

LOTHIAN ADVANCE CARE PLANNING PROJECT

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on behalf of the Advance Care Planning Project Steering Group

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EXECUTIVE SUMMARY

In 2010 NHS Lothian funded a one-year Project which, in collaboration with Marie Curie Hospice Edinburgh and St Columba's Hospice, would support health care staff across Lothian to implement Advance Care Planning (ACP). A Project Steering Group was established (Appendix 1) and Project Manager appointed. A key goal for the Project was to develop palliative and end of life care in Lothian through ACP in line with national⁽¹⁾ and local⁽²⁾ strategies and existing ACP initiatives e.g.

- Electronic Palliative Care Summary (ePCS)⁽³⁾
- Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)⁽⁴⁾
- Long Term Conditions Collaborative Generic Anticipatory Care Plan⁽⁵⁾

The Project Objectives

- Develop the Lothian Approach to ACP
- Network and engage with other stakeholders involved in ACP
- Identify the learning needs, develop learning resources and deliver ACP education to various staff groups
- Select three clinical settings to undertake more in depth facilitation of staff to develop ACP as examples of good practice

The Methods

The Lothian Approach to ACP was developed by the Project Steering Group and agreed by the Lothian Managed Clinical Network (MCN) for Palliative Care in July 2010.

Networking and Engagement was undertaken throughout the year with clinical teams across Lothian (Figure 6, page 29).

An Educational Resource and learning objectives were developed in collaboration with St Columba's Hospice education department (Tables 3 and 4 page 12. Appendix 6, 7, 8, 9).

A Combined Education and Practice Development Programme was implemented in three clinical settings – two Social Care Homes for older people (setting 1), an Acute Stroke Unit (setting 2) and a Primary Care Practice (setting 3).

Summary of Overall Key Findings

- In each setting there were gaps in understanding of palliative care definitions and of the ACP process
- Identifying palliative patients/residents who may benefit from ACP was not routine practice
- Staff were uncertain how to share the outcomes from ACP conversations or had difficulty with the IT system
- Staff were enthusiastic about reviewing current ACP practice and eager to make changes which could improve end of life planning in accordance with patient wishes

Summary of Key Recommendations on how to best support clinical teams to implement ACP in Lothian

1. Recommendations for MCN Educators

Develop a planned approach to:

- Incorporating ACP and palliative care education within social, acute and primary care undergraduate and postgraduate education
- Accessing ACP resources identified within the ACP project
- Embedding ACP education within clinical settings

2. Recommendations for NHS Lothian

Develop a planned approach to:

- Identifying patients with palliative and supportive care needs using recognised tools
- ACP education for health and social care staff
- Training primary care staff to use recognised IT systems e.g. Electronic Palliative Care Summary (ePCS)
- Promoting collaborative sharing of ACP outcomes with other health and social care teams

3. Recommendations for Clinical Settings

Develop a planned approach to:

- Collaborative review of ACP practice on a regular basis e.g. case review of good practice and not so good practice
- Defining patient outcome measures for ACP e.g. ePCS activity, preferred place of care, preferred place of death.

Conclusion

An overarching theme from the project was that the lead clinician was essentially the “gatekeeper” to ACP. If they did not identify a patient as having palliative care needs then staff were unable to promote ACP discussion.

This 12 month collaborative project has taken a practice development and education approach to promoting ACP as a means of enhancing palliative and end of life care for

patients and their families.

The main phase of the project involved in depth facilitation of ACP in three settings and the sharing of what was learned more widely with other professional groups.

Appointing 'key champions' helped facilitate ACP education. In addition staff who engaged in the educational approach have achieved the learning objectives and are more likely to use ACP themselves and prompt ACP within their clinical teams, therefore supporting the embedding of ACP into daily clinical practice.

Future change in practice will be dependent on:

- A planned collaborative approach to ACP education and the ACP process
- Greater support for staff with a sense of how ACP and efficient communication processes can improve patient care
- Case review within the clinical setting using a reflective model to identify challenges and highlight good practice

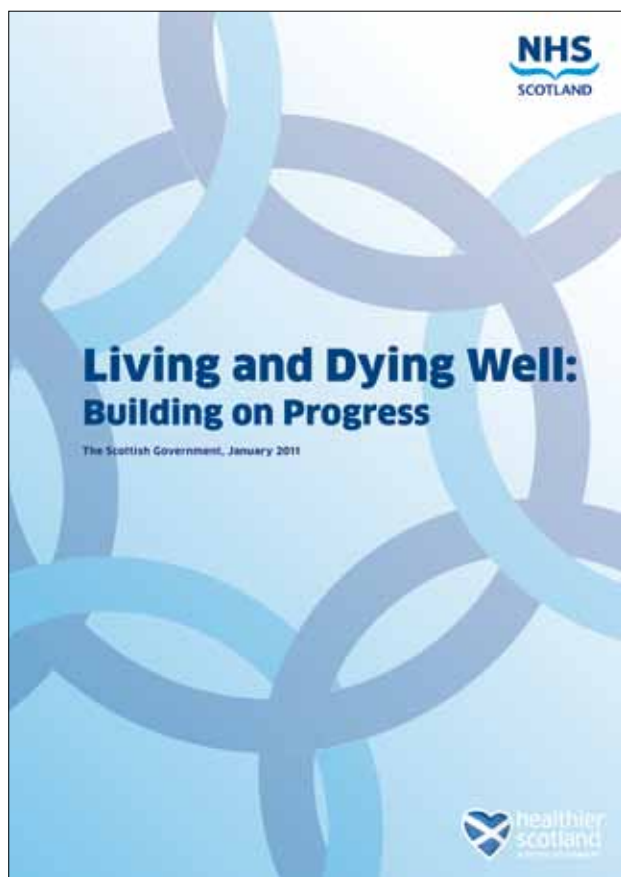
The full report has reflected on the ACP project, so that others in the future can opt to use, amend and/or develop the approach taken and resources employed in this initiative to support ACP education and practice development across Lothian.

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INTRODUCTION

This report outlines findings from a collaborative project between NHS Lothian, Marie Curie Hospice Edinburgh and St Columba's Hospice. The overall aim of the project was to support health care staff across Lothian to implement Advance Care Planning (ACP) using an integrated education and practice development approach to enhance the care of patients and families in the palliative care phase of illness and at the end of life. Three clinical settings – two Social Care Homes for older people (setting 1), an Acute Stroke Unit (setting 2) and a Primary Care Practice (setting 3). The learning from this was shared widely with other professional groups. This project was designed to support the delivery of both the national action plan *Living and Dying Well*⁽¹⁾ and the *Lothian Strategy for Palliative Care*.⁽²⁾ In the following report the background to the project, the plan, the approach taken and the findings will be discussed. Conclusions are drawn and recommendations made.



BACKGROUND

National and local strategies^(1,2) require the setting up of systems to ensure that those needing palliative or end of life care, based on need not diagnosis, are identified, their needs assessed, a care plan produced and that the delivery of care is coordinated and communicated within and between teams.

Identifying when someone is entering the palliative phase of an illness can be challenging. Tools such as the Prognostic Indicator Guidance (PIG)⁽³⁾ from the Gold Standards Framework (GSF) or the Supportive and Palliative Indicators Tool (SPICT)⁽⁴⁾ from NHS Lothian's palliative care guidelines⁽⁵⁾ are designed to help identify when a person is in the palliative phase of an illness. Earlier recognition of people in the palliative phase of an illness leads to earlier planning and better care.⁽⁶⁾

Professionals caring for people as they enter the palliative phase of their disease are involved in a number of important roles. One of which is with ACP discussions, if and when appropriate. ACP should never be forced upon a patient or their family and is usually part of an evolving discussion, or may be a chance one-off conversation, but however this discussion occurs it can be both life and death changing.⁽⁷⁾ An ACP discussion may lead onto a statement of wishes or preferences, an advance decision to refuse treatment, appointment of a power of attorney (financial and/or welfare), the patient making legal or personal wishes known. It is suggested that the use of ACP increases dignity, choice and control; makes communication between the individual, family and health care team more effective and may support more people to be cared for or to die at home.⁽⁸⁾

Clinical information from ACP discussions, usually several discussions as information evolves over the time of the relationship, should be recorded and updated with the purpose of sharing this information with the healthcare team. An anticipatory care plan is one method of sharing this information. NHS Lothian recommends that health care professionals use the electronic palliative care summary (ePCS) as an anticipatory care plan in patients identified to be in the palliative phase of their disease.

The ePCS is an electronic tool used to communicate a patient's health history with the out of hours healthcare team.⁽⁹⁾ It is essential the out of hours team are able to access the same information as the patient's primary carers, as often they will not know the patient. In addition to demographic and specific clinical information, the ePCS should contain core information including level of escalation of care should there be deterioration in their condition, preferred place of care and death, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) status and details of any appointed welfare power of attorney.

While initial work on ACP has been undertaken by a range of groups at a national level^(8,10,11), it was agreed that there was a need to develop practice in Lothian. Although existing education programmes address ACP⁽¹²⁾, the scale of the work involved in raising awareness and facilitating change in practice across Lothian, posed a significant challenge to educators.

Funding was secured to take this work forward in Lothian. A Project Steering Group, Appendix 1, of key clinicians and educators was established to plan, deliver and evaluate the project.

THE PROJECT OBJECTIVES

The aim of the project was, as already stated, to support health care staff across Lothian to implement ACP using an integrated education and practice development approach to enhance the care of patients and families in the palliative phase of an illness and at the end of life.

