Family Perception of Care Audit

Final Report       June 2016
By    Jean Levy, Frances Conway, Julie Kinley

Funded by the Burdett Trust for Nursing
# Contents

1. Executive Summary 03

2. Background to the Audit 04

3. Aims of the Family Perception of Care Audit 07

4. Audit implementation process 08

5. Challenges/enabling factors 10

6. Results 12
   - 6.1 Recruitment and progress with implementation 12
   - 6.2 Measuring satisfaction and listening to users’ views 14
     - 6.2.1 Positive responses 14
     - 6.2.2 Less positive responses 15
     - 6.2.3 Comments 17
   - 6.3 Action Plans to improve care 18
   - 6.4 Learning together/improving staff confidence 19
   - 6.5 Priorities for end of life care 20
     - 6.5.1 Questionnaire results for priority statements 20
     - 6.5.2 Results for “The staff treated the resident with dignity” 21

7. Evaluation of the project by participants 23

8. Conclusion / Future Plans 25

9. References 28

Appendices 30
1. Executive Summary

With people living longer and more people dying in care homes, the quality of end of life care provided needs to be ensured so that people are treated appropriately and according to their wishes. This report describes the implementation of a two year multi centre audit of end of life care in care homes based in South East London.

The audit, using validated questionnaires sent to bereaved relatives three months after a resident’s death, asked respondents to rate the quality of care in the last four weeks of their loved ones’ life. They responded to statements covering resident care, relative support, communication and accommodation. Results from returned questionnaires were analysed and reported back to the homes anonymously and the staff were encouraged to reflect on the feedback. Action plans to improve care were agreed where required and staff were able to develop their skills and confidence in providing end of life care.

There was an overall response rate of 44% in year one, and 38% in year two, though response rates varied across geographical location from 15% to 55%. Overall satisfaction with end of life care achieved 80% or more agreement/strong agreement in both years. Highest agreement was for staff being friendly, treating the resident with dignity and the resident’s room offering privacy. The three items with lowest agreement in both years were availability of chaplaincy services, staff asking about rites and rituals and the GP having time to discuss issues. The majority of free text comments were extremely positive. Some issues raised included being given information about imminent death and what to expect, medication needs, services from GPs and support after the death of the resident. Challenges to the process included time available, commitment of appropriate staff and ensuring action plans were developed.

The positive nature of the feedback for many homes helped to boost staff morale, and items raised helped staff to develop their care and improve end of life care provision. Some issues raised were outside the homes' control and this presents more challenges for improving quality of care for all residents. The audit will be of value to Clinical Commissioning Groups and Local Authorities as an independent outcome to judge the quality of care in the care homes that they commission. It is well recognised that how health and social carers deliver end of life care is a marker for the quality of all care delivered.
2. Background to the Audit

Against a background of increasing numbers of frail elderly people, as people are living longer with higher health and social care needs, care homes have been playing a larger part in providing care at the end of life. In 2015 in England 22% of the population died in a care home (NEoLCIN, 2016). 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 good 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, attending and facilitating coding meetings, where end of life is discussed for each resident, and attending 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 environments vary from inner city urban living through to green belt suburbs. The number of care homes in each CCG varies considerably, e.g. Southwark have three nursing homes whilst Croydon has 30. As well as the GSFCH programme, the Care Home Project Team is now offering an alternative program called Steps to Success. This is an adapted version of the Department of Health’s Route to Success, and is currently being implemented in 27 residential care homes and 22 nursing 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 auditing 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. By 2015 this had increased to 79% across 76 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 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 information provided by the FPC Audit has in this way expanded the information available to CCG and Local Authority Commissioners about the quality of end of life care in the participant homes, and may be seen as an indicator for all the care provided within the homes.

The Family Perception of Care Scale used in the audit was developed by Vohra 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 or disagree with each statement. There are 25 statements, divided into five sections covering resident care, family support, communication, rooming and one other additional section (with two questions about GP services along with demographic details). There is also one open question for any other 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 reasonable 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].
3. 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, Appendix I].

The results of the audit were intended to be used within individual homes to help them develop 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 was 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 considering various options for end of life care improvements.

