



# Enhancing Palliative Care for Patients with Nutritional Issues and their Carers

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Food, nutrition, hydration, palliative, hospice

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## Summary of project

Collaboration between the hospice movement and the primary and secondary care sectors of the health care community has been gathering pace with the government's End of Life Care Strategy. The Care Quality Commission (2010) has identified nutrition as an important aspect of patient care laying down outcome standards that are expected to be achieved.

This project comprised an audit using a validated tool adapted for hospice inpatients and a series of focus groups involving patients, carers and health care professionals. These progressively identified the care provided to the inpatient sector and formed an approach for all the hospice's patients and carers beginning with the community sector.

The conclusion of this work is a Process Map for the professionals to begin to address assessment of nutritional needs. The work itself is available for other hospices and health care organisations to have some appreciation of the task to be accomplished.

## Background

Pilgrims Hospices in east Kent is a group of three similar sized hospices each with its own inpatient unit, day hospice and community outreach. Hospices are regulated under the Health and Social Care Act 2008. It shares with the NHS and Social Services the same monitoring body, the Care Quality Commission. Hospices are an integral part of health care provision (NICE, 2004) and the national End of Life Care Strategy (Department of Health, 2008). They are also linked via Help the Hospices and the National Council for Palliative Care to the hospice community in the United Kingdom.

The inpatient units and day hospices have a statutory responsibility for providing nutrition to patients whilst they are on the hospice premises. There are also patients in the community some of whom attend day hospice but some never enter the hospice as inpatients. There is a significant difference in approach to the nutritional needs of inpatient and day hospice patients and patients in the community. The project leaders wanted to look at the nutritional needs of all their palliative care patients in all settings.

Hospices are beginning to develop nutritional assessment but it is in its infancy. An example, the Malnutrition Universal Screening Tool (MUST) (Ela and Smith, 2009) is not in use in the majority of hospices. There have been attempts to use assessment tools for palliative care patients with advanced

cancer (Hawkins, 2007). According to Hopkinson and Corner (2006), professionals in palliative care resist assessment; they feel it is a burden on the patients. There is some evidence that this conforms to patients' views and that the relationship between patient and carer can be upset by issues of weight and appetite loss (Hopkinson et al., 2006).

Adoption of a documentation system appropriate to the palliative care context should be addressed. The Food and Nutrition Group at Help the Hospices has produced a Consensus Statement which aims to provide a national agreement for the need of a nutritional assessment tool.

In Pilgrims Hospices, catering audits had been conducted at each hospice over a period of years using a locally developed questionnaire. These answered questions about satisfaction from the patients' perspective but did not include the means by which care is delivered. Inpatients and day hospice patients were included in these surveys but again the community issues were not addressed.

A nutritional assessment and associated care plan might facilitate better communication between professionals, patients and their carers and identify their needs (NICE, 2006; Aston, 2006). The communication issues relating to conflict between patient and carer over feeding are well known (Hopkinson and Corner, 2006; Hopkinson et al., 2006). However, improving care in relation to this conflict would require a clear understanding of the issues from the patients' and carers' perspectives.

The project leaders therefore decided that development of care focussed on the needs of patients, identified by assessment, should start with an audit to measure existing practice on the inpatient unit using a validated tool. Later, focus groups involving patients and carers representing community service users were set up to explore issues around nutritional assessment and conflict relating to food/feeding. The results of the focus groups were deliberated by health care professionals in Pilgrims Hospices and a Process Map for nutritional assessment was created.

It was decided from the start that the work should be disseminated for the benefit of other hospices and palliative care service providers through links with the hospice community at Help the Hospices and via FONS.