The following objectives were also set:

- Agree a working definition of advance care planning and an anticipatory care plan
- Recruit an ACP Project Lead (PL) to facilitate the project
- Review existing teaching/learning resources and key literature/policies on ACP
- Engage with others involved in related work to ensure that existing initiatives are recognised and built upon
- Select three clinical areas and undertake in-depth facilitation of staff to develop ACP as examples of good practice
- Identify learning needs of various staff groups, develop a detailed plan, deliver and evaluate a programme of education, including teaching/learning resources
- Contribute to the development and implementation of policies/guidelines/patient information
- Produce a final report to disseminate achievements

Marie Curie Hospice Edinburgh had lead responsibility for the project to ensure that reporting to the NHS Lothian Palliative Care Managed Clinical Network (MCN) and NHS Lothian Health Board was robust. The ACP PL managed the project on a day to day basis reporting to the Project Steering Group, Appendix 1. The Education Department at St Columba's Hospice provided education support and this was supplemented by the MCN Educators Group.

A practice development model was selected to underpin the project⁽¹³⁾.

THE METHODS

The selected practice development model encompasses facilitating change in practice; delivering education; promoting two-way communication between strategic management and clinical practitioners; and responding to policies/guidelines that have an impact on change.⁽¹³⁾ The one year project was planned in 4 phases: orientation; preparation for change; change and evaluation; and reflection⁽¹⁴⁾, Appendix 2.

Phase 1: Orientation Phase

This phase involved agreeing working definitions for the project, appointing a PL, reviewing key literature and teaching materials relevant to ACP and engaging with other stakeholders.

Currently there are a number of definitions of advance and anticipatory care planning and different concepts of how this might be applied in practice.^(15,16) Prior to the appointment of the PL, definitions were agreed with the MCN. These are summarised in Table 1 and detailed in Appendix 3.

Table 1: Definitions – the Lothian approach to planning in advance for palliative and end of life care

- All care planning should include thinking ahead for all patients regardless of capacity, where clinical deterioration may be anticipated
- Advance Care Planning is a process of discussion between an individual and their care provider about their preferences, wishes, beliefs and values about future care. Its purpose is to provide guidance to inform future care decisions in the event that the individual has lost capacity to make these decisions. It should be offered during routine clinical practice^(15,16)
- Advance Care Planning may lead to:
 - An Anticipatory Care Plan (see below)
 - A statement of wishes and preferences
 - An advance decision to refuse treatment in a future situation (advance healthcare directive, living will etc)
 - A DNACPR decision (only applies to the treatment of CPR)
 - The appointment of a Welfare Power of Attorney
- An Anticipatory Care Plan is a dynamic clinical document used by and for healthcare staff which provides a record of the preferred actions, interventions and responses that care providers should make following a clinical deterioration or a crisis in the individual's care or support. It will be informed by advance care planning discussions with patients or by care planning discussions with the healthcare teams, Welfare Power of Attorney or family/next of kin for patients who lack capacity to engage in advance care planning discussions.⁽⁸⁾
- The core elements of the Anticipatory Care Plan will be
 - Levels of intervention for anticipated clinical deterioration(s)/event(s) including any specific advance decision to refuse treatment
 - Preferred place of care and death
 - Resuscitation status
 - Wishes regarding organ and tissue donation
 - Contact details of any legally appointed Welfare Power of Attorney

Key literature and teaching materials were identified to ensure a sound evidence base for the project and this process continued during the project. Once the PL was appointed, contact was made with stakeholders and with those leading other initiatives relevant to ACP. These contacts included the teams implementing:

- The Electronic Palliative Care Summary (ePCS)⁽⁹⁾
- The Long Term Conditions Generic Anticipatory Care Plan⁽⁸⁾
- The national Do Not Attempt Cardiopulmonary Resuscitation policy⁽¹⁷⁾

Phase 2: Preparation for Change

In this phase the three clinical settings for practice development were identified and preparatory work for the education and practice development was undertaken.

The Project Steering Group, Appendix 1, considered a variety of clinical areas, identified by the PL through a scoping exercise, before agreeing the project settings: two Social Care Homes for older people (setting 1), an Acute Stroke Unit (setting 2) and a Primary Care Practice (setting 3). A summary of the work undertaken and the number of Staff who accessed the programme are outlined in Appendix 4.

In each setting the manager or clinical lead identified an ACP champion. It was considered crucial to have someone from the setting to work collaboratively with the PL, as the champion would have expertise in that context and the potential to optimise staff engagement with the learning objectives. In addition, the champions would lead and sustain change in practice and undertake further education of staff following the project intervention.

A specific learning needs analysis was carried out in each setting prior to implementing the education intervention with the purpose of identifying:

- The champion's learning objectives
- The setting's learning objectives
- The most appropriate educational resource
- The most appropriate educational approach

The specific learning needs analysis was useful as it identified educational gaps, some of which were common to all settings, these are set out in Table 2.

Table 2: Educational gaps identified during the specific learning needs analysis
• ACP terminology
• Palliative care definitions familiar to Specialist Palliative Care
• Identifying palliative patients/residents who may benefit from ACP
• The process used to record and share clinical information for patients with palliative care needs

The specific learning needs analysis also provided a chance to consider the most appropriate education approach to undertake in the particular setting, as it was soon evident that “one size would not fit all”. For example a workshop model, so successfully implemented in the social care homes, was not appropriate in the other settings for a number of reasons including:

- Difficulties in releasing staff from busy clinical settings for workshop
- Some staff ambivalence about ACP education
- Sense of staff feeling overwhelmed with new initiatives
- Limitations of project time scale

Core learning objectives were developed for the education in the three settings, Table 3, although a slightly different approach was taken to achieve them.

Table 3: Core ACP Learning Objectives

• Define what is meant by ACP
• Start to explore who may benefit from ACP
• Describe what ACP may lead onto
• Discuss the tools used in Lothian to record and share the outcomes from ACP discussions
• Explore their role and reflect on the ACP process in their setting

A project learning contract for ACP champions and managers, Appendix 5, was developed to detail project expectations and learning outcomes. The contract ensured that expectations were congruent and it also provided the opportunity for staff to express what they hoped to gain from the project. The contract was used in setting 1 and 3, but not in setting 2, where the educational approach did not lend itself to a contract. This is discussed in more detail on page 21.

Finally, an educational resource was developed in collaboration with St Columba’s Hospice Education Department to support the educational approach for the ACP education, Table 4.

Table 4: Educational resource

• ACP Presentation, Appendix 6
• ACP Quiz, Appendix 7
• DNACPR DVD ⁽¹⁸⁾
• Reference list (page 33)

Phase 3: Change and Evaluation

This was the main phase in which the PL supported practice development in the three selected clinical settings and also networked and shared best practice with a wide range of professional health and social care practitioners across Lothian and beyond. These activities are set out in the main body of the report as Findings in the Clinical Settings (pages 14-28) and as Other Key Project Activities (pages 29-30).

Phase 4: Reflection

This report is a reflection on the project with recommendations and conclusions set out on pages 31 and 32.

FINDINGS IN CLINICAL SETTINGS

ACP education and practice development facilitation was undertaken in three clinical areas. The following sections will discuss the work in each setting in relation to:

- Background
- Specific learning needs analysis
- Educational approach
- Evaluation
- An example of ACP practice
- Discussion

Setting 1: Long Term Care Facility for Older People

Background: Two social care homes were identified as setting 1 (66 beds). In one care home all residents had a diagnosis of severe dementia, while in the other residents had a number of co-morbidities including mild dementia. Each home had an identified GP and district nurse. This arrangement was more formal in one home, where all the residents were registered with one GP, than in the other where this was not the case. The majority of staff had worked in the social care setting for a number of years and had experience of providing end of life care. A number of staff had undertaken formal palliative care education.

Specific Learning Needs Analysis: The specific learning needs analysis for this setting illustrated that senior staff understood the philosophy of ACP. It also indicated that staff were keen to care for residents until death, but did not feel qualified to discuss this with health care staff. Their definition of palliative care was confined to the final weeks of life rather than the broader GSF definition.⁽³⁾ When asked the surprise question¹ staff identified a large number of patients who might die in the coming 6-12 months. Staff described what could be considered ACP discussions, but there was no structured or consistent approach to sharing the information gathered and staff were unaware of the ePCS. A variety of paper “anticipatory care plans” were in place however, there was no process to share this information with the wider healthcare team. All of this led to some confusion between the social care and health care teams.

DNACPR practice was not fully in line with existing guidance.⁽¹⁷⁾ An example of current practice in the setting is described in case study 1. Anecdotal conversations with other health and social care staff during the project would suggest this is not uncommon practice within the care home setting possibly due to limited understanding of existing new guidance.

¹ The surprise question “Would you be surprised if this patient were to die within the next year?” from the Gold Standard Framework Prognostic Indicator tool (PIG) is recommended to identify patients with palliative care needs⁽³⁾.

Case study 1: Variation in DNACPR practice

As part of the admission process care home staff described how they are often involved in a DNACPR conversation, if appropriate. Staff disclosed that they often found this conversation very difficult.

One recent example was where the niece of a new resident who did not have capacity was asked if she would like a DNACPR form completed for her aunt. The relative did not feel able to make a decision on admission. Staff reassured her that it was not urgent. The relative returned two weeks later and requested a DNACPR for her aunt. She disclosed that she had found it very difficult because although she was next of kin it was not something they had discussed.

This case study highlighted an example of DNACPR practice within the setting. During the projects workshop staff explored the burden this decision may have had on the relative. The case study was used to draw attention to current DNACPR guidance.