The target in year one was to recruit at least 42 care homes that had completed the Gold Standard Framework for end of life care in Care Homes (GSFCH) or the Steps to Success program. Having successfully recruited 52 homes in the first year, the Burdett Trust kindly agreed to fund the audit for a further year in order to increase numbers further, to give participants more time to embed the audit and to see whether response rates would then improve in some CCGs.
4. Audit 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 had an individual code assigned which was printed on to the questionnaires, so that feedback could 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 died they noted 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 sent out the questionnaires, they were asked to include the month of death and some kind of identifying code so that there could be individual follow up, in the event that the respondent reported something that seemed to need further investigation. The homes also included 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 aimed to measure levels of satisfaction with end of life care provided in the
homes, and therefore only deaths that occurred within the home (rather than in hospital), and those that were expected, were eligible for inclusion in the audit.

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

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

Once completed questionnaires were returned to St Christopher’s, the responses were input to datasets on SPSS (Statistical Package for Social Sciences) and Excel computer programs. The results were analysed six monthly, and reports produced for each individual home, each CCG and one overall report. The individual homes received the comments for their own home, and the other reports included anonymised comments. The reports were presented at feedback sessions for each CCG, and the attendees from the homes were able to discuss issues that were raised by the responses. Following this, feedback sessions occurred in each individual home so the homes were able to develop Action plans related to their own specific feedback, to improve their end of life care based on the results of the audit.
5. 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 were identifiable factors 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. See Table One for the challenges and enabling factors identified by the audit team.
<table>
<thead>
<tr>
<th>Challenges</th>
<th>Enabling factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Staffing levels / time</td>
<td>• Support from St Christopher’s Clinical Nurse Specialists</td>
</tr>
<tr>
<td>• Embedding the process</td>
<td>• GSFCH accreditation</td>
</tr>
<tr>
<td>• Staffing levels / time</td>
<td>• Having been part of the FPC pilot study</td>
</tr>
<tr>
<td>• Morale in care homes</td>
<td>• Sufficient staff / responsibility allocated</td>
</tr>
<tr>
<td>• Response rates</td>
<td>• Time</td>
</tr>
<tr>
<td>• Dealing with “complaint” type responses</td>
<td>• One member of staff in the care home, preferably the administrator, taking overall responsibility for the audit.</td>
</tr>
<tr>
<td>• Agreeing the Action items to help improve care</td>
<td></td>
</tr>
<tr>
<td>• How to deal with issues outside of the control of the care home.</td>
<td></td>
</tr>
</tbody>
</table>
6. Results

For this project, the results can be divided into those regarding recruitment to the audit and progress with 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.

6.1 Recruitment and Progress with implementing the audit process

All care homes offered the opportunity to participate in this audit agreed to do so. The staff in many of 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 in the first year, 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).

In year two, a further 20 homes were recruited, meaning there were potentially 72 homes participating, with the phase two homes starting from deaths occurring in December 2014. However, during this year three homes closed and seven others did not manage
to participate fully, four homes had no deaths and 13 had no responses, so the second year had feedback for 45 homes overall (39 nursing homes, six residential care homes).

Much of the work of the audit team during the first six months of both years was to visit the care homes to help them to establish systems. The homes involved were varied, some very large and others small, some independently owned and others part of corporate groups. Each home had 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 the homes to be actively involved in the audit was a major achievement for the project. Some home managers were very enthusiastic about participating, whereas others did not immediately see the value of taking on more administrative work. Future audits may benefit from CCG/Local Authority Commissioner endorsement to encourage homes to engage in the activity.

The overall response rate across the participating homes in all five CCGs in year one was 45%, with 228 returned questionnaires from 509 eligible deaths. This was 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%. For year two, the overall response rate was 38%, with 276 returned questionnaires from 725 eligible deaths. Of those homes with returned questionnaires, response rates varied from 4% to 100%. The rate again varied by Clinical Commissioning Group (CCG) area: Croydon had a 40% response rate, Bromley 54%, Lewisham 40%, Lambeth 15% and Southwark 16%. Figure two shows the differences in percentage response rates across areas for both years of the audit. Bromley was the only area that increased its response rate in the second year. The number of non-eligible deaths known to the audit facilitators was equivalent to about 4% of the total deaths, though it is likely that there were more in reality, as some care homes reported at feedback meetings that they had not told the audit team when they had not sent out questionnaires. This was usually because there had been no identifiable next of kin, as the information about place of death was available, through another audit, which meant that the audit team could check for hospital deaths directly.
The questionnaires consisted of 27 statements (including the additional two relating to GPs) 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 free text 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 6.5 of this report, along with the results overall for those items. A summary of the positive and less positive responses is provided below. Further information about the responses to each statement is available from the Care Home Project Team if required.