## Aims and objectives

The aims of the project were to:

- Develop a process to enable the provision of person centred nutritional care for patients with specialist palliative care needs across the care spectrum from home to inpatient unit
- Include the carer, where the patient had one and with the patient's agreement, in the provision of nutritional care
- Address the carers needs where possible

The objectives were to:

- Benchmark current nutritional care within the in-patient setting using an adapted Essence of Care benchmarking tool
- Explore with focus groups of patients and carers the means by which their nutritional needs were identified

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- Share the results of the benchmarking process and focus groups with health care professionals to determine a nutritional assessment programme/process for patients accessing the service
- Implement a process for identifying patient and carer needs

## Benchmarking current practice

The Department of Health's (2001) Essence of Care nutritional benchmarking tool was used as a basis for benchmarking current practice. The nutritional standards cover the following domains:

- Screening and assessment of patients' nutritional needs
- Planning implementation and evaluation of patient care
- Obtaining food
- Food availability
- Assistance with eating/drinking
- Food presentation
- Conducive environment
- Eating to promote health

The tool contains four elements: patient questionnaires, nursing staff questionnaires, nurse observation and case notes review which gives it a multi-dimensional perspective.

Adaptations were made to the benchmarking tool to make it appropriate for use in the hospice setting. For example, the local district general hospital had devised specific questionnaires which therefore had a proven record rather than attempting to "re-invent the wheel". The benchmarking tool required adaptation for the hospice to remove those questions that related to acute care that would not be appropriate e.g. maternity or paediatric issues. The adapted version was then taken for peer review within the Primary Care Trust (PCT), Local Health Economy Group and endorsed. The idea was to keep the tool as close to its original format as possible so as not to lose the benefit of a validated tool.

A link nurse was identified on each hospice site to coordinate the benchmarking process. The link nurse delivered and explained the questionnaires to the inpatients and nurse colleagues, conducted the review of case notes and completed the observations.

Patients in hospice inpatient units may be inclined to be complimentary in questionnaires (Aranda, 2001). Similarly, the hospice annual patient satisfaction survey (O'Sullivan, 2006) identified that patients would rather not complain. However, as the observation questions covered the same domains as the patient and staff questionnaires, this provided a process for cross checking and validating evidence.

In accordance with the recommended procedure for Essence of Care benchmarking, five patient questionnaires were distributed and collected by the link nurse in each hospice. Inpatients who had been admitted at least five days previously were included. Patients who were not well enough to complete the questionnaire were excluded.

A convenience sampling approach was used to select the nurses who completed the nurse questionnaire. These were nurses who were on duty at the time when the link nurse was conducting the benchmarking in each unit.

The same sample number (five per hospice) was also applied to the nurse questionnaires, observations and case notes review. As there were three hospice sites involved, 15 sets of data were gathered for each element of the benchmarking process.

The catering managers of all three sites were kept informed with regards to when, where and how the benchmarking was being conducted. This was partly to ensure that they felt supported in their work and because it was important for them to contribute to the outcome.

The responses to the questionnaires were collated on an excel spreadsheet which produced a quantitative summary. The free text comments were summarised by the project leaders and a benchmarking report produced. This was presented to the hospices' audit steering group that advised on implementation of change of practice.

## Findings from the benchmarking

The patient questionnaires, unsurprisingly, were complimentary. Most of the concerns that arose came from the observations and nurse questionnaires. Where the level of care was good it was corroborated across the benchmarking tools. Nurse observations, nurse questionnaires and documentation brought out areas for attention.

The link nurses in their observations identified long periods of time between supper and breakfast and there was an issue around availability of snacks. The observations also found before each meal patients were not consistently being offered the opportunity to go to the toilet and/or to wash their hands. An audit on falls around the same time (Fisher and Jefferies, 2008) indicated that patients got up to go to the toilet just before meals with a tendency for falls to increase during this period.

The nurse questionnaires highlighted a lack of clarity of responsibility for obtaining and providing food and the identification of roles in this respect. In hospices, volunteers have a role in providing drinks and snacks to patients and carers. Food delivery and clearing of plates and trays was shared unevenly between nursing, catering staff, health care assistants and volunteers. There was not a clear set of boundaries where nurses could leave ancillary roles to unqualified staff or volunteers

What was noticeable by its absence in the nurse questionnaires, was the lack of information about portion sizes and food record charts to ensure there was evidence that the patient was eating what was available and if not whether this would be a cause for concern. Where such information was available it was in some cases recorded by the catering staff in their own records. There was no evidence of a relationship with a dietician. The support of dietitians is considered important in the NICE Guidelines (NICE, 2006).

