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FINAL REPORT OF THE MAIDSTONE AREA SIX STEPS END OF LIFE CARE PROGRAMME

Prepared for the West Kent Clinical Commissioning Group

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Six Steps to success
The North West End of Life Care Programme for Care Homes

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1.0 Introduction

Canterbury Christ Church University (CCCU) and the England Centre for Practice Development (ECPD) were commissioned to deliver the nationally accredited 'Six Steps' training programme for care homes in the Maidstone area at a cost of £21,885 on behalf of the West Kent Clinical Commissioning Group (WKCCG) as the result of a successful competitive tendering process in January 2013. The programme started on February 18th 2013, and the educational component was completed on schedule on the 21st October 2013. The University is one of the largest providers of health and social care education in the region, and together with the England Centre for Practice Development, is committed to improving the health and wellbeing of individuals, families and communities in Kent and Medway in addition to developing the knowledge base for palliative and end of life care both nationally and internationally as evidenced by the recent appointments of two international experts in the field, Professor Chris Johns and Professor Davina Porock as honorary Chairs within the Faculty of Health and Social Care, and the establishment of a full-time university Reader's post in palliative and end of life care in August 2013.

Project outcomes

The outcomes for the project were contained in the service specification provided by West Kent Clinical Commissioning group at the start of the tendering process. These are summarised as follows:

- Actual numbers and a reduction in inappropriate emergency admissions, A&E attendances and excess bed days in acute hospitals in comparison to the start of the programme
- Actual numbers and a reduction in actual numbers and a reduction in inappropriate ambulance conveyances to acute hospitals in comparison to the start of the programme
- Actual numbers and an increase in the number of care home residents dying where they chose to die in comparison to the start of the programme
- Actual numbers and a reduction in the number of care home residents dying in hospital together with the reasons for any deaths occurring in an acute hospital during this time
- Actual numbers and an increase in residents dying in their place of normal residence and/or preferred place of care at the point of death in comparison to the start of the programme
- An objective increase in the prescription of anticipatory drugs necessary to manage anticipated end of life symptoms in comparison to the start of the programme
- Actual numbers and an increase in the proportion of care home residents having an advance care plan and DNACPR in place in the care homes in comparison to the start of the programme
- An increase in the number of care homes maintaining an end of life care register and a recorded increase in the number of care home residents on those registers in comparison to the start of the programme
- An evaluation of the use of social service packages in conjunction with care home managers, GPs providing services to care homes, and other members of the local Community Health Team
- An improvement in resident, carer and professional satisfaction as evidenced by the inclusion of resident/family member letters, cards and other indicators of quality improvement in each care home's Portfolio of Evidence.

These outcomes were to be demonstrated through the collection of audit data prior to, during, and on completion of the programme, and through the submission of a Portfolio of Evidence from each care home taking part in the project. In addition, the views of GPs providing services to the care homes

would be elicited at least twice during the course of the programme and continuously during regular Gold Standard Framework (GSF) meetings and liaison with local Community Health Teams.

Programme content

The training programme was delivered locally at one of the care homes in the Maidstone area in order to facilitate ease of access, and each half-day session was repeated twice (once in the morning and the other in the afternoon) so that the number of care home staff who could attend was optimised. Two senior members of staff from each participating care home were invited to take part in each session so that they had the capacity to act as role models to others and change agents in their organisations. Each half-day session covered one of the topics outlined in the nationally accredited programme as follows:

- Session 1: Introductory workshop (Matt Hart)
- Session 2: Step 1 – Discussions as the end of life approaches (Matt Hart)
- Session 3: Step 2 – Assessment, care planning and review (Matt Hart)
- Session 4: Step 3 – Co-ordination of Care (Matt Hart)
- Session 5: Step 4 – Delivery of high quality care in care homes (Matt Hart)
- Session 6: Step 5 – Care in the last days of life (Dr Stephen J. O'Connor)
- Session 7: Step 6 – Care after death (Matt Hart)
- Session 8: Concluding workshop (Matt Hart)

Other care home staff were invited to attend two supplementary workshops in order to inform them about the aims of the programme, the need for the audit, and the action plans being implemented within their institutions. They also provided opportunity to share the benefits of the training being provided to other more senior colleagues. These sessions consisted of a one-day communication skills workshop which was delivered twice across the locality, and a half-day care of the dying workshop which was again delivered twice. Further information about the Six Steps programme which was developed by the Cumbria and Lancashire End of Life Care Network and subsequently advocated nationally by various bodies including the NHS End of Life Care Programme can be found on: http://www.endoflifecumbriaandlancashire.org.uk/six_steps.php

The content of the workshops were practically focused, and time was provided for discussion of specific issues faced by individual care units in applying the lessons learned to practice. Practical end of life tools and measures which are nationally and locally recognised were used to facilitate and/or measure change in each setting. These were provided in the form of a CD Rom which also contained all of the teaching materials and reading lists for each session, the quality outcome measures for end of life care, a template for the portfolio of evidence to be submitted by each organisation at the end of the programme, and a template which could be used for developing and recording an end of life care policy as a final project outcome at the end of the programme. A hard copy of the portfolio was also provided for each participating home so that attendees could share the contents with other staff members in the home.

