Raising the Profile of Preferred Priorities at the End of Life with Patients at St Nicholas' Hospice

Keywords End of life, Thinking Ahead, Patient Wishes, Advance Care Planning, Preferred Priorities of Care, Hospice

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Project Team Gill Austin RN, Sally Coldrey RN, Ursula Noyce RN

Contact Details St Nicholas Hospice Care, Macmillan Way, Hardwick Lane, Bury St Edmunds, Suffolk IP33 2QY

Email: ursula.noyce@stnh.org.uk

Summary of project

A major government initiative, The End of Life Care Strategy (2008), aims to promote advance care planning (ACP) as it is recognised that ACP is the cornerstone of good palliative care. This project set out to conduct an explorative project to establish patients’ preferred priorities of care within a hospice setting. A questionnaire was sent to 56 clinical staff to ascertain the staff perspective about ACP and a purposive sample of 4 patients had semi-structured interviews to obtain a patient perspective. A response rate of 46% was achieved from the questionnaire and data produced was both quantitative and qualitative. Analysis of the questionnaires looked for common themes. Patient interviews were conducted and themes identified. The project looked for commonality in themes between staff and patients’ responses. The project findings are supported by current literature and highlight that patients want to have the opportunity to explore their end of life wishes but there are many perceived barriers to starting this process. The project team have identified some of these barriers and their findings suggest that improvements in practice could be made. Recommendations include adopting a more facilitated approach to ACP.

Background

This project was undertaken by three Registered Nurses based at St Nicholas Hospice Care (SNHC) in Bury St Edmunds, Suffolk. St Nicholas Hospice cares for people based in the West of Suffolk and Thetford. It provides a wide range of services, which include: a ten bed ward, a day therapy unit, a community team, chaplaincy and family support. The Hospice is a Registered Charity.

The project team wanted to look at how patients of St Nicholas Hospice Care are enabled to explore and discuss their wishes for end of life care and how in doing so this experience felt. The need to raise the issues surrounding End of Life Care (EoLC), and in finding out the wishes of individuals is driven by several factors; the (previous) Government’s End of Life Care Strategy (Department of Health, 2008) and resulting Key Performance Indicators (KPI); Dying Matters which is an umbrella group set up by the National Coalition for Palliative Care to promote public awareness of dying, death and bereavement. The report by Demos (Dying for Change, 2010) and the Gold Standards Framework (GSF) are also influential drivers for good EoLC. The GSF identifies three simple steps which encompasses identifying patients in their last year of life; assessing their clinical and personal needs which includes advance care planning, and then developing an action plan of care. “Advance Care Planning (ACP) is a process of reflection on and communication of a person’s preferences for future healthcare, to be used in the event they become incapable of giving informed consent,” (Simon, Murray, Raffin, 2008, p 256). The above literature suggests that current service care provision does not match that desired by the public.
The belief of the project team was that patients had to be at the centre of exploring EoLC issues and it should be their experiences that frame and inform clinical practice. Black (2008, p 65) highlights the National Council for Palliative Care (NCP) comment, “that there is a lack of rigorous research into the efficacy and benefits of user involvement” in palliative care. According to NCP (2004,) as cited in Black (2008, p 65) “users add a perspective that comes from their unique response to their situation and their care, which is vital and might otherwise be missed.” In order to gain richness and depth within the project, the project team wanted to gather information and experiences from staff, patients and carers. (This project did not include the carer’s perspective but it remains an objective of the project team.)

Project focus

The focus of the project evolved through discussion by the project team members. There was both audited and anecdotal evidence within SNHC that obtaining patients’ opinions about their preferred priorities for care at the end of life was limited. It was felt by the project team members that Hospices should be leading the way in achieving patient’s wishes at the end of life. According to Simon, Murray and Raffin (2008, p 256), “there is little known about the patient experience of participating in facilitated advance care planning (ACP)”. The project team recognised that by exploring current practice at SNHC in addressing this issue, and evaluating the findings, that this could lead to improvements not only in SNHC data collection but more fundamentally, in improvements in understanding, recognising and fulfilling patients’ wishes. Fisher as cited by Locke (2011,) comments “breaking the taboo of discussing dying is the first step in ensuring good end of life care.”