Educational Approach: A blended educational approach was adopted in setting 1 with the aim of achieving the core learning objectives, Table 3 (page 12). The approach included:

- Completion of Project Learning Contract, Appendix 5
- Pre and post workshop meetings with the champions
- Weekly workshops delivering the agreed learning objectives over 4 weeks
- Evening workshop delivering agreed learning objectives in one session

As part of the collaborative approach the PL met with the champions prior to each workshop to prepare them for the workshop, identify potential concerns, answer questions and assess their learning objectives.

The workshop format facilitated discussion on the benefits of a “thinking ahead” approach for residents. Staff identified a number of barriers to ACP. These included the residents’ loss of capacity, sometimes prior to admission and the time consuming nature of ACP discussions. A variety of health care staff visit the care home and care home staff were uncertain who should be having ACP discussions with the resident. The majority of staff did not understand the information sharing process that health care should use to record outcomes from an ACP discussion. There was also a lack of confidence about exploring cues regarding end of life concerns with residents. However, the workshops did facilitate discussions of how to change practice and implement ACP. It was acknowledged by staff that ACP discussions might be initiated at various time points including:

- On admission
- When there was a change in the resident’s physical condition or function
- When the resident’s care was being reviewed
- During a GP review appointment
- When a resident initiates a discussion about their wishes for the future, case study 2

Case study 2: Example of change in practice

A member of the team described how a female resident often voiced concerns about dying, particularly during the night. Staff usually soothed her with a cup of tea.

Following the ACP workshop where the poem *Listen*, Appendix 8, had been played the social care worker reflected on how perhaps staff blocked an opportunity for the resident to discuss her beliefs and wishes.

The next time the resident voiced her concerns the social care worker made her a cup of tea and went to sit with her and said *"Tell me what is troubling you?"* As a result, the resident disclosed that she felt her life was coming to an end and that although she was not afraid of dying, she was afraid of being on her own as she did not have any family. The social care worker, after listening to her concerns, acknowledged them and reassured her that when the time came the team would do everything in their power to ensure a member of staff was with her at the end of her life.

The champions and PL developed an ACP resource folder, Table 4 (page 12), which in addition to the core project tools contained a contact flow chart for future educational palliative care advice. The champions in both care homes agreed to locate the ACP folder next to the NHS Lothian Palliative Care Guidelines.⁽⁵⁾

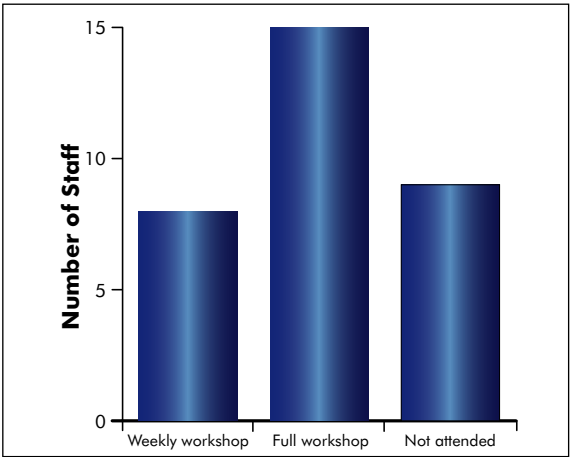
Evaluation: In terms of engagement with the education, both managers were proactive in promoting palliative care education and welcomed the opportunity to take part in the project. Both were eager that as many staff as possible achieved the learning objectives and not only encouraged this, but provided staff backfill if necessary. This enthusiastic engagement was crucial due to the time limited nature of the project.

Education was aimed at all social care staff involved in the palliative care of residents as they approached the end of life.² In care home one, the manager encouraged ancillary staff to attend if they wished. This group played an important part in the workshop discussions and highlighted that often residents or families disclose information to them. The workshops provided a valuable forum to explore how they then shared this information with senior staff.

² End of life as defined by the GSF for patients in the last 6-12 months of life⁽³⁾.

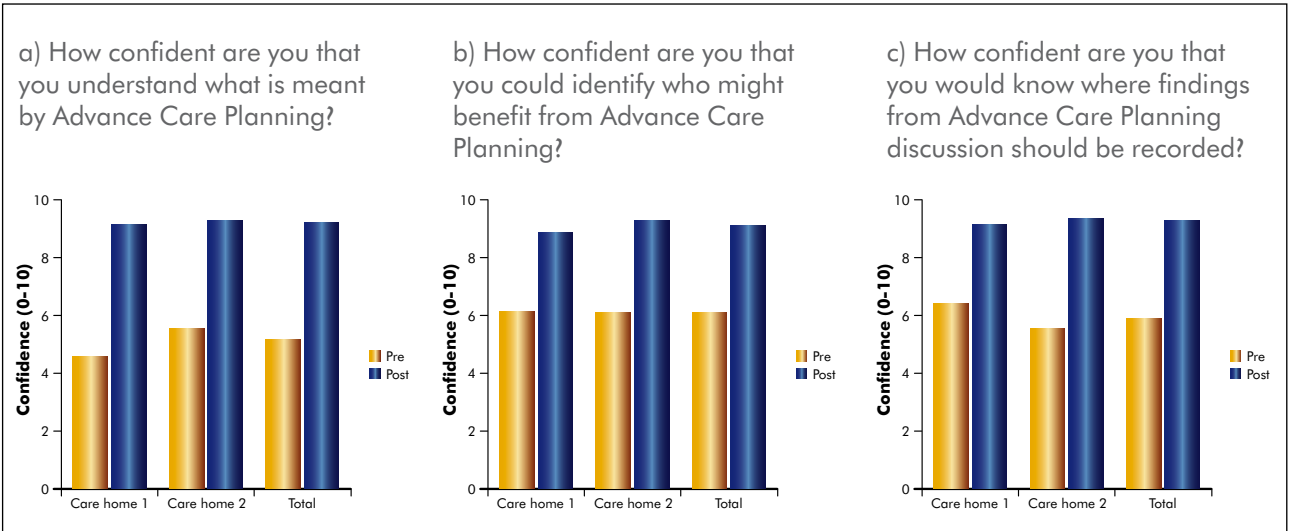
The learning objectives were either delivered over four workshops or during one full (concentrated) workshop, Figure 1. Overall the workshops were well attended with 52% of staff in care home one able to attend and 72% in care home two. The champions in each setting committed to providing education to staff who were unable to attend and to future new social care home staff.

Figure 1: Workshop attendance in one social care setting.



Evaluation of learning outcomes was carried out in a number of ways including pre and post workshop questionnaires, a feedback board in each care home where staff could post comments or questions, interviews with champions and managers and a post workshop questionnaire. Figure 2 demonstrates the increased confidence displayed by care home staff in terms of the workshop learning outcomes.

Figure 2: Outcomes from workshop learning outcomes.



Comments left on the feedback board demonstrate that the project was thought provoking both professionally and personally:

“It has made me think about talking to my family about what I would want”.

“We should all do some advance care planning”.

Evaluation of change in practice was assessed through an evaluation questionnaire and exit interview with champions and managers.

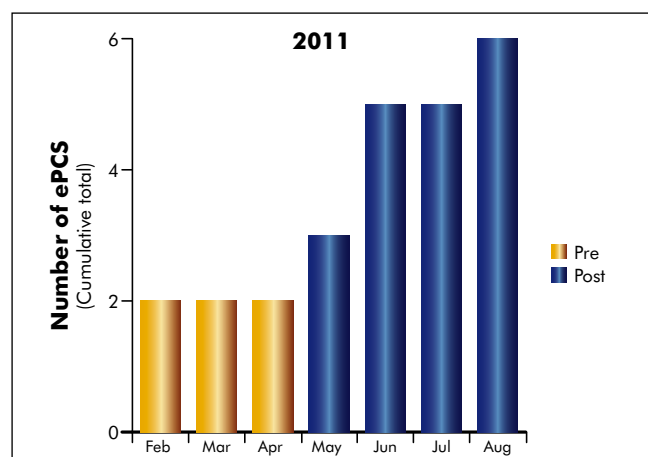
Their comments included:

“Staff have an increased understanding of what advance care planning and the anticipatory process means for residents in a care home” (Care Home Manager)

“Staff have started to ask questions about advance care planning for the residents during clinical supervision” (Senior Member of Care Home Team)

Additionally, the PL attended the relevant Primary Care practice group meeting which provided an opportunity to present the project aims and outcomes. The majority of the staff at the meeting had limited understanding of the ePCS and had reservations about using it for patients who they would not be surprised if they died in the next 6-12 months. Figure 3 demonstrates some change in ePCS activity in the GP practice attached to setting 1 over time.

Figure 3: ePCS activity in primary care practice attached to setting February – August 2011.



An example of ACP Practice: The workshops also offered opportunities for staff in the social care homes to discuss future changes in practice. Staff were not aware of options should there be a deterioration in a resident's medical condition, believing that the majority of residents would go to hospital if they developed symptoms requiring medical assessment. A recent example of this was case study 3 which highlighted a clinical situation where perhaps the resident did not have an ePCS.

Case study 3: Example of where ePCS may have improved patient care

Staff described a number of examples where residents were taken to the acute setting when they felt it would have been more appropriate to have cared for them in the care home setting.

One example was an 86 year old resident with a history of dementia and terminal cancer who fell during the night sustaining a skin laceration. NHS 24 sent a paramedic crew who transferred the resident to the acute setting. Following treatment he was transferred to medicine of the elderly where he died a few days later.

Staff were disappointed that it appeared necessary to transfer him to hospital and questioned why treatment did not happen in the care home setting. The scenario highlighted how perhaps an ePCS with clear advice in relation to escalation of care may have provided a different outcome e.g. Out of hours doctor assessing and treating in the setting, thus potentially avoiding hospitalisation and allowing the resident to die in preferred place of death.