2.0 Operational delivery of the project

Recruitment

All of the care homes which had not previously undertaken a Six Steps training programme within the Maidstone locality were invited to participate in the training. Recruitment was carried out by Matt Hart in liaison with the West Kent Clinical Commissioning Group which approved each participant prior to

the start of the programme. Nine residential care homes were recruited. Many others had either completed the programme in previous years, or had failed to engage with the programme at all. At least one nursing home agreed to take part in the programme but was then convinced that it should undertake the programme being delivered elsewhere by an unsuccessful bidder for the programme funding. Therefore, following discussion with the commissioners, 2 ‘extra care’ sheltered housing units and 2 nursing homes were also recruited onto the programme in order to offset these loses and make full use of the available funding to enable as many care centres as possible to participate in the programme. One nursing home was mutually withdrawn from the programme due to a lack of engagement, the second time that this particular home had dropped out of a Six Steps programme.

Baseline audits

After recruitment, each care home was visited by the programme facilitator (MH) to orientate them to the programme outcomes and clarify their responsibilities with regard to its completion. Three baseline audits were then undertaken with his support to gauge the level of knowledge about end of life care planning in each home, and the application and quality of end of life care planning and provision.

Ongoing Audits

Participating organisations were visited each month by the programme facilitator (MH) to offer support as they started to implement the programme into their practice settings. During these visits, the programme facilitator assisted staff in auditing the care delivered to residents at the end of life and in compiling their portfolio to evidence delivery of the programme outcomes. Follow up audits were conducted at the midway point in June and at the end of the programme in October to gauge progress and any improvements in end of life care in each participating organisation. An individual post-death audit was conducted for each resident dying during the course of the programme – whether in the usual place of care or another setting to establish whether or not, and the extent to which the programme outcomes had been achieved. These data will be discussed separately in the results section.

GP visits and participating practices

From the start of the programme, the programme facilitator (MH) attempted to make contact with each of the general practices associated with the homes in order to gain their support for the programme and explore ways in which they could work more closely with them to improve end of life care planning and co-ordination for residents. Seven GP practices were contacted and five agreed to have a meeting with the project facilitator. Many practices covered more than one home as indicated below. Pseudonyms have been used throughout the report for both GP practices and nursing/care homes or sheltered housing accommodation for the purposes of confidentiality.

- Ash Street Surgery (Clematis Lodge, Rose Lodge, Thistle Lodge, Iris Lodge)
- Beech Street Surgery (Rose Lodge, Iris Lodge, Thistle Lodge, Chrysanthemum Lodge)
- Oak Street Surgery (Lobelia Lodge)
- Maple Street Surgery (Iris Lodge)
- Sycamore Street Surgery (Petunia Lodge)

Contact was also made with one other GP surgery covering Azalea Lodge, Clematis Lodge, Thistle Lodge, Rose Lodge, Iris Lodge, Crocus Lodge and Chrysanthemum Lodge, and they signalled their willingness to be involved in the project but the GP specifically responsible for covering care homes

left the practice soon after this and there was inadequate time to interview his replacement by the time he was appointed at the end of the programme.

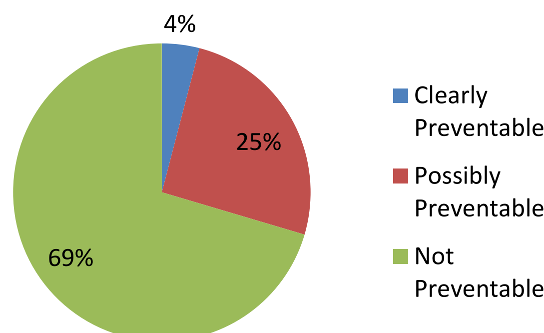
One GP surgery did not respond to repeated attempts of the programme facilitator to meet with them about the project which was regrettable since it left Tulip Lodge unrepresented by any GP contact with the project. The general practice at Maple Street Surgery (Daffodil Lodge) was undergoing major restructuring at the time of the project so they were unable to take part although keen to do so. Consequently, the managers at Daffodil Lodge plan to contact them once the restructure is completed to further these discussions although this did mean that they too were left without identified GP support or representation for the duration of the programme. It is noticeable that some care homes are very well represented with more than one GP practice providing services for them, and unfortunate that these two practices were unable to take part as they covered homes which were otherwise unrepresented by those GPs covered by the interviews with the programme facilitator.

3.0 Outcomes of the programme

Numbers and reduction in inappropriate emergency admissions, A&E attendances and excess bed days in acute hospitals

In order to calculate the actual numbers and reduction in inappropriate emergency admissions via A&E units to acute hospitals, baseline data for the 12 months preceding the programme and a case by case audit of each admission occurring during the programme was undertaken. Seventy-eight admissions were made to an acute hospital during the course of the programme. However, of these, it is estimated that only 3 (<4%) were definitely preventable, 19 (25%) were possibly preventable, and 56 (69%) were preventable (Figure 1). One preventable admission from a residential care home was due to 'mobility problems'. The resident was subsequently discharged from hospital to the care of a nursing home. The second was admitted with cancer and heart failure and in our view, they could have been managed in the care home or alternatively, a nursing home given the clearly terminal nature of the symptoms, and the third who was admitted with an apparently minor condition 'constipation' actually died in hospital, although the actual cause of death remains unknown to the care home staff as often happens, making it difficult to ascertain whether admission to hospital was appropriate or not. Chest infections (including pneumonia), urinary tract infections one case of renal failure and one case of sepsis make up the majority of the possibly preventable admissions, but residents location on an end of life pathway is not clear in every case so it is difficult to judge whether hospitalisation for these potentially reversible causes were warranted although it is noticeable that most of these returned back to the care home after successful treatment indicating that it was.