An underlying purpose of the project would be to establish and develop best practice. Although principally a nursing based project, it was agreed that the inclusion of other multidisciplinary team members was essential as they too have a role to play in end of life care.

Selection of this subject was given much thought and consideration. “ACP can encompass rich conversations, which go beyond ‘to resuscitate or not to resuscitate’, and may include meanings and fears around illness and dying, generativity, preferences for after-death rituals, and spirituality,” (Simon, Murray and Raffin, 2008, p 256). Although preferred priorities for care (PPC) at the end of life as part of advance care planning is a well documented requirement of NICE and GSF, it was recognised by the project team that investigating this subject would probably create some particular difficulties. End of life care is an emotive subject, and seeking the opinion of patients on this matter would require great tact and sensitivity. There was the obvious consideration that the patient group had life limiting illness and the project team could not rely on patient participation on any reliable timescale. Black (2008) highlights some of the reasons why professionals may be reluctant to involve service users within end of life care. Those reasons pertinent to this particular project are listed in Box A below.

**Box A**

- It can be difficult to broach the subject of end of life. This appears to be more common in long-term conditions where the illness trajectory is unpredictable, and from fears of mentioning the patient’s mortality.
- Staff members may presume that patients are too ill to get involved.
- Towards the end of their lives, people may have more immediate, pressing concerns. It may not be thought right to ask people if they would like to get involved in anything else.

Black (2008, p 67)
Seeking the opinion of staff was not without some drawbacks. The Hospice as an organisation, had many other initiatives underway at the time of the project (not least the opening of additional inpatient beds) and the refurbishment of the Day Therapy Unit, and therefore enlisting the support and participation of staff in this project was almost certain to conflict with other interests. However, stakeholder inclusion was seen as a major requirement.

Aims and objectives

**Aim:**

The project team agreed that the project must represent the staff and the patient’s perspective. The aim of the project was to establish working practices that would ensure:

“Every patient within St Nicholas Hospice Care is able to express and plan their preferred priorities of care for end of life.”

**Objectives:**

- To establish what is current practice in identifying patients preferred priorities of care for end of life
- To explore and understand the subject of preferred priorities of care for end of life from the staff and patient’s perspective
- To identify recommendations to improve practice

Methods and approaches

A number of approaches were used to achieve the project objectives. These included, staff questionnaires, a discussion during a staff education session and patient interviews.

Although plans were initially made to include a support group of staff and volunteers who, it was envisaged, would assist in later discussions and evaluation, utilisation of this support group did not happen. Reasons for this were related to personal availability and timings. The project team agreed to meet regularly (weekly) in order to discuss the project development and keep the focus of the project aims. A Gant chart was devised to assist the project team to adhere to these timings. A log of time spent on the project was set up, to record each individual project members’ project time.

Establishing current advance care planning at SNHC

Advance care planning at SNHC (which includes preferred priorities for care at the end of life) has specific documentation under three separate sections. This documentation was devised by senior SNHC staff (including the Consultant in Palliative Medicine and the Senior Educational Facilitator) in 2008 and is called ‘Thinking Ahead’. This document is considered to be a ‘dynamic’ planning document that can be completed over time. No one professional role is seen to be responsible for its completion.

To establish current practice with regards to ACP, the project team decided to undertake an audit of this documentation. 20 sets of notes of patients who had been in-patients were randomly selected and audited by the project team. The audit looked at completion of the Thinking Ahead Sections 1, 2 and 3. Results showed that only 10% of Section 1, and 5% of Section 2 and 3 were completed within a week of admission to Sylvan Ward. Although further aspects of this ACP document could have been completed later in the patient’s admission and during the uptake of other services within the Hospice, there remained a significant shortfall in the recording of patients preferred priorities for care at the end of life. Thus the audit data provided the project team with crucial hard evidence that this was an issue that lent itself to further investigation. Due to the sensitive nature of the subject, it
was agreed that the project team would start with the staff perspective. The evidence from the staff perspective would then be used to shape the plans to obtain the patients’ perspective. It is worth noting, that at this point in the project, the project team did not have the permission from Senior Management at the Hospice, to approach patients directly as it was important that the project work did not cause distress to patients.