A further case study, case study 4, was useful in facilitating exploration of how change in practice could help another resident in a similar scenario. The case study was also adapted and used as a teaching tool during various educational opportunities and shared with others involved in ACP education, Appendix 9. In this way learning from setting 1 has been used to support the development of practice in the wider project.

Case study 4: Example of where ePCS may have improved patient care

An 84 year old resident with a history of dementia and general frailty experienced respiratory distress during the night. Staff called NHS 24 for advice and following assessment a paramedic crew transferred the resident to emergency medicine. The resident died in unfamiliar surroundings four days later.

Both the care home manager and GP were surprised that the resident had been transferred to the acute setting as both felt the paper anticipatory care plan in the resident's notes would have negated an escalation of care to the acute setting.

Exploration of this case study revealed that there was no process for sharing the clinical information held in the paper anticipatory care plan with the wider health care team. It highlighted how an ePCS may have provided a more favourable outcome for the resident and those involved in their care.

Discussion: Collectively staff reported that residents are frailer on admission when compared with those admitted in the past and they require more input from staff. This information highlights how important early identification of palliative patients is, if they are to receive effective anticipatory care. Evaluation identified that the educational approach was effective in increasing staff awareness and understanding of ACP and the process. Future social care education regarding the level of training on a wider scale with limited resources may be challenging in replicating the ACP project's model. However the local palliative care team is currently involved in an initiative aimed at delivering palliative care education in the social care setting.

The ePCS activity in the primary care setting attached to the social care home has increased post implementation although not as significantly, Figure 3, as one may have anticipated after an educational intervention. However this may be due to contradictory assessment between health and social care staff on identification of palliative care patients.

Future evaluation of post project education, ACP process and ePCS activity would provide valuable information relating to the longer term impact on patient care.

Setting 2: Acute Stroke Unit in University Hospital

Background: An Acute Stroke Rehabilitation Unit was identified as setting 2 (18 beds). A variety of healthcare professionals are involved in the multidisciplinary team (MDT) caring for patients following a stroke including medical, nursing and Allied Healthcare Professionals. Rehabilitation is often a long process which can take weeks to months until full rehabilitative potential has been achieved. A number of patients die in the unit as a result of their stroke³; the remaining patients are discharged to their home, transferred to a short term facility whilst awaiting suitable long term care or transferred to a continuing care facility.⁴

Specific Learning Needs Analysis: The specific learning needs analysis for this setting highlighted that some staff had a limited understanding of terminology which is familiar in Specialist Palliative Care. Table 5 provides an example of this.

Table 5: Example of limited understanding of palliative care terminology

PL question: "How many palliative patients were discussed today (18 patients discussed)?"
MDT answer: "One maybe two."

PL question: "Of the patients discussed today (18 patients discussed) how many would you not be surprised if they were to die within the next year?"
MDT answer: "Oh maybe 8-10."

It was established that the learning objectives were the same as in setting 1 and that the educational resource used would be appropriate. As discussed on page 11 it was evident that the educational approach would not be suitable in setting 2 and that the model would need to be adapted.

Educational Approach: A blended educational approach was adopted in setting 2 with the aim of achieving the learning objectives, Table 3 (page 12). The approach included:

- One to one/small group discussions using a question and answer approach, Table 6
- Attendance and discussion at weekly MDT meeting
- Attendance and discussion at weekly long term care facility MDT meeting followed by a workshop

Table 6 Example of questions used during one to one/small group meetings

- Can you tell me about your understanding of the term "palliative care"?
- Do you currently practice advance care planning?
- Do you feel advance care planning using the definition I have described fits with your clinical practice in the stroke unit?
- Can you describe the challenges to advance care planning discussions in your clinical practice?
- Are you aware of any tools used in primary care to record the outcomes from advance care planning discussions?

³ NHS Lothian's LCP initiative has recently been implemented in the unit⁽¹⁹⁾.

⁴ Long term care is a facility where the residents need help with daily living. In a continuing care facility residents require nursing care in addition to help with daily living.

As previously discussed in the specific learning needs analysis some staff had a limited understanding of palliative care terminology. Most felt, when asked initially, that they did not discuss patients' beliefs or wishes about the future as this would mean talking about "death and dying" and this was not felt to be appropriate in a rehabilitative environment. Only senior medical staff knew about the ePCS.

The one to one/small group discussions provided an opportunity to explore if staff could identify any benefits of a "thinking ahead" approach for patients who have had a stroke. The majority of staff felt an ACP discussion would not be timely during the patient's treatment/rehabilitation in setting 2, identifying a number of barriers, these are described in Table 7.

Table 7: Barrier's identified by staffing Setting 2 to ACP
<ul style="list-style-type: none"> • Patients often have to adapt to a number of physiological and psychological changes and starting an ACP discussion would be "a blow too far"
<ul style="list-style-type: none"> • Timing of ACP in relation to future care not thought to be appropriate for the majority of patients
<ul style="list-style-type: none"> • Moving a stroke patient to a quiet area to have an in depth discussion would be challenging e.g. moving patient, moving equipment, timing
<ul style="list-style-type: none"> • Starting conversation would not be easy, as stroke patients do not ask the same questions as cancer patients
<ul style="list-style-type: none"> • Allied Healthcare Professionals have defined time managed role
<ul style="list-style-type: none"> • Current HEAT targets⁽²⁰⁾ – Clinicians have to provide more input at the front of patient journey which without extra time/staff may mean there is less time for the middle part of journey when ACP discussions may take place

One to one discussions with medical staff provided ideas for when they felt ACP discussions may be appropriate, Table 8.

Table 8: Medical staff's suggestions on when ACP may be appropriate
<ul style="list-style-type: none"> • When patient expresses a wish to discuss future prognosis
<ul style="list-style-type: none"> • When family express a wish to discuss future prognosis
<ul style="list-style-type: none"> • When there is a decline in a patient's condition
<ul style="list-style-type: none"> • Prior to discharge to care home/interim facility

Initially one champion (Doctor) was identified in setting 2, however, over the course of the educational approach, it became apparent that another member of the team (nurse) would be an ideal second champion. The second champion had expertise in managing stroke patients and supported those who were discharged home. The champion was also keen to incorporate ACP into their practice as they felt relationships evolved and ACP discussions may be more appropriate when patients are in their own home.

The one to one discussions with the champions provided an opportunity to clarify the learning objectives and also allowed the champions to convey their concerns about ACP in setting 2. Both expressed concerns that ACP may not be timely during the patient's treatment and rehabilitation, especially when trying to build hope for the future. This provided the opportunity to:

- Clarify that ACP is not always appropriate for all, should never be forced and that it may or may not evolve over time
- Clarify how their role could influence change in ACP practice through the knowledge they have gained from the project

The champions both agreed an electronic ACP folder would be the most appropriate resource for the setting and that they would refer to and add to it as part of their educational role within the unit.

Evaluation: Various members of staff engaged in small group discussions: Consultant, Staff Grade, Physiotherapist, Speech and Language Therapist, Stroke Liaison Nurse, Occupational Therapist. Unfortunately it was not possible for nurses to attend for reasons discussed in the specific learning needs analysis (page 12). However the opportunity arose for the PL to use the workshop model with nursing staff caring for patients transferred from the stroke unit to one of NHS Lothian's continuing care facilities.

Overall non medical staff reported that it would be difficult to identify when it would be appropriate for them to have an ACP discussion unless the patient introduced the subject. Some staff discussed a lack of confidence to explore ACP, even if the patient brought it up. Reasons for this included:

- Lack of ACP knowledge
- Lack of confidence in their communication skills
- Fear of destroying hope

The majority of staff felt it should be the unit's medical team who had an ACP discussion. It was suggested this should be either in the unit, or when the patient was due for discharge or transfer. Some felt that ACP should not be addressed by the Acute Stroke Unit team, but by the medical team taking over the patient's care thereafter.

Although the continuing care facility was not initially included in clinical setting 2, engagement with the team provided a useful insight into how ACP evolves for those patients transferred from the stroke unit. In the continuing care facility the same Consultant continued to review and assess patients first seen in the stroke unit. The weekly MDT discussion in continuing care appeared to be consistent, structured (weekly paper template recorded outcomes) and collaborative with the healthcare team. Nevertheless it was unclear if there was a structured process for sharing the outcomes with the primary care and out of hours team who have clinical responsibility outwith the Consultant's weekly review.

Group discussion in continuing care also highlighted that there may be occasions where there is a difference of opinion between medical and nursing staff with regard to recognising that best supportive care would be more appropriate for patients as they near the end of life. There was a feeling that sometimes the “need to do something” by the clinicians mean that opportunities for earlier ACP discussions are missed.

An example of ACP Practice: Staff in the Acute Stroke Unit who said they did not have confidence to have an ACP discussion, but who had a patient expressing a wish to discuss their beliefs or wishes, all acknowledged that they would either bring it to the team’s attention immediately or raise it at the weekly MDT meeting.