Figure 1: Preventable admissions to (and from) hospital



Indications for non-preventable admissions consisted for the most part of head or other traumatic injuries including for the most part fractures, cerebrovascular accidents, and one case of severe dyspnoea, angina, twisted bowel and haematemesis amongst other conditions. This group had the largest number of hospital deaths with at least five deaths occurring in the hospital and another in a nursing home to which the resident was discharged, but in many cases, care home staff simply do not know what happened to the residents who did not return such is the paucity of information provided to them by the acute Trusts and in many cases, care home staff are reluctant to contact family members for fear of upsetting them should a death have occurred in the hospital. This is a sad indictment of the lack of communication between the different sectors which it is hoped, the Six Steps programme will help to overcome in future. Likewise, for this reason, it is difficult to calculate with any degree of accuracy the likely excess in unwarranted bed days lost to the acute sector, although on the basis of our data, it may be much less prevalent than is often presumed, many care home staff indicating that they would much rather care for residents in the home that transfer them to hospital if at all possible and indicating that such admissions are invariably due to failures in Out Of Hours (OOH) provision or other systemic failure. Conversely, on two occasions care home staff could not account for the reasons a resident was admitted to hospital or indeed, what had happened to them, indicating that incomplete and inaccurate data are not the sole preserve of the acute sector. Appendix 1 contains full details of the audit of admissions to and from hospital during the programme.

Actual numbers and the reduction in actual numbers in inappropriate ambulance conveyances to acute hospitals

Given the above, it is difficult to calculate the actual number of inappropriate ambulance conveyances to and from acute hospitals, although anecdotally, care home staff felt that these were happening less often and the surprisingly low number of preventable admissions number and the high number of residents admitted with potentially reversible conditions such as a fracture or severe infection indicate that these may not be as common as first thought. There is also anecdotal evidence that in the area, at least some admissions are due to the actions of paramedic ambulance staff who refuse to recognise the validity of advance care plans made more than a year (and occasionally less) in advance. Care home staff found these actions disturbing and at times upsetting when in fact they had only contacted the ambulance service out of hours because they lacked vital equipment of drugs to care for the individual satisfactorily within the care home.

Actual numbers and the increase in the number of care home residents dying where they chose to die

The baseline audit indicated that in the year prior to the programme starting, 65% of the 85 residents who had died did so in their usual place of residence. This decreased to 57% of the 21 deaths between February and June, and increased again to 75% of the 24 deaths between July and October. It should be noted that prior to the programme starting, very few residents were given the opportunity to discuss where they might prefer to die, so assumptions about the care home as the preferred place of death are based on presumption rather than fact. For the most part however, it seems likely that older residents would prefer not to be moved to alternative settings when they were actively dying, so this would appear to be a fair assumption. This could be interpreted as an indication of the improved proactive planning of end of life care as the care units fully embed the programme within their practice settings. This reflects the numbers of residents dying in their preferred place of care. However, given the sharp variation in results during the period of the programme, other factors outside the scope of this audit cannot be excluded.

Actual numbers and the reduction in the number of care home residents dying in hospital together with the reasons for deaths occurring in acute settings

There was evidence of a small drop in the number of residents being transferred from residential care homes to nursing homes at the end of life during the course of the project, indicating that there was increased confidence in these areas where nursing as opposed to acute medical care may have been indicated at the end of life. However, there was a mixed picture regarding the number of residents admitted to hospital who subsequently died in hospital. The baseline audit at the beginning of the programme demonstrated that 23% of the 90 residents who died did so in hospital. There was a sharp increase between February and June to 41% (n=22) followed by a sharp decrease between July and October to 22% (n=23). Further analysis of the nature of all admissions to hospital (not necessarily resulting in death) may help to explain the reasons why residents were admitted and died within a hospital setting. Each of the admissions to hospital during the implementation of the programme between February and October were audited. Of these, 69% or 75 of these admissions may not have been prevented due to the uncertain nature of the presenting symptoms or the rate of deterioration of the resident in question. Many of the admissions were for potentially reversible conditions.

Actual numbers and the increase in residents dying in their place of normal residence or preferred place of care at the point of death

It was difficult to ascertain the preferred place of care of residents as advance care planning was not embedded prior to the start of the programme, and during this time there was still only a minority of residents with an advance care plan in place. However, staff were asked to give an intuitive answer to the question regarding residents preferred place of care if that information was not available. The residents' preferred places of death in Figures 2 and 3 on the following two pages are only based on a proxy measure therefore, and may not be completely accurate. However, following the audits it can be estimated that prior to the programme only 63% (n=90) of the residents died in their 'usual' place of care which, we hypothesise, would also have been the preferred place of death in most cases. Changes in the numbers of people dying in their preferred place of death in the two audit periods during the programme of 59% (n=22) between February and June and 65% between July and October are not statistically significant and would nevertheless be smaller than the previous year if trends in the latter half of the programme period are maintained for the next three months.