Exploring the staffs’ perspectives

In order to obtain staff perspectives on planning end of life care, a number of data collection techniques were considered by the project team. This included one to one interviews, discussion groups and questionnaires. The questionnaire was selected for the following reasons:

Anonymity – The project team felt this was an essential requirement for any data collected. Theoretically, all patients who received any care input from SNHC, be it Family Support Involvement, Specialist Community advice, Rehabilitation, Orchard Day Therapy or admission to Sylvan Ward, should have an opportunity to participate in ACP using the Thinking Ahead documentation. Asking staff to say why they had not addressed all or any aspect of a patient’s preferred priorities of care could be interpreted as a direct question of their integrity by highlighting a failure to complete this aspect of patient care; an anonymous questionnaire might therefore enable greater honesty.

Ability to collect quantitative and qualitative data – It was felt by the project team that one to one interviews or discussions may lead to a great deal of narrative information which would be more difficult to analyse. The advantage of a questionnaire was that the questions could be devised so that responses could be both quantitative and qualitative. In essence there was more than one aspect of information to collect; on the one hand the project team needed to collect numerical information about how often PPC documentation had been completed (or attempted to be completed), but they also realised that some narrative content was essential to ensure richness of data and to understand why the documentation was incomplete. The narrative content of the completed questionnaires would enable the project team to identify common themes. It was anticipated that this information would provide individual staff perspectives. As the questionnaire enabled staff to indicate their role (Doctor, Registered Nurse, Nursing Assistant, Other (e.g. physiotherapist), it was hoped that variations in response with regard to role may also generate interesting data.

Having decided to use a questionnaire, the project team devised a draft set of questions and showed it to key members of the multidisciplinary team to help with clarity of wording. The questionnaire was also shown to the FoNS practice development facilitator, who suggested including an additional question about the value of obtaining a patient’s PPC.

When deciding on how to collect numerical data about how often staff had completed each section of the Thinking Ahead documentation, the project team felt that a Likert scale would be the most useful approach to use in terms of later analysis. However, the project team needed to quantify answers; they considered having numerical sections within the Likert scale of 0-5 or 6-10 etc., however, it was felt that accuracy in real terms may be difficult for staff to recall and therefore a Likert scale based on words to indicate frequency was chosen instead. The words used were “always”, “sometimes” and “never.”

Once the questionnaire wording and lay out had been agreed, 56 questionnaires were printed and individually sent to all Doctors, Registered Nurses and Nursing Assistants on the Hospice in-patient ward. The questionnaire included instructions for completion including a completion date. A neutral collection point was selected. See Appendix 1 for example of the questionnaire.
Questionnaire findings

The initial response rate to the questionnaire was poor. Although the questionnaire had identified a date for return, this date had to be extended by two weeks to ensure a higher percentage of response. Signs were placed in strategic places in the Hospice to remind staff about the questionnaire and the In-House Network bulletin also ran a brief outline of the project. The final response rate was 46%.

The analysis of questionnaires was conducted by the project team. Each member selected questionnaires at random and looked through them to establish themes. The team then discussed these themes to look for common elements throughout all the questionnaires.

During the analysis, it became obvious that the subjectivity of the word “sometimes” provided staff with the option to choose this word even if they had only completed (or attempted to complete) the PPC documentation on one or more occasion. This was probably a significant flaw in the data collection.

Table to demonstrate responses from all respondents to Question One

How often do you complete the St Nicholas Hospice Care Thinking Ahead documentation with a patient?

<table>
<thead>
<tr>
<th>Section</th>
<th>Always</th>
<th>Sometimes</th>
<th>Never</th>
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</thead>
<tbody>
<tr>
<td>One</td>
<td>3</td>
<td>13</td>
<td>10</td>
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<tr>
<td>Two</td>
<td>0</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>Three</td>
<td>1</td>
<td>8</td>
<td>15</td>
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</table>

NB. 2 respondents did not answer the question

Qualitative questions

Box B

What factors influence you initiating the conversation with a patient about the St Nicholas Hospice Care Thinking Ahead documentation?