It was evident that the medical team were often involved in difficult conversations which had an ACP theme to them, an example is described in case study 5. There were also examples of good ACP practice including:

- Weekly coordinated structured MDT approach to care following recognised framework⁵⁽²¹⁾ discussing a number of key aspects: number of weeks in unit, DNACPR status (if in place), physical, psychological, short term goals and long term goals
- Patient and carer information recognised by team as very important
- Regular progress discussions with patients and family
- A dedicated member of staff who follows up patients who are discharged home

Case study 5:

The unit’s Doctor gave an example of an ACP conversation she might have with relatives when a patient has lost capacity following a stroke:

Doctor: *“Have you thought about what your mum would have wanted in relation to the amount of intervention she would want in this situation?”*

Relative: *“Oh mum would not want you to prolong her life like this. She would want to be comfortable and not in pain”.*

Staff in the continuing care facility described frustration with a recent out of hours decision to transfer a patient to the acute setting. Staff considered the documented advice in the patient’s notes relating to the escalation of care should have negated transfer. It was unclear if this information was shared directly with primary care and out of hours teams, which, in turn, may have prompted an ePCS and provided clearer escalation of care advice.

⁵ SIGN guidance 108⁽²¹⁾

Discussion: In setting 2 collectively staff reported that patients who have had a stroke do not ask questions about prognosis and future care in a similar way to cancer patients. Additionally terminology and definitions used in specialist palliative care were not familiar to all staff. ACP practice was evident with excellent examples of good practice. However this information was not consistently shared with primary care.

Although the project did not lend itself to formal evaluation of learning objectives or change in practice, feedback from the champions would suggest that the intervention has raised awareness of ACP in the setting. Exploration during a final interview with the champions revealed that they had both been reflecting how they could make changes to their own practice e.g. prompting GPs that a patient has future advance care planning requirements and may benefit from an ePCS/anticipatory care plan.

The champions have committed to review ACP practice with the wider team. In addition both will continue to raise awareness of ACP as part of their educational role with input or support from the hospital palliative care team if required. The medical champion has committed to provide data on how many times a GP has been prompted to start an ePCS over a 6 month period. The outcomes will be fed back to NHS Lothian's Palliative Care Managed Clinical Network (MCN) by the MCN representative from the setting (Palliative Care Consultant).

Setting 3: Primary Care

Background: A primary care practice was identified as setting 3: a team of 7 GP's and 4 District Nurses provide care for a population of approximately 9,000 patients. Staff report that historically patients and families look to the District Nurse and GP practice to provide palliative and supportive care, rather than seeking referral on to specialist palliative care. However the team does have a collaborative link with the community specialist palliative care team for support and advice.

Specific Learning Needs Analysis: The specific learning needs analysis for this setting highlighted that although the team believed they practised ACP, there were some educational gaps when measured against the project's learning objectives, Table 3. This validated using the same learning objectives and educational resource as used in the previous settings. However, as in setting 2, it was apparent that the educational model would need to be adapted. A new IT platform was also reported to be challenging for staff, acknowledging that they did not feel confident using the ePCS section.

Educational Approach: The ACP workshop used in setting 1 was not suitable for the whole team in setting 3 for a number of reasons including:

- Time constraints on clinical team
- Clinical team believed the setting champion should lead future education following the intervention
- An ambivalence in relation to project's objectives until staff could operate the new IT platform

In response to the specific learning needs analysis a blended educational approach was adopted in setting 3, primarily with the champion, with the aim of incorporating the learning objectives which would then be shared with the wider team. The approach included:

- Project learning contract, Appendix 5
- One to one/small group discussions using a question and answer approach, Table 6 (page 21)
- An adapted ACP workshop with the champion
- IT training in the use of ePCS

Using a workshop approach with the champion provided an opportunity to deliver the learning objectives and explore how future ACP education may be delivered. It was foreseen that ACP education would be offered to the rest of the team through an experiential approach e.g. when the opportunity arose through case discussion either on one to one basis or at team meetings.

The champion developed a mixed learning resource which included paper and electronic tools for a resource file. The champion had developed a resource folder following completion of NHS Lothian's District Nurse shadowing project⁶⁽²²⁾ and anticipated the ACP resource would be kept with this.

⁶ NHS Lothian's District Nurse shadowing project, funded by Macmillan, aims to improve palliative care knowledge and skills of District Nurses & GPs through shadowing their specialist colleagues.

Evaluation: The primary care team adopted a “thinking ahead” approach and used the Gold Standards Framework as their evidenced based model for optimising care for their cancer and non cancer patients who were nearing the end of life. Of the 8 patients discussed at the GSF meeting only 1 was thought to require an ePCS. Exploration of why those on the register did not have an ePCS identified a number of reasons for this including:

- Differences of opinion about the criteria for starting an ePCS
- Differences of opinion about the effectiveness of sharing information with out of hours services in this way
- Time consuming to complete form
- IT challenges

Collectively the team had a limited knowledge of the prognostication tools⁷ available to help diagnose the palliative phase of a patient’s illness^(3,4), a finding replicated on a number of occasions in different settings throughout the project. The community Specialist Palliative Care Nurse hoped to explore more effective ways to identify patients with palliative and supportive care needs, for example the GSF traffic light system, Figure 4. The system recognises that in depth assessment for each patient on the register may not be necessary at every GSF meeting but helps focus the right care at the right time during review.⁽³⁾

Figure 4: Extract from GSF prognostic indicator tool.⁽³⁾



Used with permission from Prof. Keri Thomas, The GSF Centre in End of Life Care, Prognostic Indicator Guidance, 2011 © K. Thomas, GSF Centre.

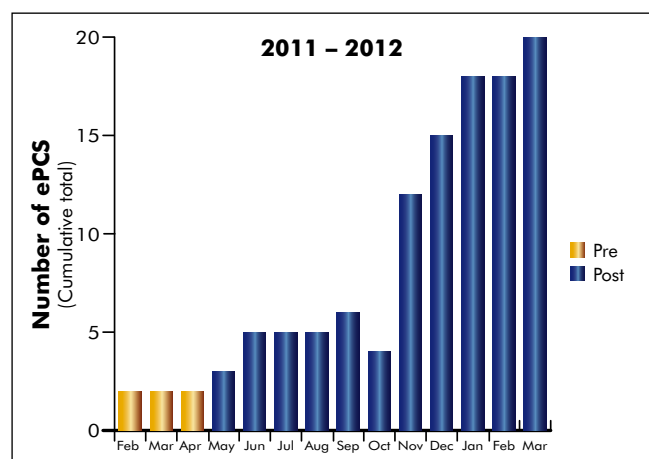
Although the educational intervention did not lend itself to formal evaluation the setting champion reported feeling confident to deliver future ACP education. The champion commented that the educational approach would not have been useful if the IT challenges had not been addressed:

“Understanding how the ePCS works now allows us to share information and hopefully enhance the care we give to our patients” (Setting 3 champion)

⁷ Tools used for recognising patients include the prognostic indicator and the specialist palliative indicator tool.

A follow up discussion with the setting champion revealed that she had started an ePCS for a number of patients following the educational intervention as she felt more confident in using the IT platform. Figure 5 demonstrates change in ePCS activity in setting 3 over time.

Figure 5: Setting 3 ePCS activity February 2011 – March 2012.



An example of ACP Practice: The one to one discussions with the setting champion highlighted how, as the setting's lead District Nurse, she is often responsible for assessing the individual needs of patients and communicating these to the Primary Care Team ensuring continuity of care. The District Nurses are often ideally placed to have an evolving ACP discussion with their patients. Additionally they may be in a position to prompt other members of the team to consider if it is appropriate to initiate ACP discussions.

The team had an agreed process for DNACPR discussions, which indicates that it is the best placed healthcare professional who should have the discussion when, and if, appropriate. For example if the district nurse is with a patient and it is appropriate to have a conversation about DNACPR, she feeds the outcome back to the GP who then completes the form for the district nurse to take back to the patient.

In setting 3 the primary care and community palliative care team have coordinated Gold Standard Framework meetings, chaired by a GP, every 6 weeks.

Discussion: The champion in setting 3 was a dynamic and well respected member of the primary care team. As a senior member of the team she had an excellent knowledge of the team's various learning styles which will be crucial when leading future changes in ACP practice or processes.

In addition to the challenges of completing an ePCS using the new IT system, a number of staff reported uncertainty about the benefits of using it to share clinical information with the out of hours service. However, as illustrated in Figure 4, there has been an increase in the setting's ePCS activity.

The champion has committed to review ACP practice with the wider team and to lead in-house ACP education.

ADDITIONAL EDUCATIONAL OPPORTUNITIES

In addition to exploring ACP implementation in the three clinical settings the PL has delivered ACP education in a variety of settings both formally and informally, Figure 6. The educational approach has developed and adapted over the period of the project. Lessons from the project have been shared with others involved in ACP education including the social care team, paediatric palliative team, local specialist palliative care teams and the MCN Educators Group with the purpose of translating experience to other areas and not “re-inventing the wheel”.

Figure 6: Various staff groups project came in contact with.



Additional educational opportunities to support disease specific teams to implement ACP arose during the time of the project including East Lothian district nursing team, Parkinson, Stroke and Oncology Clinical Nurse Specialist teams. A workshop was the educational approach used which covered the same educational outcomes as were addressed in the clinical settings. Each group committed to include ACP into their clinical practice as appropriate and to provide ACP education to their healthcare teams. A number of useful educational resources were identified during the project and recommended during formal and informal educational opportunities.^(23,24,25,26) An example of change in practice was reported in the Parkinson nurse specialist team's quarterly newsletter.⁽²⁷⁾ Initial project findings have also been presented both locally and nationally.^(28,29)

EXAMPLES OF OTHER ACP PROJECT/INITIATIVES

The PL met a number of healthcare professionals who were involved in promoting ACP in a variety of settings using a range of models.

On the back of a successful initiative in Lanarkshire⁽³⁰⁾ a number of national site specific conditions are piloting hand held anticipatory care plans and exploring how the process for updating clinical information can be done effectively.⁽³¹⁾

A questionnaire⁸, is currently used in a Lothian setting to prompt and support ACP discussions with residents on admission to a social care home, Appendix 10. An adapted questionnaire is used with relatives of those residents who have lost capacity, Appendix 11.