Increases in the prescribing of drugs necessary to manage anticipated end of life symptoms

Anticipatory prescribing of drugs necessary to manage end of life symptoms had taken place for 36% of the 85 residents who died in the twelve months leading up to the programme. This increased to 48% of the 21 deaths between February and June, but dropped to 33% of the 24 deaths occurring between July and October. Overall therefore, there would not appear to have been a dramatic increase in the use of anticipatory prescribing apart from the initial period covered by the programme. It is important to note however, that anticipatory prescribing is outside the scope of staff working in the homes, and programme participants felt that there was still a pronounced reticence on the part of some GPs to prescribe proactively for residents considered to be at the end of life. The picture is further confused by the fact that only 29% or 45 of the deaths occurring during the programme could have been anticipated whilst in a further 36% of deaths, it was not clear whether the death could have been anticipated or not.

Figure 2: Place and cause of death for residents dying during the first half of the programme (February to June 2013 n=22)

	Cause of death	EOLC care register Y/N	Advance Care Plan in place Y/N	Preferred place of care if known	DNACPR in place	Place of Death
1	?	n	n	?	n	Hospital
2	Deterioration	n	n	CH	y	CH
3	Pneumonia	n	n	CH	y	CH
4	In sleep	n	y	CH	y	CH
5	Deterioration	y	n	CH	y	CH
6	CVA	n	n	CH	y	Hospital
7	Haemorrhage	n	n	CH	n	Hospital
8	Cardiac Arrest	y	n	CH	y	CH
9	Pneumonia	n	n	CH	n	Hospital
10	Heart failure	n	n	CH	n	Hospital
11	Brain Haemorrhage	n	n	CH	n	Hospital
12	?	y	n	CH	y	CH
13	?	n	n	?	n	Hospital
14	Refused treatment	y	n	CH	y	CH
15	Deterioration	n	n	CH	y	CH
16	Deterioration	n	n	CH	y	CH
17	Deterioration	n	n	CH	y	CH
18	Gangrenous leg	y	n	CH	y	CH
19	Cancer/HF	n	n	?	y	Hospital
20	Deterioration	n	n	CH	y	CH
21	CVA	n	n	CH	y	Hospital
22	Deterioration	y	n	CH	y	CH
22		**N=6 (27%)**	**N=1 (5%)**		**N=16 (73%)**	**PPD achieved N=13 (59%)**

Figure 3: Place and cause of death for residents dying during the second half of the programme (July to October 2013 n=23)

	Cause of death	EOLC care register Y/N	Advance Care Plan in place Y/N	Preferred place of care if known	DNACPR in place	Place of Death
1	Deterioration	y	n	CH	y	CH
2	Twisted bowel	n	n	CH	y	Hospital
3	Old age	y	y	CH	y	CH
4	Chest infection	y	n	CH	y	CH
5	Deterioration	y	n	CH	y	CH
6	Deterioration	y	n	CH	y	CH
7	Chest infection/UTI	y	y	CH	y	CH
8	CVA	y	n	CH	y	CH
9	Deterioration	y	n	CH	y	CH
10	Deterioration	y	n	CH	y	CH
11	CVA	y	n	CH	y	CH
12	Chest infection/UTI	y	n	CH	y	CH
13	Deterioration	y	n	CH	y	CH
14	CVA	y	n	CH	y	CH
15	?	y	n	CH	y	CH
16	Constipation Cardiac arrest	y	n	CH	y	Hospital
17	Cardiac arrest	n	n	CH	n	CH
18	Burst Cyst	n	n	y	y	Hospital
19	Pneumonia	y	n	n	n	Hospital
20	Sudden deterioration	n	n	Home	n	CH
21	Deterioration	y	y	CH	y	CH
22	Sepsis	n	n	CH	y	Hospital
23	Chest Infection	y	n	CH	y	Other care
23		**N=18 (78%)**	**N=3 (13%)**		**N=20 (87%)**	**PPD Achieved N-15 (65%)**

Numbers of care home residents having an advance care plan and DNACPR in place

Between February and June 5% (n=22) of residents had an advance care plan and this rose to 13% (n=23) between July and October. There is clear evidence that staff undertaking the programme gained the confidence and skills necessary to enter into end of life care discussions with residents and their families, and many of the homes were beginning to include advance care planning as part of their routine care of residents by the end of the programme. However, there is still need for further training around advance care planning within care homes to take account of changes arising from the discontinuation of the Liverpool Care Pathway (LCP).

Conversely, 85 or 66% of the residents who died in the twelve months preceding the programme had a DNACPR order in place. This is not unexpected however, as health and social care staff are far more familiar with the concept of DNACPR orders than advanced care plans at the end of life, and discussions about this are more likely to have taken place with the residents, their GP and their family members. Establishing the futility of cardiopulmonary resuscitation is easier to achieve than the conduct of more proactive and wide ranging discussions about end of life care planning, although it is my no means clear if residents were always included in these discussions. This figure fell slightly to 62% or 21 of the residents who died between February and June, although the reasons for this slight fall are unclear and may simply be due to seasonal fluctuations or artefact. However, between July and October 24 residents or 88% of those who died in this period had a DNACPR order in place, demonstrating a heightened awareness of the need to discuss DNACPR orders and growing confidence in requesting that DNACPR orders are completed for eligible residents as part of the boarder advanced care planning process.