### 6.2.1 Positive responses:
There was high overall satisfaction with the end of life care given during both years (84% agreed or strongly agreed in year one, 80% in year two). Most of the responses were extremely positive, with 80% or more agreement for seven statements across resident care, communication and accommodation in year one and for five statements in year two. Highest agreement across both years was for staff being friendly (93% of respondents agreed or strongly agreed in year one, 86% in year two), staff treating the resident with dignity and the room providing privacy (88% agreed or strongly agreed with both in year one, 87% agreed re privacy, 84% re dignity in year two). Figure three below
shows the comparison of percentages across both years for the five items with most agreement in year two.

Figure 3: Items with most agreement across (in percentages)

Compared with the first year, in year two 20 items achieved higher agreement/strong agreement and six had less agreement. One item had the same percentage agreement in both years – that other symptoms were eased to the greatest extent possible (71%). The items with most increase in agreement were that staff informed the respondent about care options during the resident’s last days (62% agreed/strongly agreed versus 53% in year one), and the staff informed the respondent when they thought that death was at hand (71% agreed/strongly agreed versus 63% in year one). Both these items had been targeted as action points across a number of homes in year one, so this was a very positive outcome.

6.2.2 Less positive responses:

Three items had less than 60% agreement or strong agreement across both years. The lowest agreement was regarding GPs having time to discuss issues (Year one 44% agreement, year two 43%), and availability of chaplaincy services (48% agreement in both years). The other item was staff asking about rites and rituals (50% agreement in year one, 54% in year two). The full spread of responses for each of the three items (shown in percentages) is outlined in Figures four to six. It may be worth noting the number of “neutral” and missing responses across all three, which may indicate that respondents did not find these items as important as some others in the questionnaire.
Figure 4: The GP had time to discuss issues (in percentages)

Figure 5: The staff asked about rites and rituals (in percentages)
Figure 6: Chaplaincy services were available (in percentages)

6.2.3 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 would just like to add that the care and dedication from all the staff at xxx shown to my mum and my family throughout her time there was outstanding. Her death could not have been more dignified or peaceful and for that I am eternally grateful.”

“I was very satisfied with the way my husband was looked after. The staff were wonderful and I can’t speak highly enough of them.”

“Cannot fault the care and compassion shown to our father and the family during his time in care.”

Issues raised in some comments included communication, particularly being given information about imminent death and what to expect, some items re staffing attitudes; food and feeding issues; use of equipment; availability of physiotherapy; medication needs, services from GPs and support after the death of the resident. They illustrate the
potential value of the audit where feedback from relatives could be used as a mechanism for learning. Each home has had a list of the comments specific to them.

Examples of these comments are shown below:

“I feel we could have been notified earlier so that we could have been with my dad when he died, instead he was alone.”

“As soon as my father died, the night nurse in charge was very keen for the funeral directors to come as soon as possible. We felt rushed out at the end which caused some anxiety. My father died at 2/3pm Sunday. We would have liked to have sat with him on Sunday before they took him away.”

“My mother passed away on Easter Sunday at 11pm. Although a doctor was called at approximately 6pm, he or she never turned up. Mum could have done with some pain medication. But the NHS failed her in her final hours. The locum finally put in an appearance some time after she died. However, I cannot fault the care home or the staff as they were very comforting during mum's final hours.”

6.3 Action Plans to improve care:

Following the six monthly feedback sessions, each care home was encouraged to develop an Action Plan for improvement, where items had been identified. After their first six month reports, for many homes their plan centred around embedding the audit process, and taking steps to improve response rates. Where possible, individual homes made 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 were some issues that occurred across many homes and areas, some of which were 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. During the second year some comments received were around support provided to carers and family after the resident died, and discussions at the feedback sessions led to an
agreement to produce written information for each area about what happens after a death, and what will be required of the family. Homes had different processes following a resident’s death: some families were able to keep a resident’s room for a week after the death, whilst others (particularly those with residents receiving Continuing Care funding) had their payments stopped as soon as the resident died and therefore required the families/carers to remove the resident’s possessions immediately in order to re-use the room. In addition, procedures for registering the death and access to the “Tell Us Once” service that advises all government departments differed slightly across the CCG areas involved.

For those homes that had no issues raised in returned questionnaires and very good response rates we advised examination of the comments that had 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.

6.4: 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 at the beginning of the audit. Each joint feedback meeting enabled care home staff to hear about issues raised and to discuss possible actions – often ideas were sparked from these meetings. Even homes with no responses could learn from others’ experiences.