What suggestions do you have about completing the process of Preferred Priorities for End of Life Care, with a patient?

The qualitative component of the questionnaire (see Box B) generated a lot of different narrative responses. From these responses the project team identified a number of common and recurring themes; these are identified below:

- **Time** - Lack of time to start any of the process, timing (appropriateness), lack of total time to complete the process, plan ahead for the time
- **Patient illness state** - patient’s emotional state and the patients physical condition, i.e. too early in illness journey for patient to want to consider PPC or patient condition deteriorating rapidly raising the priority to address PPC
• Environment – privacy, space, time
• Documentation – volume of, repetition, jargon, accessibility in notes, medical orientation
• Patient led – directly or indirectly taking into account defence mechanisms, conversation to be brought up by patient or relative, identified patient objective
• Relationship with patient - establishing a rapport, shift work patterns, trust, being realistic about meeting patients’ expectations for PPC
• Emotive subject – triggering emotional reaction, not wanting to add to vulnerability of patients
• Staff – confidence and competence to address PPC, lack of understanding of documentation, shift work, not perceived as their role – Some people felt it was not their role at all
  o Professional Issues/ Guidance, - MDT, GSF, End of Life Care Strategy, hospice business

Discussion during education session

Having analysed the questionnaire responses, the project team felt that it would be useful to create an opportunity to explore staff perspectives further. The hospice has an education programme which includes all aspects of palliative care and as an education session had been arranged for nursing staff about ACP, the project team recognised that this forum could be used to gather further information. A discussion took place during the session about patients preferred priorities of care. Ideas and opinions were shared and the themes that emerged mirrored the findings of the questionnaire. This point was shared with the 11 Registered Nurses who attended.

Following the education session, the project team were able to combine the themes identified from the questionnaires and education session discussion to assist in the completion of establishing patients’ preferred priorities of care, see Box C below.

<table>
<thead>
<tr>
<th>Box C</th>
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<tbody>
<tr>
<td>• Reduce repetition</td>
</tr>
<tr>
<td>• Simplify – less jargon</td>
</tr>
<tr>
<td>• Make the process more informal</td>
</tr>
<tr>
<td>• Plan ahead in order to complete, can be over a period of time</td>
</tr>
<tr>
<td>• Identify which professionals can/should complete the process</td>
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<tr>
<td>• Maintain flexibility to patient need</td>
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<tr>
<td>• File for ease of accessibility in notes</td>
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<tr>
<td>• Give realistic explanation of meeting patient’s expectations (resources)</td>
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<tr>
<td>• Start the process early in the assessment process</td>
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<tr>
<td>• Encourage patient to read relevant literature beforehand</td>
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<tr>
<td>• Should be opt out points throughout documentation</td>
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<tr>
<td>• Make it a habit/routine</td>
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<tr>
<td>• Have set phrases to use</td>
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<tr>
<td>• Could be part of the 48 hr review (especially re. power of attorney)</td>
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<tr>
<td>• Complete the process in pairs</td>
</tr>
<tr>
<td>• Start by making a will</td>
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<tr>
<td>• Discuss PPC more at MDT meetings and handovers and then nominate someone to start the conversation</td>
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</table>
Establishing the patient’s perspective

Having established the staffs’ perspective on planning for EoLC, the project team now needed to compare the staff perspective with the patients’ perspective.

Black (2008) has identified three principles of user involvement, see Box D below.

**Box D**

- Valuing patient and carer knowledge: Patients and carers know better than anyone, what it feels like to experience a life-limiting condition and receive services. They are therefore likely to know what they need and may have an idea of what is needed by others. They also have skills and qualities developed through work and life experience
- Listening to patients and carers: Providing opportunities for people to share their views and listening to them
- Working in partnership: Working alongside patients and carers as equal partners to ensure that what is learnt from patients and carers is included in decisions about care.

Black (2008, p 67)

With these principles in mind, the project team decided that patient interviews would be the most effective approach to explore patients’ perspectives. The reasons for this were:

- It was felt that an interview would enable the patient to express their feelings about the experience
- The subject matter was emotive and an interview provided the opportunity to explain and explore these issues in depth and identify themes
- The project team wanted to obtain rich qualitative data and felt that an interview with open questions would achieve this.