The PL met a number of GP's and district nurses during the project. The majority were keen to draw attention to how challenging they found advice to use the ePCS for all patients who would answer "yes" to the surprise question⁽³⁾ and how time consuming it was to complete an ePCS.⁽⁹⁾ A number reported that they did not have the time to use it and preferred to use the special notes if required on a Friday. Many enquired if there was evidence to demonstrate that ACP and the ePCS improved patient care. It was acknowledged that although this was limited there were a number of national and local initiatives currently exploring the benefits with some promising outcomes.^(32,33)

⁸ The questionnaire has been developed by Dr Andrew Mackay (GP – St Triduana's Medical Practice, Edinburgh) and Dr Harissa Hasbullah (FY2). It has been reproduced for this report with permission from Dr Mackay.

RECOMMENDATIONS

1. Recommendations for MCN Educators

Develop a planned approach to:

- Incorporating ACP and palliative care education within social, acute and primary care undergraduate and postgraduate education
- Accessing ACP resources identified within the ACP project
e.g. NES educational resource⁽³²⁾, National End of Life Care Programme resource^(23,24)
- Novel approaches to embedding ACP education within clinical settings
e.g. learnPro module on NHS Lothian's educational site

2. Recommendations for NHS Lothian

Develop a planned approach to:

- Identifying patients with palliative and supportive care needs using recognised tools
e.g. Prognostic Indicator Guidance tool (PIG)⁽³⁾ Supportive & Palliative Care Indicator Tool (SPICT)⁽⁴⁾
- ACP education for health and social care staff e.g. communication skills
- Training primary care staff to use recognised IT systems e.g. Electronic Palliative Care Summary⁽⁹⁾
- Promoting collaborative sharing of ACP outcomes with other health and social care teams

3. Recommendations for Clinical Settings

Develop a planned approach to:

- Collaborative review of ACP practice on a regular basis e.g. case review of good practice and how things could be improved
- Defining patient outcome measures for ACP e.g. ePCS activity

CONCLUSION

This 12 month collaborative project has taken a practice development and education approach to promoting ACP as a means of enhancing palliative and end of life care for patients and their families. The main phase of the project involved in depth facilitation of ACP in three settings and the sharing of what was learned more widely with other professional groups.

A specific learning needs analysis was undertaken in the three settings: two Social Care Homes for older people (setting 1), an Acute Stroke Unit (setting 2) and a Primary Care Practice (setting 3). In each setting some good ACP practice was identified. Also evident were some gaps in understanding of palliative care definitions and of ACP processes. In addition some staff expressed uncertainty about how to share the outcomes of ACP conversations, or had difficulty using the IT system. Overall it was clear that lead clinicians often act as “gatekeepers” to ACP. If the lead clinician does not identify a patient as having palliative care needs, then staff may not be able to promote ACP discussion.

An education intervention, which was adapted to meet the needs of the various settings, was successfully employed. Appointing “key champions” in each setting helped facilitate ACP education. Staff who engaged in the educational approach not only achieved the learning objectives, but also indicated that they are more likely to use ACP themselves and to prompt ACP within their clinical teams. Learning from each setting was used to develop practice in subsequent settings and more generally among a wide range of professionals through sharing of the project work. All this supports the embedding of ACP into everyday practice.

The time frame for the project did not allow for longer term evaluation, but it is hoped that NHS Lothian’s Palliative Care MCN will support ongoing evaluation through current and future projects. In the meantime some conclusions and recommendations are drawn.

For ACP to be integrated more widely into clinical practice there is a need for a stronger evidence base for its use and for ongoing education to support staff. A planned and collaborative approach to education should be undertaken ensuring that ACP is included in the preparation and continuing professional development of health and social care practitioners. In the clinical setting, case review using a reflective model is of value in identifying challenges and highlighting good ACP practice.

This report has reflected on the ACP project, so that others in the future can opt to use, amend and/or develop the approach taken and resources employed in this initiative to support ACP education and practice development across Lothian.

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APPENDIX 1 – STEERING GROUP MEMBERSHIP

Name	Title	Place of Work
Juliet Spiller	Consultant in Palliative Medicine	Marie Curie Hospice Edinburgh
Anne Willis	Hospice Manager	Marie Curie Hospice Edinburgh
Margaret Colquhoun	Senior Nurse Lecturer	St Columba's Hospice
Jackie Whigham	Project Manager	NHS Lothian
Shirley Fife	Nurse Consultant in Cancer & Palliative Care	NHS Lothian
Rosemary Cairns	Specialist Palliative Care Nurse	NHS Lothian
Peter McLoughlin	Strategic Programme Manager	NHS Lothian

Original Project Steering Group Membership

Name	Title	Place of Work
Juliet Spiller	Consultant in Palliative Medicine	Marie Curie Hospice Edinburgh
Anne Willis	Hospice Manager	Marie Curie Hospice Edinburgh
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Carl Bickler	Lead GP for Long Term Conditions	NHS Lothian
Patricia Black	Senior Palliative Care CNS/Lecturer	NHS Lothian
Kirsty Boyd	Consultant in Palliative Care	NHS Lothian
Shirley Fife	Nurse Consultant in Cancer & Palliative Care	NHS Lothian
Carol Lumsden	Programme Manager Long Term Conditions Collaborative	NHS Lothian
Debbie McCraw	Lead for Clinical Education	NHS Lothian
Peter McLoughlin	Strategic Programme Manager	NHS Lothian

APPENDIX 2 – PROJECT PLAN

Advance Care Planning Project	Phase 1	Phase 2	Phase 3	Phase 4
	11/2010 – 03/2011	04/2011 – 08/2011	09/2011 – 10/2011	11/2011
Phase 1 – Orientation				
Agree definition of ACP (Project Steering Group)	Achieved			
Recruit Facilitator	Achieved			
Review resources/literature/policy	Continuous			
Engage with other stakeholders	Achieved			
Explore potential clinical settings	Achieved			
Phase 2 – Preparing for Change				
Plan educational resource	Achieved			
Select and engage with 3 clinical areas	Achieved			
Engage with other healthcare professionals	Continuous			
Contribute to guideline/policy implementation	Continuous			
Phase 3 – Change and Evaluation				
Plan, deliver and evaluate education in settings		Achieved		
Plan, deliver and evaluate education to other HCP's		Continuous		
Phase 4 – Reflection				
Final report/seminar				Achieved

APPENDIX 3 – DEFINITIONS

The Lothian approach to planning in advance for palliative and end of life care.

Introduction

This short paper outlines the approach to planning ahead for palliative and end of life care that will underpin the Lothian Anticipatory Care Plan Project. In presenting this paper the project steering group is seeking agreement from the MCN on the terminology to be used and the key messages of the approach to planning in advance that will be adopted in the project.

Background

At the last MCN meeting it was reported that funding had been secured for a collaborative education/practice development project to take forward aspects of anticipatory care planning to enhance palliative and end of life care in Lothian. This collaborative initiative between NHS Lothian, Marie Curie Hospice Edinburgh and St Columba's Hospice, will be facilitated by a steering group and a project lead has been appointed. A key feature of the project is engaging with others in Lothian and elsewhere to use and build upon existing work, such as the generic Anticipatory Care Plan developed by the Long Term Conditions Collaborative⁽¹⁾ and the electronic Palliative Care Summary (ePCS)⁽²⁾ and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)⁽³⁾ initiatives. The collaborative project will support the delivery in Lothian of both the national action plan Living and Dying Well⁽⁴⁾ and the Lothian Strategy for Palliative Care.⁽⁵⁾

Terminology

Currently there are a number of definitions of advance and anticipatory care planning and different concepts of what these are, and how they could be applied in practice.^(6,7) For the purpose of the project the following definitions will be used:

Advance Care Planning:

- Is a process of discussion between an individual and their care provider about their preferences, wishes, beliefs and values about future care. Its purpose is to provide guidance to inform future care decisions in the event that the individual has lost capacity to make these decisions. It should be offered during routine clinical practice^(6,8)
- May lead to:
 - An Anticipatory Care Plan (see below)
 - A statement of wishes and preferences
 - An advance decision to refuse treatment in a future situation (advance healthcare directive, living will etc)
 - A DNACPR decision (only applies to the treatment of CPR)
 - The appointment of a Welfare Power of Attorney

An Anticipatory Care Plan:

- Is a dynamic clinical document used by and for care staff which provides a record of the preferred actions, interventions and responses that care providers should make following a clinical deterioration or a crisis in the individual's care or support. It will be informed by advance care planning discussions with patients or by care planning discussions with the care teams, Welfare Power of Attorney or family/next of kin for patients who lack capacity to engage in advance care planning discussions⁽¹⁾
- Has the following core elements:
 - Levels of intervention for anticipated clinical deterioration(s)/event(s) including any specific advance decision to refuse treatment
 - Preferred place of care and death
 - Resuscitation status
 - Wishes regarding organ and tissue donation
 - Contact details of any legally appointed Welfare Power of Attorney

Key messages

While these definitions may be helpful theoretically, they do not in themselves directly support adoption into clinical practice. In Lothian a pragmatic approach to planning care in advance with people is recommended. It will be based on the model of care outlined in the Lothian Palliative Care Strategy⁽⁵⁾, that involves starting to plan early, often in the context of long term conditions and of an increasing progression of the illness to a more clearly palliative stage. This approach can be helpful to the clinician, the patient and family to establish the goals of care.