The feedback meetings led to agreement to produce posters about the audit to put up in the care homes and about its results; to provide information about GP visiting hours and how to access the resident’s GP; and to develop information booklets about what to do after a death as described in the paragraph above. The feedback meetings also enabled staff from different homes to discuss issues such as how often their GP visits – in one CCG area it was discovered that some GPs were carrying out visits in order to put together “Hospital Avoidance” plans at the behest of the CCG, whilst others in the same area had no idea that was happening and indeed had GPs that were unable to make routine, regular visits, nor to take on more than 35 older people. Just having an idea of what might be possible gave some home managers and staff more confidence about suggesting possibilities to other health professionals that they rely on for support.
6.5 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. The three statements that received the most votes were as follows:

1. treating the resident with dignity
2. pain being relieved to the greatest extent possible
3. being sensitive to the resident's needs.

The results for the combined rankings for these statements are shown in Figure 7 below:

![Rankings for importance](image)

**Figure 7: Combined rankings for importance in end of life care**

**6.5.1 Questionnaire results for these priority statements**

Two of the statements associated with these top ranked priority items achieved over 80% agreement in the first year: staff treated the resident with dignity (88% agreed/strongly agreed) and staff were sensitive to the resident's needs (83% agreed/strongly agreed). The item regarding pain relief being achieved to the greatest extent possible achieved 74% agreement in year one, 75% in year two. In year two the three items all had slightly lower agreement, though staff treated the resident with dignity still achieved 84% agreement. Figure eight shows the results for these statements (in percentages) across all care homes in the audit.
6.5.2 Full results for “The staff treated the resident with dignity”

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 well over 80% of respondents agreeing or strongly agreeing that their loved one had been treated with dignity over both years. The full responses to this statement are shown in Figure 9.:
The chart shows that although there was a slight dip in agreement/strong agreement in the second year, in fact the numbers strongly agreeing increased in year two (from 57% to 61% strongly agreed).
7. Evaluation of the project by participants

At the feedback session covering the full second year results, care home Managers were given a form to help them to evaluate their participation in the audit. A short questionnaire asked them what went well with the audit, what could have been done better, what changes had been made as a result of taking part in the audit and for any other comments. Fourteen questionnaires were returned.

Items identified that had gone well with the audit included providing an insight into what is important and relevant for end of life care for the families, receiving the feedback, being able to identify the areas where improvements could be made and being encouraged by the responses received. Some specified that they are now able to speak to families six weeks after the resident’s death, to ask them how they are getting on, which they did not do previously; others stressed how positive and reaffirming the feedback has been, and that they have been able to make positive changes to their practice which staff have been happy to embrace.

Items that could have been done better included better communication with the relatives about the audit and helping them to realise the importance of returning the questionnaire without pressurising them. Several homes identified that they had not let the Audit team know if they had not been able to send questionnaires (for example, because there was no identifiable next of kin to send to) and this had affected their response rate. Others questioned the wording used – in particular asking about “Chaplaincy” which did not fit with any services they provide. They also had some doubts about the GP items, and
pointed out that the out of hours doctors provide a very different service from the normal GP attending the home, and some comments may be about these. Another home wondered whether asking the question about GPs raised people’s expectations of the amount of support they could have had from the GP.

Changes made as a result of participating in the audit included making more time for families, trying to get the doctor to speak to families more often, trying to involve the GP more, including more staff in training for end of life care, providing better support to families both while the resident is living in the home and after their death, having more discussions with families and residents about spiritual issues, and giving more information about what to expect as death approaches – one home has developed a “coping with dying” leaflet.

Other comments covered appreciation of having been part of the project, having discussed with all staff the need to spend more time with family members and providing food and drink for them, ensuring staff are aware that the family need support from staff and making sure that someone is always available, staff understanding that they must be sensitive to the families and try to understand their feelings. Two positive comments from homes about participating follow:

“I feel the perception of care audit has been a great help to our home to help us understand the families’ needs when they have a dying relative and to show us where we need to improve”

“We are very appreciative of being part of this project – as we recognise it has encouraged us to reflect on the results and has encouraged us to provide better end of life care to those relatives and residents in our home. It has been a very positive and helpful experience”
8. Conclusions and future plans

Change takes time. Having recruited more than the original number of homes to participate in the first year, 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 first year at 45% overall showed that the processes, where implemented efficiently, do lead to good participation.

The Care Home Project Team was fortunate and very grateful to receive one year’s further funding from the Burdett Trust for Nursing to continue with the audit for a second year. The plan was to expand the numbers of care homes participating and to improve response rates further. With another 20 homes recruited for the second year, the audit was able to reach more homes and help to improve quality of care for more residents, despite the closure of some homes and others not fully managing to embed the audit processes.