## Patient and carer focus groups

Many patients receiving palliative care lose their appetites, sense of taste and or sense of smell. They may complain they cannot eat or want to give up trying to eat. To their carers they seem to be wasting away which is distressing. Patient and carer focus groups were therefore set up to explore the issues further:

- What nutritional issues could be included in assessment regardless of the patient's condition
- How the assessment questions could be relevant, appropriate and helpful in terms of time, condition and feelings
- How to overcome potential objections to the raising of issues that the literature identified as contentious
- In what way the carers could be included in the process
- How the conflict identified in the literature between patients and their carers could be addressed

The intention to involve patients and carers in focus groups was discussed with the local Research Ethics Committee who confirmed that ethical approval would not be necessary for this work providing the process was reviewed by the Pilgrims Research Facilitation Forum, which it was.

In total, three focus groups took place; the first involved six patients, the second involved five relatives/carers and the third involved five of the patients who attended the first session and the five carers/relatives from the second session. Each focus group was run as a half day session.

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Community nursing staff recruited the patients and carers. None of the patients were related or otherwise connected to the carers. They selected patients with appetite/weight loss issues including non-cancer patients and carers of patients with similar nutrition issues. They were asked to include as far as possible patients/carers who had experience of either home care, day hospice, outpatient and inpatient services to obtain a range of experience of the hospices' services. Recruitment of user groups tends to show there are "hard to reach" groups in palliative care who are either too frail or emotionally vulnerable (Johnston, Forbat and Hubbard, 2008). It is acknowledged as a limitation of this work that the patients and carers recruited would not represent these "hard to reach" groups.

All of the patients (six) were receiving care at home, five of these were also attending the day hospice; one had attended an outpatient clinic. Their length in the service was from 0-3 years, mostly 0-1 years. Their age range was 57 – 88 years, average 74 years. There was an equal ratio of males to females.

Four of the five carers were caring for relatives at home, one was related to a day hospice patient and two had attended an outpatient clinic. All except one were relatively new to the service. Ages ranged from 45 to 74 years, average 58 years. The ratio of males to females was three to two.

The patients and carers were sent an invitation to attend the focus groups which explained the project and included examples of questions from two nutritional assessment tools to inform the discussions. One, the Patient-Generated Subjective Global Assessment (PG-SGA) (Bauer et al., 2002) was validated for palliative care scenarios. The other was an evidence based working tool from a hospice in the east of England. This was included because the hospice using it was involved in the development of food and nutritional assessment with the Food and Nutrition Group from Help the Hospices.

The patients and carers responded by post to this initial invitation so it was accepted by the project leaders and the research facilitation group in the organisation that this constituted consent to participate.

All the sessions took place in a building near, but not in one of the three hospices. Refreshments, parking and all facilities to ensure participation was free of tension were provided.

The first focus group with the patients went through the nutrition assessment questions to determine whether they were relevant to patient care and in what circumstances they would enable health care professionals to provide them with a benefit.

The second focus group of carers were invited to discuss their contribution to nutritional assessment and what common ground they had with the patients in terms of how they might resolve conflict in issues around weight and appetite loss.

The third focus group brought the patients, carers and relatives together to identify the questions that are perceived to be relevant and meaningful; how they could be addressed and in which order.

At each session the work of each group was recorded on a flip chart as proposals and ideas were expressed. These were summarised after each session and distributed to the group members by post for their comments. At the next session they were asked to confirm that the summary was accurate and any amendments made. After the final session responses were asked for by post. All sessions were recorded on compact disk (CD Rom) only so that the summary could be confirmed as accurate and to ensure that nothing meaningful had been overlooked before sending out the summary after each session. All this material will be

destroyed when the Nutritional Management Process Map has been adopted.

## Findings from the patient and carer focus groups

The patients and carers designed a "Programme" based on the questions from the nutritional assessments that were presented to them (see final project report <http://www.fons.org/library/report-details.aspx?nstd=6124>).