The following key messages will underpin the project:

- The remit of the project is to promote the development and facilitation of an Anticipatory Care Plan for palliative and end of life care which should evolve from the process of care planning irrespective of a patient's capacity
- All care planning should include thinking ahead for all patients regardless of capacity, where clinical deterioration may be anticipated
- Advance Care Planning (as defined above) should be offered during routine clinical practice
- An Anticipatory Care Plan (as defined above) should be made by care staff for all patients, irrespective of capacity, identified as requiring palliative or end of life care
- The format for the Anticipatory Care Plan will be based on one/both of the existing templates in Lothian i.e. the generic Anticipatory Care Plan⁽¹⁾ or the ePCS⁽²⁾
- The Anticipatory Care Plan will be stored to be easily accessible to all relevant health and social care staff
- All the above planning processes, whether they result in an Anticipatory Care Plan or not, need to be led by the needs and wishes of the patient and carefully documented. They require skilled and sensitive discussion and must not be undertaken as a "tick box" exercise.

Conclusion

This collaborative education project will promote the development and use of an Anticipatory Care Plan, adopting a pragmatic approach of working with existing initiatives in Lothian. Agreement within the MCN on the terminology and key messages is a crucial first step towards ensuring successful outcomes.

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APPENDIX 4 – SUMMARY OF SETTINGS

	Setting 1	Setting 2	Setting 3
	2 Social Care Homes for residents with Continuing Care needs	Acute Care	Primary Care
Number of patients	Care Home 1 = 22 residents Care Home 2 = 44 residents	18 beds	9,000 with 9 patients on palliative care register however only 1 with ePCS
Number of staff	Care Home 1 = 32 social care staff Care Home 2 = 38 social care staff		7 GPs 4 District nurses
Setting Champion	Care Home 1 = 2 social care staff Care Home 2 = 2 social care staff	Doctor Nurse	District nurse
Learning needs analysis	Lack of awareness of: 1. ACP terminology 2. Palliative care definitions 3. How to identify palliative patients/residents who may benefit from ACP 4. The process used in healthcare to record and share clinical information for patients with palliative care needs.	Lack of awareness of: 1. ACP terminology 2. Palliative care definitions 3. How to identify palliative patients/residents who may benefit from ACP 4. The process used in healthcare to record and share clinical information for patients with palliative care needs.	Lack of awareness of: 1. ACP terminology 2. Palliative care definitions 3. How to identify palliative patients/residents who may benefit from ACP 4. The process used in healthcare to record and share clinical information for patients with palliative care needs.
Primary educational approach	Weekly ACP workshops over 4 weeks Evening ACP workshop	One to one small group meetings using a question and answer approach	ACP workshops with champion
Additional educational approach	Pre and post workshop meetings with the champions. Discussion meetings with managers.	Attendance at weekly multi-disciplinary team meeting. Attendance at NHS continuing care facility.	Small group meetings using a question and answer approach. ePCS workshop with champion and clinical lead for ACP.
Future ACP practice	Staff will review current ACP practice and process in collaboration with primary care team prompting earlier identification of residents with palliative and supportive needs.	Champions plan to introduce ACP review as part of MDT discussion. Discharge advice in patients identified with palliative and supportive needs will include prompt for primary care to continue ACP discussion and to start ePCS.	Patients who are discussed at GSF meeting will now have an ePCS Champion will develop strategy to ensure staff are trained to use new IT system and be able to use ePCS.

APPENDIX 5 – LEARNING CONTRACT

The core project outcomes will be agreed in each clinical setting prior to project implementation. The following learning contract aims to clarify what the ACP project lead will provide and what is essential from the identified champion in the clinical setting

Proposed Project Lead Learning Contract

Advance Care Planning Project Lead Contact
1. Work collaboratively with identified key champions to:
<ul style="list-style-type: none">• Identify specific learning needs analysis for the setting• Facilitate any agreed training needs• Explore current advance care planning practice• Promote the use of advance care planning, in particular the ePCS, for patients with palliative and end of life care needs• Share best practice with other health and social care professionals
2. Work collaboratively with other health and social care professionals/agencies to:
<ul style="list-style-type: none">• Identify training needs and support collaborative delivery as appropriate

Proposed Clinical Setting Learning Contract

Identified clinical settings Advance Care Planning Manager/Champion Contract
Lead Clinician will identify a key champion and support them to undertake the key champion components identified below.
Key champions will work collaboratively with ACP project lead to: <ul style="list-style-type: none">• Identify specific learning needs analysis for the setting• Support any agreed training needs• Support exploration of current advance care planning practice• Promote the use of advance care planning, in particular the ePCS, for patients with palliative and end of life care needs• Share best practice with other health and social care professionals

Clinical setting:

Date of contract:

Clinical Lead signature:

Date:

Key Champion signature 1:

Date:

Project Lead signature:

Date:

APPENDIX 6 – POWERPOINT PRESENTATION

Advance Care Planning

Outline of presentation

- Describe NHS Lothian's Advance Care Planning Project
- Describe drivers behind ACP
- Define Advance Care Planning (ACP)
- Explore who may benefit from ACP
- Explore the triggers, tools and NHS Lothian's clinical documents
- Share some of the projects findings

Poem ⁽¹⁾ – Listen by anonymous

Drivers, Guidance...



Ensuring the right palliative and end of life care, at the right time, in the right place consistently for everyone who needs it.

Living well Dying Well 2008, NHS Lothian Palliative Care Strategy 2010, Building on Progress 2011

Advance Care Planning:

Is a process of discussion between an individual and their care provider about their preferences, wishes, beliefs and values about future care. Its purpose is to provide guidance to inform future care decisions in the event that the individual has lost the capacity to make these decisions. It should be offered during routine clinical practice. ⁽³⁾

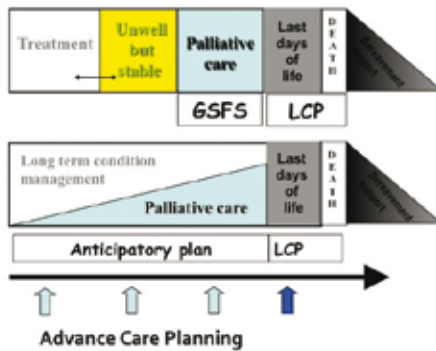


The Maze of Trees

Michele Petrone ⁽⁷⁾

A full electronic copy of the presentation can be obtained from the report authors (page 2).

Care Models



Who would benefit from Advance Care Planning?

All of us

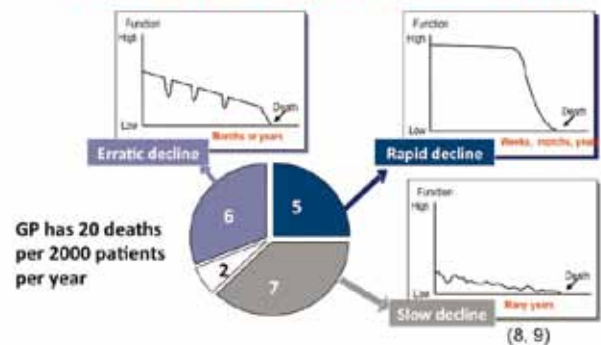
In particular those with:

- Long term condition(s)
- Palliative care needs
- End of life care needs
- Carers
- Health and social care professionals

When is it appropriate?

- Diagnosis of metastatic disease
- Discontinuing chemotherapy
- Prognostic indicator/surprise question
- Person's choice/need
- Clinical indicator
- Multiple hospital admissions
- Admission to a care home
- After exacerbation
- Reduced functioning/ADL

When? Selectively and Opportunistically ...



Prognostication tools...



Prognostication tools...



(10, 11.)

Triggers

- Surprise question: Would you be surprised if this person were to die within a year, 6 -12 months, weeks, days?
- Performance status poor &/or deteriorating
- Unplanned hospital admissions: new or more
- Increasing care needs/ care home setting
- Critical events/ new diagnosis
- Disease related indicators.... (10)

What ACP discussion may lead to -



Anticipatory Care Plan

The aim of ACP care plan is to develop better communication and recording of decisions, thereby leading to provision of care based on the needs and preferences of patients and carers (12).

Anticipatory Care Plan

- **Core information:**
 - Instructions for decline in condition
 - Patient's understanding of condition
 - Preferred place of care/death
 - DNACPR status
 - Power of attorney details
- **Documents:**
 - Clinically the outcome of an Advance Care Planning discussion should be recorded on either:
 - Generic Anticipatory Care Plan
 - ePCS (Anticipatory Care Plan)

An Anticipatory Care Plan

(13, 14)

DNACPR

The NHS Scotland DNACPR policy applies to cardiopulmonary resuscitation. A form should be completed if the patient decides they would not want this treatment or if the healthcare team decides that CPR would not have a medically successful outcome (15)

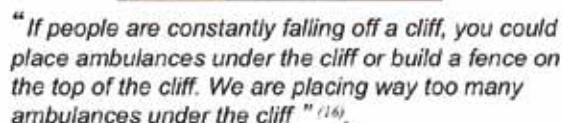
ePCS Overview

```
graph TD; A[GP/Nurse adds Palliative Care data] --> B[System generates lists for review/reminders]; A --> C[Patient consents to share electronic Palliative Care Summary (PCS)]; C --> D[ePCS sent to ECS Store]; D --> E[NH524 accesses ePCS]; E --> F[OOH centre accesses ePCS]; E --> G[Patient care improved OOH]; F --> G; G --> H[Patient care improved in-hours]; H --> A;
```

The flowchart illustrates the ePCS (electronic Palliative Care Summary) process. It begins with a GP/Nurse adding Palliative Care data, which leads to two parallel paths. The left path shows the system generating lists for review/reminders, leading to improved in-hours patient care. The right path shows patient consent to share the ePCS, which is then sent to the ECS Store. NH524 accesses the ePCS, leading to improved OOH patient care and OOH centre access to the ePCS. Both improved patient care outcomes (in-hours and OOH) feed back into the initial data entry step.