The project team planned to recruit five patients to interview using the following criteria to select a purposive sample. The patient:

- Was present on the Hospice ward or regularly attended ODT
- Had already completed PPC documentation
- Was well enough to undergo an interview
- Agreed to participate in an interview

The project team recognised that selecting five suitable patients may be difficult and in the event, interviews took place with 4 patients; problems with selection for interview centred on patients meeting all the above criteria.

Three patients were diagnosed with a malignant disease, and one had a neurological disease. According to Crawford (2010, p 1164), “there is little evidence that open discussion regarding end of life decision-making are taking place routinely with patients who have non-malignant disease.”

The project team recognised that this was a small sample and any findings would not necessarily reflect the opinions of a larger group of patients. To illustrate the point about timing in relation to the patient’s illness trajectory, it is worth noting that one patient died within three weeks of completing the patient interview.
Interviews were conducted by the project team in a location in which the patients said they felt comfortable. The patients had agreed to participate and this was obtained by informed verbal consent. It was made clear by the interviewer that at any time the patient could withdraw from the project without affecting the care that they received.

The approach used was based upon Experience Based Design for the collection of patient stories because it is a recognised method developed by the NHS Institute for Innovation and Improvement (2009). This approach deliberately draws out the subjective, personal feelings a patient and carer experiences at crucial points in the care pathway. It does this by encouraging and supporting patients and carers to tell their stories. This approach met with the approval of the senior management of St Nicholas Hospice Care. Before the interviews took place, a project team member with the FoNS practice development facilitator devised a number of open questions to capture the patient’s experience of voicing their end of life wishes. See Appendix 2 for questions used.

The patient was offered the opportunity to record their thoughts and feelings in a Patient Experience Log, but the patients elected to tell their story instead. During the interview brief notes were taken and after the interview, aspects of the conversation were written down in greater detail and then stored securely.

Findings from the patient interviews

The notes taken during and after the patient interviews were discussed and compared by the project team and key themes were identified. See Box E for examples from patients’ narrative.

Box E

“I’m gobsmacked, didn’t realise we could do these things.”

“It’s such a relief to tell you that I don’t want to die at home.”

“I want to be able to change mind about where I die, as my condition deteriorates.”

“I can now tell my family what I want so they don’t have to worry.”

The key themes are identified below:

- **Talking it through** - Some patients expressed surprise that they could talk about their wishes for end of life care. Patients found it helpful to explore end of life issues and for some it was a cathartic/liberating experience
- **Enabling further discussion (with family/carer)** - Patients stated that having an opportunity to explore end of life issues with a professional at the Hospice, gave the patients the confidence to then discuss these matters further with their families/carers
- **Clarification of issues** - Having the opportunity to discuss end of life issues with a professional enabled there to be clarification of some points regarding treatment options and their implications. However, even after further clarification, some patients found it difficult to see themselves in a situation that they had not yet experienced
- **Comfort/relief at having been able to make their wishes known** - One patient acknowledged how difficult it was to explore issues of end of life. However, although she had had found it difficult to think about what she would like to have happen to her at the end of life, she achieved an immense sense of relief when she had been able to state where
she would like to die. This patient had young children, and it was very important to her that she did not die at home, leaving a lasting memory of her death at home for her children

- **Timing of end of life conversation** - A number of issues were highlighted around timing:
  - The time to have the conversation and complete the documentation – the patients interviewed highlighted how long it takes for patients to have sufficient time to consider EoLC in a thoughtful way. It is not a subject that can be addressed lightly. It requires full commitment from the patient and the professional
  - The time to return to the patient for them to reflect on the experience - once ACP had taken place with a patient, additional time was needed for the project team member who had completed the ACP to return to the patient to establish how it had been for them to participate in the process
  - The time of the conversation in relation to the patient’s illness trajectory i.e. if the conversation took place too early in the patient’s illness journey the patient was not ready to explore these issues; however, too late in the disease process, when the patient had more significant symptoms and the patient would be too unwell to participate. One patient highlighted how as a hospital patient (rather than hospice) she had been asked whether she would wish to be resuscitated before she had even been asked her presenting problems or clarified her personal details