Use of the Liverpool Care Pathway

During the period of the programme, the results of Julia Neuberger's investigation of the use of the LCP were published, and a committee is still to decide on the approach to be taken going forward. However, the LCP is being phased out by March next year (2014). This is reflected in the post death audit. At the beginning of the programme 6 deaths in two residential care homes (7% of total deaths) were cared for under the LCP framework, but since this time, no other care home resident has died under this framework. An element of the Six Steps training included 'care in the last days' which covered the evidence base for interventions formerly described under the LCP but also included a significant amount of information on end of life prognostication based on the presenter's (SO'C) own research on behalf of the National Director of End of Life Care since it is the failure to prognosticate properly rather than the interventions themselves which lie at fault in the recent and much published failures to implement the LCP correctly. There should, when the national response to the report is published, be some funding for bespoke educational interventions to alert care home staff to these changes.

Increases in the number of care homes maintaining an end of life care register

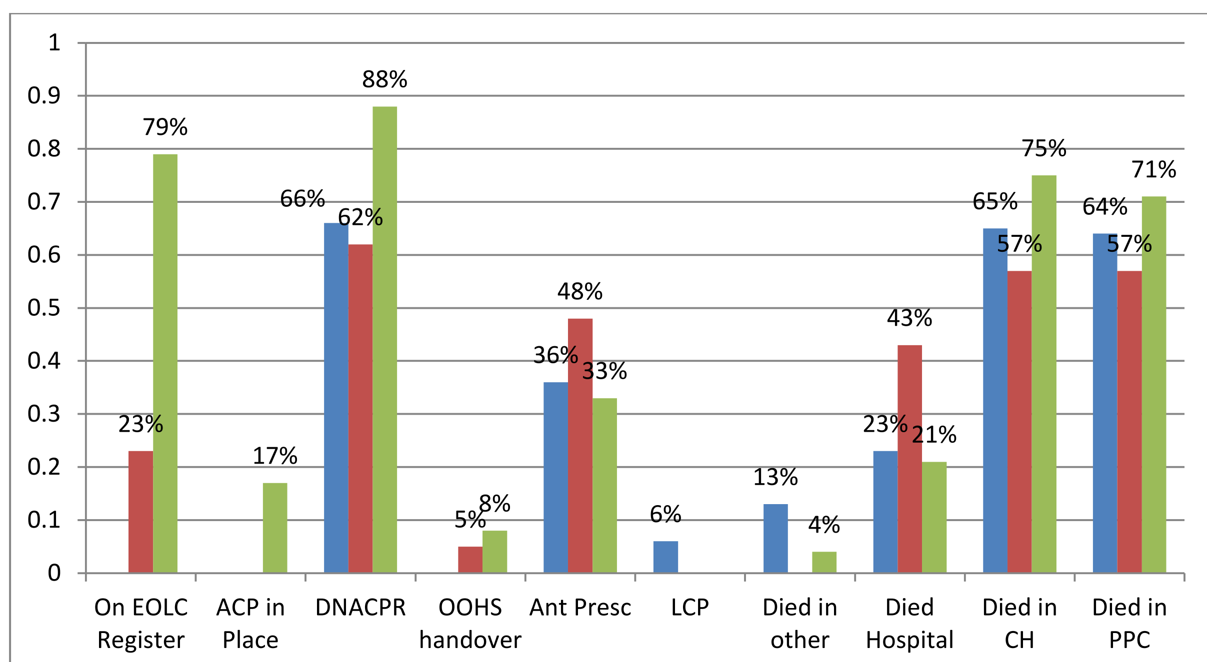
The baseline audit data showed that no care home residents had been identified as being at the end of life in the twelve months preceding the start of the programme. This was due to the fact that none of the care homes had an end of life register in place, and consequently, none of their residents were formally registered as being within the last year or months of life. It is possible that some residents had been identified as such by their GPs, but care home staff were unaware which, if any of their residents had been placed on an end of life register maintained by the GPs. Between February and June however, 27 (22%) of the residents who died within the homes had been included on an end of life care register maintained by the care home. Between July and October this figure had increased to 23 residents or 78% of those dying within that period. There is evidence therefore, that information about the need for, and formulation of an in-house end of life care register has significantly improved

performance in relation to this important outcome and that care home staff are clearly beginning to embed this important principle into their practice.

