
3. Time is available for the care home team to reflect on the bereaved family members' views.

Process:

- 1.1 On admission to the care home, staff will record their next of kin/friends' contact details, including their full name, telephone number and postal and/or email address.
- 1.2 Details to be updated at each resident review meeting
- 2.1 There is a ready supply available of photocopied, correctly coded FPC questionnaires that include the NCH code, resident code, and month of death along with an accompanying letter
- 2.2 An account/diary is kept of the date of each death and every month a list made of the questionnaires to be posted
- 2.3 Care home staff to phone family member 4-6 weeks after death
- 3.1 Questionnaire and letter to be sent to the family member of **every** resident who died in the care home three months after the death. The envelope will also contain a stamped envelope addressed to Jean Levy, Care Home Project Team, St Christopher's Hospice, London SE26 6DZ. In complex situations e.g. multiple bereavement FPC questionnaire to be sent after six months
- 3.2 The Care Home Project Team will analyse results
- 3.3 Jean Levy will contact individual NCH managers if there is cause for concern when a questionnaire is returned.
- 3.4 Jean Levy to meet with the NCH managers every six months to give them feedback from those questionnaires returned
- 3.5 NCH managers, supported by the Care Home Project Team, to share this with their staff twice a year as a reflective process
- 3.6 Following the twice yearly reflective sessions on the FPC audit, care home staff will work together to make changes, organise training, give support and celebrate good feedback.

3.7 Evidence of improvements in the quality of end of life care provision arising from this process will be incorporated into their GSFCH accreditation portfolio

Outcome:

1. Family members have an opportunity to share their experience of end of life care in the care home
2. The care home staff will reflect on, and learn from the family members' experience to continue to develop their provision of end of life care.
3. The care home will improve the quality of end of life care provision in the care home and be able to evidence that they have done this.
4. Care home staff gain confidence and skills in end of life care

Appendix II: Guidelines - Family Perception of Care Audit

Please send to the family member of ALL bereaved relatives of residents who died in your care home.

DO NOT send to relatives when the resident died in hospital or if it was a sudden death.

Taking part in this audit needs planning. Here are a number of helpful hints gathered from our pilot study which we recommend you follow.

1. Nominate two people to take on the project with one person to assume overall responsibility
2. **Add your individualised code (showing e.g. patient initials + month of death) to the printed version of the FPC questionnaire before you send it out**
3. Start a record in a separate book and record for every resident who **dies** in your care home:
 - a. Resident's name
 - b. Date of death
 - c. Code for questionnaire – to be written on questionnaire and to include residents initials and the first few letters of the month they died
 - d. Their NOK details – full name and full postal address
 - e. Date of follow up phone call (4-6 weeks after the death) – tell them about the questionnaire
 - f. Date to post FPC questionnaire (3 months later)
 - g. Date the questionnaire was actually posted and **tick that the code was inserted BEFORE posting**

Response rates are improved by:

- Including a stamped addressed envelope with the questionnaire so it can be returned to Jean
- Talking to your relatives early on - after a death tell them you will ring them in a month or so and that in a few months they will receive a questionnaire
- Showing sensitivity re time of posting – delay if multiple bereavements/time of year

Appendix III: Project evaluation/monitoring

This project is monitored by Julie Kinley, the Care Home Project Team Manager. At the Care Home Project Teams monthly team meetings updates are given as to the progression of the audit, and the results for the first six months have also been reviewed by a multi professional Information Exchange seminar at St Christopher's. In addition, the care homes are asked for feedback about participating in the audit. Some examples of their comments are given below:

“We find the feedback of the result analysis is very useful. The staff are rewarded and motivated by the positive comments from the relatives as they feel their hard work is valued and appreciated. It also helps us to learn about issues highlighted as important or needing improvement by the relatives so that action plans could be made to improve and develop the end of life care within the home. In conclusion, we think the Family Perception of Care Audit is a potentially valuable method to help us to measuring the quality of care and making improvement in our service.”

“From talking to staff at the home it was clear that in certain situations where relationships with relatives were not always as close as with others there good be a reluctance to contact them after the death. They were concerned that this might upset people or leave them to have difficult conversations that they may not be fully confident to hold. By using the Family Perception of Care audit this has given staff a structure and although there were still concerns these have been alleviated as the response from relatives when contacted has been generally positive. This with the reflective discussions following deaths in the home have helped staff not only helped staff deal with the deaths in the units but have helped improve the level of communication around death and dying generally.”

“Thank you for the results of our Perception of Care audit. Although I started out thinking the Perception of Care audit was just another paperwork exercise, I have found the feedback from past patients very beneficial. As the questionnaire is anonymous I feel relatives/advocates are able to give true impressions of the home. We can definitely learn from the results where we may improve, especially with end of life care. From the minimal amount of paperwork from the home this is a very beneficial exercise.”