- **Preparation** - Patients acknowledged that the conversation needed to take place in a safe place i.e. a place where their conversation would be confidential. Therefore planning the discussion allowed for a suitable venue to be established in advance

- **Documentation** – A number of issues arose under this theme:
  - Patients were given the ACP documentation to look at before the planned session to explore their wishes. This was in order that the patient had time to consider their wishes. There are many issues for patients to think about, from the more clinical treatment options e.g. use of antibiotics in the event of infection, fluid therapy (intravenous or subcutaneous) for dehydration, personal issues of choice in relation to communication such as who the patient would choose to share in discussions about their wishes from their family/friends, and choice regarding preferred place of care; home, hospice or hospital. (This final option aspect was included notwithstanding the fact that choice of place of care is highly dependent upon bed availability and community care support)
  - The patient was given a basic explanation of each Section in the Thinking Ahead documentation by a professional. However, some patients found the volume of documentation “overwhelming”. Having someone who understood the process, to go through it with them, alleviated some of the anxiety
  - One patient highlighted that the documentation felt remote, detached, even blunt. She described it as “black and white”. These comments were said in context of the documentation having very explicit questions that required clear considered answers. This patient felt unsure about her answers. More than one patient said how difficult they found it to imagine what they would like to happen in the event of a situation which they had not yet experienced
  - Patients were concerned that in expressing their wishes at one given time, that they may wish that this decision should be reversed on another occasion. Patients did not want to feel bound by their recorded decisions
  - One patient highlighted how a member of the Family Support Team had given her a leaflet about planning funerals. This leaflet she was able to take away and show to her family. This patient said how helpful this was in enabling her to tackle the issue which she acknowledged to be very emotive. The project team had considered the idea of a Patient Information Leaflet for PPC and felt this comment reinforced such an idea
• **Final arrangements** - Patients acknowledged that their wishes were being heard by someone who would endeavour to act upon them. This was seen as a source of great comfort. Patients went on to state that they wanted to have decisions made so that their families/carers did not have the burden of having to do this.

**Discussion**

The project team found that although there were many issues around planning for EoLC that resonated with both staff and patients, patients focused more on the importance of being able to talk through this subject and have issues clarified while staff highlighted considerations about the actual activity of carrying out the process.

See Boxes F and G for those issues that patient and staff expressed as areas of concern.

<table>
<thead>
<tr>
<th>Box F</th>
<th>Completing ACP: areas of concern for patients</th>
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<tbody>
<tr>
<td>Timing</td>
<td></td>
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<tr>
<td>Environment and preparation</td>
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<tr>
<td>Opportunity to talk</td>
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<tr>
<td>Clarification of issues</td>
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<td>Documentation</td>
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<table>
<thead>
<tr>
<th>Box G</th>
<th>Completing ACP: areas of concern for staff</th>
</tr>
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<tbody>
<tr>
<td>Timing</td>
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<td>Environment</td>
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<td>Documentation</td>
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<td>Patient led</td>
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<td>Relationship with patient</td>
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<td>Staff confidence and competence</td>
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<td>Emotive subject</td>
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<td>Professional issues/guidance</td>
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Patients said how comforting it was to be able to express their wishes for end of life care yet staff identified many concerns they had in starting this conversation. Dean (2002) proposes that nurses develop communication skills that not only allow them to talk sensitively about death and dying with patients but also give them the capacity to assess whether or not this is what the patient wants.

Hilary Fisher, Director of Dying Matters as reported by Locke (2011) in the Guardian says “unless we can start conversations about dying, we end up with people receiving unwanted medical attention or leaving behind an emotional mess for their families who feel they weren’t able to fully support the dying person.”

Outcomes of the project have identified problem areas/concerns with the process of obtaining patient’s PPC and the project team have been able to state some of the reasons why the audit of PPC demonstrated poor completion. As yet, practice with regard to establishing patients’ PPC has not changed on either the ward or ODT but the project team hope that having identified the areas of concern, their findings can go on to inform ways in which improvements can be made.