Evaluation of the use of social service packages in conjunction with external agencies

Any evaluation of collaborative team working between each of the different agencies involved in the care of patients at the end of life is likely to be subjective. However, one possible and more objective proxy for this is the 'Out of Hours Handover' (OOH). Data from the baseline audit covering the twelve months prior to the start of the programme showed no evidence of any Out of Hours Handovers having taken place for residents prior to their deaths. This increased to 5% (n=22) between February and June and to 9% (n=23) between July and October. Whilst disappointing that OOH are still not being implemented as widely as they should, this may be due to the fact that there is still a lack of agreement within the locality regarding the use of a locality register for end of life care which would enable information to be shared electronically between the different services and agencies involved in the care of residents at the end of life. It is notable however, that the 3 residents who were the subject an OOH did manage to die in their usual place of residence which was also their preferred place of death. An overview of all of the above outcomes can be seen in Figure 4 below, which show significant improvements in the two project audit points (red and green) over baseline (blue – or blank for zero data). It is worth reviewing these before moving on to more qualitative aspects of the data collected during the project which also show, albeit less conclusively and more anecdotally, some quite significant improvements in practice and culture in relation to end of life care in the homes during the course of the programme when compared to the baseline of one year prior to the programme (Appendix 2).

Figure 4: Post death audit comparison of outcomes at baseline (July and October 2013)



Baseline 2/12-2/13 (n=85)

Feb - June 2013 (n=21)

July- Oct 2013 (n=24)

Improvement in resident, carer and professional satisfaction

On the basis of evidence contained within the portfolios, it would seem that there have been some very positive outcomes from the programme. Many of the portfolios contain cards and letters received from the families of residents who have died in the homes of which the following are but three examples:

- *'I would just like to thank you and your staff for your dedication and compassion that you all showed to mum in her last few weeks. No-one could have done more to make her comfortable, and I had no concerns for her knowing that you were all looking after her, especially on her last day when your concern extended to us too….'*
- *'Thank you for taking care of my husband during his stay with you, it was nice to know he was in good caring hands….'*
- *'To all the staff: A big thank you to all who helped our dad during his time with you, we thank you so very much….*

Quality markers Audit

At the beginning of the programme, each care unit manager undertook an audit to explore the quality of end of life care. Different aspects of care were audited and rated between 0 to 3, 0 indicating nothing in place and 3 indicating something in place and recorded in the care plan with another form of written evidence. (Appendix D). The scores were added up and an overall score per care unit was calculated. The same audit was undertaken at the end of the programme to indicate the improvements. The aggregated pre-programme audit mean score between all the care units was calculated at 1.4, indicating that according to the care home managers they had a reasonable level of implementation of end of life care. The aggregated mean score rose to 2.3, when the audit was repeated at the end of the programme. This indicates that the care home managers perceive that the quality of end of life care has improved significantly within their practice settings as a result of the six steps programme.

Knowledge, Skills and Confidence audit

At the beginning of the programme each participant from the care homes was asked to complete a questionnaire regarding their knowledge, skills and confidence in relation to end of life care (Appendix E). Various areas were explored and the participants had to rate themselves between 0 and 5, 0 indicating no knowledge, skills or confidence and 5 indicating a high level of knowledge skills and confidence. The scores were added up and an overall score for every participant was calculated. The aggregated pre-programme audit mean score between all the participants was calculated at 2.6, indicating that they had reasonable knowledge skills and confidence. The audit was repeated at the end of the programme, and the aggregated mean score rose to 4, indicating that the participants felt significantly more knowledgeable, skilled and confident following participation in the programme.

4.0 Participant evaluation of the programme

Evaluation forms

The participants of the programme filled in an evaluation form following each workshop. Six aspects of the workshops were evaluated and the aggregated scores under each of these categories can be seen overleaf.

Figure 5: Aggregated evaluation scores for each workshop

	Excellent	Good	Average
Degree of learning	52.5%	43.5%	2.5%
Pitched at right level	50%	49%	1%
Quality of content	47%	51%	2%
Relevance to role	60%	40%	
Quality of hand-outs	48%	50%	2%
Quality of venue	45%	54%	1%

At the end of the programme the participants were asked to evaluate the programme as a whole. Overall the participants felt that they had benefited from having participated in the programme, and said that they had gained confidence in the delivery of all aspects of end of life care. Many felt that the programme had made a real and lasting difference in their practice areas as the following quotations from the qualitative feedback gained on the last day of the programme demonstrate:

- *'I have gained confidence to talk about end of life with my staff and residents, which will enable us to provide a better quality of end of life care. Although I was confident we were doing the right thing, the course has underlined that structured method mean that nothing is left to chance'*
- *'The whole programme has changed my outlook about death on a personal level. Although my portfolio is to be done, I have already started reviewing many aspects of the programme'*
- *'It has given me more confidence to work with residents and to discuss their wishes for their end of life'*
- *'Staff are asking more questions about what help is on the outside and also what they are able to help with in the home when the time comes'.*

Focus group evaluations

Participants were also asked during the last workshop to discuss those factors which had improved during the course of the year as a result of the programme, and secondly, to identify those factors which make it difficult to deliver good end of life care at present. The responses were different for each participant as one might expect, but answers to the first question included improvements in the continuity of care provided by different agencies, better liaison with the GP practice covering the home, regular weekly visits from the GP (although it is not clear if they occurred prior to the programme or not), and more regular reviews of residents' end of life status at other times. Other specific improvements included better and more rapid access to a specialist respiratory nurse for a resident with end-stage COPD and a quicker response and referral time for physiotherapy and review by a chest consultant. Others talked about the earlier booking and delivery of specialist equipment such as hospital beds and mattresses to the homes as a result of proactive planning and earlier engagement with logistics departments elsewhere.