Benefits of Advance Care Planning

It is suggested that the use of Advance Care Planning increases dignity, choice and control; makes communication between the individual, family and health care team more effective and may support more people to be cared for/ die at home (2,3,4,5,6).



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Marie Curie Palliative Care Institute Liverpool:
www.mcpcil.org.uk

Anticipatory Care Planning: Frequently Asked Questions
<http://www.scotland.gov.uk/Publications/2010/04/13104128/1>

APPENDIX 7 – ACP QUIZ

1. Describe what the term Advance Care Planning means?
2. An advance care planning discussion may lead onto three main headings of discussion. What are the three main headings the discussion might lead to (think umbrella)?
3. What groups of patients/residents do you think would benefit from an advance care planning discussion?
4. It can be difficult to predict when we should start advanced care planning with individual patients. The 'surprise question' can help us make this decision. What is the 'surprise question'?
5. A person can request that they have a specific treatment in advance. **True or False**
6. A patient's next of kin can consent or refuse treatment on their behalf. **True or False**
7. A patient has a current 'Do Not Attempt Cardiopulmonary Resuscitation' form completed. He has a severe chest infection that requires IV antibiotics. In light of the DNACPR form, can this medication be administered?
8. It is important that all healthcare and social care staff know the outcomes from an advance care planning discussion. What way is the best way to share this information? (**circle your answer**)
 - (a) Written in the resident's/patient's notes
 - (b) Electronically using the electronic palliative care summary (ePCS)
 - (c) Using the generic anticipatory care plan
 - (d) Either using the electronic palliative care summary or the generic anticipatory care plan and having this documented in the care home notes.
9. A resident's condition deteriorates in the middle of the night and the care home staff feel they require medical assessment for their symptoms. They call NHS 24. What core information should the staff ensure they pass onto NHS 24 in relation to the resident's wishes?
10. The resident has an anticipatory care plan which says that should their condition deteriorate they would like to be cared for in the care home. The patient also has a DNACPR form completed and in date. Who will NHS 24 send:
 - (a) A paramedic team?
 - (b) An out of hours GP?
11. Write down 2 advantages of using anticipatory care plan.

APPENDIX 8 –

Listen – by Anonymous

When I ask you to listen to me
and you start giving advice,
you have not done what I asked.

When I ask you to listen to me
and you begin to tell me why I shouldn't feel that way,
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something to solve my problem,
you have failed me, strange as that may seem.

Listen! All I asked was that you listen.

Not to talk or do – just hear me.

Advice is cheap. Ten cents will get you both Dear Abby and
Billy Graham in the same newspaper.

And I can do for myself. I'm not helpless.

Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself,
you contribute to my fear and weakness.

But, when you accept as a single fact that I do feel what I feel,
no matter how irrational, then I can quit trying to convince
you and get to the business of understanding what's
behind this irrational feeling.

And when that's clear, the answers are obvious
and I don't need advice.

Irrational feelings make sense when we understand
what's behind them.

Perhaps that's why prayer works, sometimes, for some people
because God is mute, and He doesn't give advice or
try to fix things. "They" just listen and let you
work it out for yourself.

So, please listen and just hear me. And, if you want to talk,
wait a minute for your turn, and I'll listen to you.

– Anonymous –

APPENDIX 9 – ADAPTED CASE STUDY*

Following the death of her husband last year and her failing health, Mrs Jessie Brown (80) entered a care home in January 2011. At her initial assessment meeting she told her key worker that she had a desire to “hang my hat somewhere I feel safe and cared for and that when the time comes, that will be where I will die peacefully.”

She has two daughters who visit regularly and she is keen they should be involved in all care decisions. As a family they are very open in their discussions. She has a medical history of diabetes, end-stage heart failure and early vascular dementia.

Her GP informed staff, following a visit in March, that he felt her heart failure was not responding to current medication and that there were no other changes he could make to her medication.

How things progressed

Care home staff recorded in her notes that Jessie was sleeping more and was breathless when walking short distances. They also reported that she seemed to be more forgetful than normal. She started to deteriorate on a Friday night and staff called NHS 24. Following telephone assessment, NHS 24 sent an ambulance crew out to assess her condition. On arrival the staff informed the crew that Jessie had stopped breathing as the ambulance parked outside the home.

Outcome

The ambulance crew arrived just as Jessie’s condition deteriorated dramatically and her heart had stopped. She did not have Do Not Attempt Cardiopulmonary Resuscitation form (DNACPR). Ambulance crew attempted cardiopulmonary resuscitation (CPR) – unsuccessful. GP Out Of Hours (OOH) attended and verified the death however did not know patient and therefore did not sign the death certificate. Police were called and Procurator Fiscal were involved (treated as an unexpected death). Body moved to police mortuary. Her daughters were informed of her death, which they said they had not been prepared for which was traumatising for them. Staff who witnessed the CPR found her death traumatising. They described her last minutes as “undignified and not peaceful at all”.

Discussion points

- At what point do you think an advance care planning discussion could have been introduced? What triggers were there?
- What do you think the discussion may have led onto?
- What do you think the advantages of an anticipatory care plan would have been to:
 - Jessie, her daughters and Care home staff

*Names/details changed for teaching purposes.

APPENDIX 10 – CARE HOME QUESTIONNAIRE – RESIDENTS⁸

Anticipatory Care Survey – Patient

As you are currently living in a nursing home, I am writing to ask what you would like to happen to you if you suddenly become unwell. This information will be very useful in helping medical staff decide how best to treat you and whether they should admit you to hospital if you become unwell.

Here are a series of situations which unfortunately may occur. Please put a tick in the box which corresponds to your answer.

1. If you had a stroke which meant that you were unable to communicate at all.

Would you wish to be:

a) Admitted to hospital for invasive treatment such as drips, antibiotic treatment into a vein and feeding via PEG tube (feeding tube into stomach)	
b) Kept comfortable in your current environment and every effort made to relieve any distress that you are experiencing	

2. If you had a serious infection which was not improving with antibiotic tablets.

Would you wish to be:

a) Admitted to hospital for invasive treatment such as drips and antibiotic treatment into a vein	
b) Kept comfortable in your current environment and every effort made to relieve any distress that you are experiencing	

3. If you were so unwell that you could not eat or drink.

Would you wish to be:

a) Admitted to hospital for invasive treatment such as drips, antibiotic treatment into a vein and feeding via PEG tube (feeding tube into stomach)	
b) Kept comfortable in your current environment and every effort made to relieve any distress that you are experiencing	

Please note that it would be our usual practice to refer any patient with a suspected fracture to hospital, in order to best relieve their pain.

To ensure these views influence the care provided by the GP service that covers evenings and weekends our policy is to share our care plans with them. Please tick this box if you **DO NOT** wish this to happen ☐

Any comments

⁸ The questionnaire has been developed by Dr Andrew Mackay (GP – St Triduana's Medical Practice, Edinburgh) and Dr Harissa Hasbullah (FY2). It has been reproduced for this report with permission from Dr Mackay.

Thank you for your help.

APPENDIX 11 – CARE HOME QUESTIONNAIRE – RELATIVE⁸

Anticipatory Care Survey – Relatives

As your relative is currently living in a nursing home, I am writing to ask what you would like to happen to them if they suddenly became unwell. In order to answer these questions, it may be helpful to think about any wishes that your relative has expressed to you in the past. This information will be very useful in helping medical staff decide how best to treat your relative and whether they should be admitted to hospital.

Here are a series of situations which unfortunately may occur. Please put a tick in the box which corresponds to your answer.

1. If your relative had a stroke which meant that they were unable to communicate at all.

Do you feel that it would be most appropriate to:

a) Admit them to hospital for invasive treatment such as drips, antibiotic treatment into a vein and feeding via a feeding tube into stomach	
b) Discuss with a family member as soon as possible to decide whether to admit them to hospital	
c) Keep them comfortable and relieve any distressing symptoms in the environment that is familiar to them	

2. If your relative had a serious infection which was not improving with antibiotic tablets.

Do you feel that it would be most appropriate to:

a) Admit them to hospital for invasive treatment such as drips or antibiotic treatment into a vein	
b) Discuss with a family member as soon as possible to decide whether to admit them to hospital	
c) Keep them comfortable and relieve any distressing symptoms in the environment that is familiar to them	

3. If your relative was so unwell that they could not eat or drink.

Do you feel that it would be most appropriate to:

a) Admit them to hospital for invasive treatment such as drips, antibiotic treatment into a vein and feeding via a feeding tube into stomach	
b) Discuss with a family member as soon as possible to decide whether to admit them to hospital	
c) Keep them comfortable and relieve any distressing symptoms in the environment that is familiar to them	

Please note that it would be our usual practice to refer any patient with a suspected fracture to hospital, in order to best relieve their pain.

To ensure these views influence the care provided by the GP service that covers evenings and weekends our policy is to share our care plans with them. Please tick this box if you **DO NOT** wish this to happen ☐

Any comments including contact details for next of kin.

⁸ The questionnaire has been developed by Dr Andrew Mackay (GP – St Triduuanas Medical Practice, Edinburgh) and Dr Harissa Hasbullah (FY2). It has been reproduced for this report with permission from Dr Mackay..

Thank you for your help.