“Most people would prefer not to die in hospital but a lack of NHS and social care support services means that many people do so when there is no clinical need for them to be there” (Comptroller and
Auditor General, 2008, p 11). Therefore, enabling people to talk through their wishes raises the likelihood of appropriate planning for them to die in a place of their choice. Additionally, it reduces the burden and stress of the bereaved in trying to guess the wishes of the person who died. Detering et al (2010, p 1) in their study concluded that “Advanced care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety and depression in surviving relatives.” More than one patient said how difficult they found it to imagine what they would like to happen in the event of a situation which they had not yet experienced as supported by the findings of Simon, Murray and Raffin (2008). Similarly, Munday (2009, p 2) highlights how patients’ preferences evolve and change over time, “The most widely reported change was a reversal of the preference for dying at home owing to the patient experiencing distressing symptoms, becoming frightened, feeling vulnerable, or becoming concerned for his or her family.”

The factors identified above highlight the need for healthcare staff to have the appropriate skills to enable patients to discuss their EoLC wishes and to recognise that these wishes may change over time and may therefore need to be an ongoing conversation.

Challenges for the project

Although the overall project aim, to enable all patients within STNHC to express their preferred priorities of care at the end of life was not met, some of the reasons why patients have not been able to express their PPC have been identified by exploring the perspectives of patients and staff and this has paved the way for the next stage of the project.

However, there were several issues that impeded the progress of the project; these will be outlined below.

- **Finding time for the project team to meet** - The three project team members worked in different locations (two in Day therapy, one on the ward). All three were part time (between 22 ½ and 30 hours per week) and quite often worked on different days of the week. As senior management at the Hospice did not permit the two members from ODT to be absent from the day therapy unit at the same time due to difficulties finding suitable back fill in their absence, it was very difficult to find times when all three project team members could work together

- **Achieving stakeholder involvement** –
  - Although there was initial enthusiasm within the organisation for the project and key members of the multidisciplinary team showed an interest, it soon became apparent that the responsibility for the project would rest with the project team alone. As a consequence, maintaining the momentum of the project was more difficult. The workshops facilitated by FoNS as part of the Patients First Programme as an external influence helped to keep the project on track, but there were no additional internal motivators
  - The questionnaire response rate was 46% despite an extension to the return date for the questionnaires; the project team had hoped for more. The project team acknowledge that staff had many other priorities and possibly did not feel engaged with the project, even though it was a subject that was an important part of all RNs workload, and a subject that any nursing assistant could be exposed to in their daily work

- **Planning** - In retrospect, the project team were naïve when planning sufficient project time. Although a Gant chart was devised at the start of the project, most of the project team meetings were arranged a week or so in advance when the off duty rota permitted. The staff off-duty rota was written two months in advance and once established it was difficult to obtain suitable backfill
• **Other Hospice priorities** - During the course of the project, there were many other initiatives in the Hospice which had an impact on the project work. Early on in the project the ward had increased its beds from eight to ten and this meant that care was being provided by a number of new staff who were less familiar with ward practice. The most significant impact resulted from a major refurbishment of the Day Therapy Unit which entailed a wholesale removal of this unit to a temporary location. This had inevitable consequences on the usual working day. Timing of this refurbishment was also significant since it took place in the final three months of the project

• **Patient involvement** - Finding suitable and willing patients to interview for the project was a major challenge. A number of the patients who the project team had identified as suitable for the project, having met the criteria of completing their ACP, were too ill, or died before they could be interviewed. Whilst the project team recognised that they did not want to burden the patients with involvement in the project, the literature suggests that even very unwell patients should still be asked to express their wishes

**Conclusion**

The project team wanted to gather information and experiences from staff, patients and carers to inform the development of practice to ensure that all patients could plan their end of life care; however during the project they realised that this aim was too ambitious within the timescales of this project. Despite this, information collected by the staff questionnaire, patient interviews and the staff discussion identified many of the possible barriers to completing advance care planning with hospice patients. Staff placed a high value on identifying a patient’s preferred priorities for end of life care and patients had expressed the importance of having a healthcare professional to talk through end of life issues. The project team conclude that further project work to further explore the possible barriers to advance care planning will help clarify understanding of this subject and may improve uptake of advance care planning so that patients are facilitated to express their preferred priorities for end of life care.