The format of the assessment they suggested would follow this order:

- Q1. Are you enjoying your food at the moment?
- Q2. Do you live to eat or eat to live?
- Q3. Are you on a special diet?
- Q4. What are your symptoms?
- Q5. Provision of information and care plan
- Q6. Activities and functions
- Q7. What are your own goals to improve nutrition?

The patients and carers also formulated the following summary of their opinions:

*"The foundation of a good relationship is that the approach to nutritional needs should be positive and forward looking rather than fact gathering and historical in nature. For this reason it should not begin with factual questions about weight, food intake or symptoms relating to the past.*

*The first question: [in their "Programme"] 'Are you enjoying your food at the moment?' seeks to engage with the patient where they are on the journey with an attempt to gain their confidence that their wishes and feelings will be respected. At the same time the possibility of future realistic goals are opened up. The wording of the questions is not prescriptive so long as they elicit a response that tells the health care professional whether this patient has food issues that they can address.*

*At the outset it would be helpful to check with the patient and carer as to who will answer these questions and the role each will take in the discussions. This needs to bear in mind the medico-legal relationship that predominates between the health care professional and the patient. It also needs to remember that a simple patient/carer relationship may not exist."*

Contentious issues such as weighing patients and taking blood samples were discussed in the focus group. It was clear from this admittedly small sample that patients did not object to being weighed or tested so long as they could see a potential benefit. This Programme should be examined by the health care professionals to identify appropriate times and circumstances when questions about blood tests or weight need to be repeated.

For carers, lack of information on how they could cope in caring for the nutritional needs of the patient was identified as necessary early on in the relationship with the health care provider. Goal setting needed to be pragmatic for both the patient and carer so that expectations could be grounded in reality.

## Health care professionals focus groups

The findings from the patient and carer focus groups were shared with professionals to inform the development of a workable and meaningful tool to assess the nutritional needs of patients receiving hospice care. The group included two clinical nurse specialists (CNS) working in the community, a hospice physician, a counsellor, a social worker and a catering manager. The CNS members of the group and the counsellor were selected because of their interest in nutrition. The remaining members were chosen for their availability and

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willingness to contribute. The social worker had experience in research. Three half day meetings were planned. The "Programme" written by the patients and carers was distributed and discussed in the professional group.

## Findings from the health care professionals focus groups

The professionals met twice and provided the content for a Process Map for assessing nutritional needs and referral to specialist professionals and interventions. The third (final) meeting could not go ahead due to workload commitments however an ongoing discussion took place by email and face to face discussion with group members.

The Process Map was designed to encourage the professionals who provide the first assessment on the patient's referral to the hospice to address nutritional needs. All too often these amount to the patient's plea not to be pressed to eat because the relative is anxious that the patient is declining in health and the loss of appetite is linked to decline and imminent death. The patient may not need the quantity of food the carer is cooking for them. On the other hand, according to the counsellors and social workers in the hospice, the plea may signify an existential need that the patient finds difficult to express in other ways than through the very essential medium of eating difficulties.

The Process Map is developing into a useful teaching document to assist with the professionals' engagement with the patients. Furthermore it is proving to be a dynamic document that is provoking valuable discussion within the organisation (see final project report <http://www.fons.org/library/report-details.aspx?nstd=6124>) for the current version of the Process Map at the time of publication).

## Conclusion

Using the benchmarking process, current nutritional practice within hospice care has been explored and by engaging with patients and carers, a deeper understanding of nutritional issues from their perspective has been gained. These approaches have enabled the development of a Programme to inform the provision of person centred nutritional care for patients with specialist palliative care needs across the care spectrum from home to inpatient unit.

The project leaders acknowledge that at the time of reporting, this work had had only a limited impact on practice. Whilst the hospice movement has a very good reputation for providing quality of life in end of life care, nutritional assessment is complex and as yet, an appropriate assessment tool for palliative care is not available. The Process Map has been designed to provide a stimulus to address nutritional needs first and from that to promote the idea of and eventually introduce nutritional assessment.

The project work has been shared widely amongst the hospice community to stimulate debate and encourage further development.

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## Further information

The full project report including the Programme and Process Map can be downloaded from:

<http://www.fons.org/library/report-details.aspx?nstd=6124>

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