Many participants felt that more DNACPRs were in place as a result of the programme and that staff had a better understanding of where they stood regarding such orders. Anecdotally, they felt that they had made fewer referrals to hospital or a nursing home, and had felt more confident to provide end of life care with improved support from the GP and care home managers/course participants in the resident's usual place of care. They felt that the knowledge base of all staff had improved as a result of the additional workshops, and that talk about death and dying which had previously been a difficult

and taboo subject had become easier. Better awareness of the importance end of life care planning and improved knowledge and confidence in managing symptoms were also cited by many as outcomes from the programme whilst a reduction in stress and anxiety about delivering an acceptable standard of end of life care was also noted. Additional benefits included better communication with residents and family members about end of life issues and a more open and truthful communication context which made it easier to discuss such issues. One surprising aspect was that staff in one care home realised for the first time that hospices and specialist palliative care services were not simply there to provide help and support for cancer patients and were available to help residents with non-malignant symptoms at the end of life as well.

The main obstacles to the delivery of good end of life acre in the homes were identified as a lack of support from other agencies, particularly the poor access to GP services out of hours services. This often caused delays in getting appropriate help and support for residents which might have prevented a crisis in care from occurring instead of which, some residents may well have been referred to the hospital instead. The implementation of the 111 service had hit several homes badly with poor reported responses and inappropriate advice given by call handlers. The lack of access to end of life care funding for some residents was also regretted as it meant that in some cases, residents could only receive the help they needed by transferring them to a nursing home when they would rather have stayed in the care home. Staff shortages, high turnover and inadequate hospital discharges back to the homes were also identified as problematic.

Some felt that individual care staff still lacked confidence or the requisite skills to deliver good end f life care while others were regarded as being prejudiced in certain areas. It was particularly frustrating when staff had to work with multiple GP practices which had very different views about the benefits of anticipatory prescribing for instance. They were also frustrated by those that refused to write a DNACPR order until it was evident that the resident was already dying – or failing to do so completely, particularly at the end of the week or as holidays were approaching. This left care home staff in a difficult situation as regards their management of the death when it ultimately occurred. Participants were also surprised at the numbers of other professionals who simply refused to accept that the resident may be dying or recognising obvious signs such as increasing frailty as signs that death was likely to occur sooner rather than later.

5.0 Conclusions and recommendations

These results demonstrate that there is a definite improvement in both the objective quality and the perceptions of care provided for residents at the end of life within care homes/units following completion of the Six Steps programme. The main improvements of note include:

- improved communication with residents and families regarding their care needs, enabling more person centred approaches to end of life care to be provided
- improved professional communication and care coordination within the homes and with external agencies leading to better multi-agency working where GP practices in particular actively support the programme
- greater numbers of residents receiving proactive as opposed to reactive care as a result of having an advanced care plan in place
- greater numbers of residents dying in their usual place of residence and/or their preferred place of care
- fewer admissions to nursing homes and acute hospitals as a result of improved symptom management and end of life care skills being available in the homes and consequently,

- a greater number of residents and family members experiencing a dignified death without inappropriate medical intervention or transfer to an unfamiliar and oftentimes inappropriate care setting elsewhere.

There are still many challenges faced by care homes or similar units when seeking to provide a high standard of care for people at the end of life. Many of these relate to the transitory nature of senior staff within the care sector which curtails continuity and denudes the homes of valuable expertise. It also prevents the development of good working relationships with external partners and agencies necessary for the delivery of a comprehensive end of life care package. This was manifested several times during the delivery of the programme as highlighted in this report. Care homes are only able to give a high standard of care if essential support services are available, supportive, and fully accessible in a timely manner when needed. Several participants identified what can only be described as poor practice on the part of some GP services in refusing to allow discussion of advanced care planning or the prescribing of vital medications for residents who were evidently dying. The situation is particularly difficult with out of hours services and those who are unfamiliar with the residents' medical background and histories. The positive outcomes outlined in this report will only be sustained with continued support for those seeking to provide end of life care in care homes and perhaps, stronger action against individual professionals who continue to remain disengaged from the inevitable process of dying faced by the residents of these institutions.

Most of the participants of the programme have now completed a portfolio of evidence and an end of life action plan which clearly demonstrate the achievements they have made and the University will continue to support those who have yet to complete their portfolios and actions plans to do so. The lack of funding for further follow-up and a long term evaluation of the benefits of the programme is regrettable, but the University is considering the establishment of an informal 'Six Steps Forum' so that those who have engaged with this and other programmes can continue to benefit from mutual peer support and the encouragement of the programme facilitator. Others are progressing at a slower pace and through no fault of their own (often due to the rapid turnover of senior care home staff) are constantly having to 'reinvent the wheel'. There is however, clear scope in evaluating the successes of the project over the longer term, and extending the benefits of the programme to more care home staff so that such organisational knowledge is not lost. Finally, in relation to the demise of the LCP, there should be funding for bespoke educational interventions to alert care home staff to any changes in end of life care planning decided in response to the current consultation being conducted by the Department of Health.