Feedback received from the returned questionnaires was reported to the homes in groups as well as individually. Issues were discussed between care homes and within care homes, sometimes along with the St Christopher’s Care Home Project Team, which enabled learning about the areas that needed to be developed within some homes in order to improve the end of life care they provide. Home managers received information that could help them lead and bring about change in their homes, and family members 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 feel like a rather thankless environment, and in a world in which care homes receive much negative publicity. Participating in this audit has helped the care home staff to become more confident and skilful in the care they provide for residents at the end of life.

Areas for possible further consideration include the problem of low response rates. The second year of the project experienced lower response rates than the first and the reasons for this are unclear. Homes recruited for the first year were chosen because they had already achieved an accreditation in an end of life care programme, whilst the recruitment was broadened in the second year to those who were just beginning to think about following such a programme. It is not possible to tell whether this is why there were lower response rates: even in those homes who were involved in the pilot study there were lower response rates during the second year. Possibly some of the homes were less committed to the audit in the second year and therefore did not manage to send out their questionnaires when needed, or maybe staff changes meant they did not fully understand what was required.

From the evaluation questionnaires several homes stated they had not sent questionnaires out because there was no next of kin, but they did not advise the audit team and therefore their response rates were shown as much lower (because their returned questionnaires were measured against a higher number of resident deaths than was valid). One home stated that no questionnaires were actually sent out, due to a lack of communication within the home. These sorts of issues can sometimes be overcome with a longer term project, though conversely with time there can also be a lessening of enthusiasm which can adversely affect participation.

Another area to consider is how best to share the results with others in order to improve care provided. Some of the issues raised concerned issues outside the care homes, for example, chaplaincy, GPs, other therapists. How to encourage better cross organisations working remains a challenge. St Christopher’s staff are closely involved with end of life care plans for all the CCGs covered by this audit, which presents a
natural opportunity for feeding back our results and any concerns we may have over broader issues regarding end of life care locally. Some issues may be relevant on a wider scale too.

To that end, the Team has been sharing the results of the audit and describing how the audit was set up and operated, 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 produced a Poster presentation for the European Association of Palliative Care Research Conference in Copenhagen in May 2015, (Levy et al, 2015). The Hospice UK Annual Conference 2015 also displayed a poster about the audit, published in the BMJ Supportive & Palliative Care journal (Levy et al, 2015). An article has been submitted for review to a major international specialist journal which will hopefully be published during 2016. Presentations have been made to local Healthwatch members, a local Safeguarding Committee, who were very interested to hear about the audit and its results, and at a national Care Home Conference. The audit team also presented to a training course for clergy involved in end of life care and highlighted the possible need for better support for care homes – for care home staff as well as their residents.

The audit is continuing for at least one more year in one CCG, and the homes in other CCGs are being encouraged to continue the audit, but asking for questionnaires to be returned direct to them rather than to St Christopher’s. This changes the anonymous nature of the audit but does mean they would still have the opportunity to hear what carers thought of their care. The overall results for both years have shown much satisfaction with the end of life care provided within the participating care homes. The homes are still learning, and trying to improve the care they offer. One final comment received sums up the experience of excellent end of life care that was provided by one of the homes in the audit, and any organisation providing end of life care would surely be proud to have received such a comment:

“I have tried to vary the scoring away from the perfect seven but I can only add that my mother was treated with respect, dignity and had all physical and spiritual needs attended to by the team at xxx. The entire team took responsibility for her care, including a dedicated GP attached to the Unit. Specifically, her end of life care plan was executed with tact and dignity, giving mother the most control possible over her choices until she was unable to do so. Staff members/ chaplain visited off duty to provide companionship in her final hours as I was travelling.”
St Christopher's is extremely 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 is 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.

References


Gold Standards Framework Centre CIC:  http://www.goldstandardsframework.org.uk/


National End of Life Care Intelligence Network Place of Death (NEoLCIN) data: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death, accessed May 2016


Expert in end of life care

St Christopher’s provides and promotes skilled and compassionate end of life care of the highest quality, working with, and through, our communities.

StChristopher’s

Sydenham site
51-59 Lawrie Park Road, Sydenham, London, SE26 6DZ
Telephone 020 8768 4500 Fax 020 8659 8680

Bromley site
Caritas House, Tregony Road, Orpington, Kent, BR6 9XA
Telephone 01689 825755 Fax 01689 892999

info@stchristophers.org.uk
stchristophers.org.uk
May 2016
St Christopher’s is registered charity number 210667.
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