**Recommendations**

A number of recommendations and areas for future work have arisen from this project:

1. **Share the project findings with senior management at STNHC to help to generate a collaborative approach to overcoming some of the barriers to completing ACP**

2. **Enable staff to enhance their communication skills**

   Many of the staff concerns hinge upon areas of communication especially initiating the conversation.

   The project team had opportunities to consider for themselves how it felt to explore issues around EoLC with patients and to reflect back upon the process. The project team feel that to look more closely at the staff experience of exploring these issues with patients could generate useful information around the barriers to starting the conversation with patients and their end of life wishes; how barriers can be overcome; and how ACP can become more integral to palliative care.

   There were some useful suggestions made by staff members about completing the process of obtaining patients’ PPC. The project team feel that developing some of these ideas could have positive consequences. For example:

   • Identify some set phrases that staff feel comfortable saying, which can trigger deeper discussion about patient wishes for EoLC; this would help to simplify the
documentation. This is supported by Bass (2009) who advocates the use of a model for breaking bad news as a framework for such discussions.

- That SNHC adopt a facilitated method of ACP although there is little evidence to support this approach at present (Karel, Powell and Cantor, 2005)
- Ensure there is planned time within an in-patient stay or ODT session to start the process of exploring EoLC, enabling the process to be patient led but not left up to patients to trigger the discussion
- Use the weekly multidisciplinary team meetings to identify which patients have no recorded PPC and plan to rectify this

3. **Make an information leaflet about ACP available to patients**

Both staff and patients stated that a patient information leaflet with useful details about ACP would have been helpful to give to patients before embarking on a discussion. The project team are aware of patient information leaflets already in existence and have looked at a number of these with a view to devising one of their own or selecting one in current use. Examples of patient information leaflets are the Advance Care Plan – personal preferences and choices for end of life care, St Christopher’s Hospice and Preferred Priorities for Care, Lancashire and South Cumbria Cancer Network (2004). Planning for your Future Care produced by The National Council for Palliative Care/The University of Nottingham and the National End of Life Care.

4. **Explore the carer’s perspective of PPC**

This is an important area of care that has yet to be explored.

**Note:**

Since the completion of this project, St Nicholas Hospice Care has adopted a new “Thinking Ahead” ACP document which reflects the new standardised ACP documentation that is being introduced throughout Suffolk.

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**References**


Appendix 1. Questionnaire for Clinical Staff regarding Preferred Priorities for End of Life Care

Question One

How often do you complete the St Nicholas Hospice Care Thinking Ahead documentation with a patient?

Please circle the appropriate answer below:

Section One  Always  Sometimes  Never
Section Two  Always  Sometimes  Never
Section Three  Always  Sometimes  Never

Question Two

Please state your reasons for your answer to Section One of Question One
.......................................................................................................................

Please state your reasons for your answer to Section Two of Question One
.......................................................................................................................

Please state your reasons for your answer to Section Three of Question One
.......................................................................................................................

Question Three

..............................................................................................................................

Question Four

What value do you place on identifying a patient’s Preferred Priorities for End of Life Care? Please circle the answer that most represents your response

Very High  High  Medium  Low

Question Five

What suggestions do you have about completing the process of Preferred Priorities for End of Life Care, with a patient?
..............................................................................................................................
..............................................................................................................................
..............................................................................................................................

Thank you for taking the trouble to complete this questionnaire.
Appendix 2. Open questions to capture patient experiences

What is the ebd approach?

The ebd approach involves patients, carers and staff in the design of healthcare and harnesses the energy of both patients and staff to make meaningful and lasting improvements.

It provides the opportunity to focus attention on the experience of care – how it feels to use or be part of the service.

Your Experience

What would you like your experience of talking about your end of life wishes to look like?

Your Experience about voicing your end of life wishes

Is there anything else you would like to tell us about your end of life wishes?

How did it make you feel?