Appendix 1: Audit of admissions to and from hospital during the programme

ID	Reason for admission	Clearly preventable	Possibly Preventable	Not preventable	Outcome
1	Deteriorated/ unresponsive		x		?
2	Sepsis		x		Died in hospital
3	Fall/head injury			x	Returned
4	Vomiting Blood			x	Returned
5	Fractured wrist			x	Returned
6	CVA			x	Died in Hospital
7	Fall/tissue damage			x	Returned
8	Fractured hip			x	Returned
9	Pain due to fractured hip			x	Returned
10	Fall - pain in hip			x	Returned
11	Cancer/heart failure	x			Died in hospital
12	Abdominal pain/ twisted bowel			x	Died in hospital
13	Mobility Problems	x			Discharged to nursing home
14	Chest infection		x		Discharged to nursing home and then died
15	Chest infection		x		?
16	CVA			x	Returned
17	Fractured femur			x	Returned
18	Fall			x	Died in hospital
19	Chest infection			x	?
20	Angina			x	Returned
21	Chest pain			x	Returned
22	Chest infection / unstable diabetes			x	Discharged to family home
23	Anuria/pain			x	Returned
24	Chest infection/UTI		x		Died in hospital
25	Sudden deterioration			x	Died in Hospital
26	Brain haemorrhage			x	Died in hospital
27	Constipation	x			Died in hospital
28	Fall			x	Returned and died in home
29	Renal failure		x		Discharged to a nursing home and died
30	Move closer to family			x	To other RCH
31	Increased needs		x		To Nursing home

ID	Reason for admission	Clearly preventable	Possibly Preventable	Not preventable	Outcome
32	Chest infection		x		Discharged to a nursing home and died
33	UTI/ Deterioration		x		?
34	Fall			x	?
35	Pneumonia		x		Returned
36	CVA			x	Died in hospital
37	Haemorrhage			x	Died in Hospital
38	Dyspnoea			x	Died in hospital
39	Fall/fractured rib/ collapsed lung			x	Died in Hospital
40	? fractured wrist			x	Returned
41	Fall head injury			x	Returned
42	Fall ripped septum			x	Returned
43	Resident picked stiches out			x	Returned
44	Fall/fractured hip			x	?
45	Fall/fractured hip			x	Returned
46	?		x		?
47	?		x		?
48	PE			x	Returned
49	Chest pain			x	Returned
50	Fall			x	?
51	? fractured hip			x	Returned
52	?CVA			x	Returned - no CVA
53	Fall head injury			x	Returned
54	Fall			x	?
55	Haemoptysis			x	Returned
56	Fall/fractured hip			x	?
57	? fractured arm			x	?
58	Gastroenteritis			x	Returned
59	Unresponsive			x	?
60	Fractured elbow			x	Died in hospital
61	Hypotension			x	Returned
62	?CVA			x	Returned
63	Fractured hip			x	Discharged to nursing home
64	CVA			x	Returned
65	Fractured hip			x	?
66	Diarrhoea and vomiting			x	Returned
67	Feeling unwell		x		Returned

ID	Reason for admission	Clearly preventable	Possibly Preventable	Not preventable	Outcome
68	Insertion of catheter			x	Returned
69	Requiring nursing care			x	To Nursing home
70	Catheter retention		x		Returned
71	Deterioration		x		Returned
72	UTI		x		Returned
73	UTI/fall			x	Returned
74	UTI		x		?
75	Fractured hip			x	Returned
76	Fall / chest infection			x	?
77	? Infection		x		?
78	Infection of catheter		x		Returned

Appendix 2: End of life care 6 Steps to Success Programme in Care Homes

Care Home	Thistle Lodge NH	Rose Lodge RCH	Azalea Lodge RCH	Petunia Lodge RCH	Clematis Lodge RCH	Daffodil Lodge RCH	Crocus Lodge SH	Gerbera Lodge SH	Tulip Lodge CH	Freesia Lodge RCH	Iris Lodge CH	Lobelia Lodge RCH
Pre programme: post death audit	X	X	X	X	X	X	X	X	X	X	X	X
Post programme: post death audit	X	X	X	X	X	X	X	X	X	X	X	X
Pre programme: CH Audit	X	X	X	X	X	X	X	X	X	X	X	X
Post programme: CH audit	X	X		X	X	X				X	X	X
End of life care policy	X	X	X	X	X	X				X	X	X
End of life care coding	X	X		X	X	X				X	X	X
End of life care register	X	X		X	X	X				X	X	X
System for advance care planning	X	X	X	X	X	X						X
System for holistic assessment	X	X		X	X	X						X
Out of hours handover												
Discussion meeting with GP(s)	X	X		X	X					X	X	X
System for regular review with GP(s)	X	X	X	X	X					X	X	X
Key worker system in place		X		X	X	X			X	X	X	X
Services network information	X	X		X	X	X				X		X
Training needs analysis	X	X		X	X	X						X
System for reviewing all transfer of residents	X	X		X	X	X			X	X	X	X
Significant event analysis	X	X		X	X	X					X	X
Facilities leaflet, after death leaflet	X	X		X	X	X				X		X
On-going post death audit	X	X	X	X	X	X	X	X	X	X	X	X
Portfolio completed	X	X		X	X	X						X

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