FOOD AND NUTRITION IN PILGRIMS HOSPICES

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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 for the last two years. 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.

A project to enhance palliative care for patients and their carers with nutritional issues was conducted in Pilgrims Hospices in east Kent between 2008 and 2010.

The project comprised an audit using a validated tool adapted for hospice inpatients, 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 our 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 evaluated their current practice in nutritional care using an adapted Essence of Care (EoC) benchmarking tool and a series of focus groups. This report summarises the findings from the work, supported by the Foundation of Nursing Studies (FoNS).

Pilgrims Hospices 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 (DoH 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 the patients whilst they are on the hospice premises. There are 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 leads 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) (Elia and Smith 2009) is not in use in the majority of hospices. 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.

There have been attempts to use assessment tools for palliative care patients with advanced cancer (Hawkins 2007). According to Hopkinson & 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).

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 know (Hopkinson & 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 leads 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
- 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
METHODS

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 co-ordinate the benchmarking process. Their role was to manage the identification of patients and nurses to complete the various benchmarking tools. The link nurse explained and delivered 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). 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 nurse lead was conducting the benchmarking in each unit. The records used were current under the new documentation system (known as the “Patient Profile”) i.e. those under the old documentation system were excluded.

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 leads and an benchmarking report produced. This was presented to the hospices’ audit steering group that advised on implementation of change of practice. A copy is available on the FoNS website.

RESULTS OF 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 audit 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 & 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 dietitian. The support of dietitians is considered important in the NICE Guidelines (NICE 2006).

ETHICAL ISSUES

The only part of the project that might have been considered to require research ethics approval (NRES 2009) was the patient and carer focus groups. However, following discussion with the Local Research Ethics Committee, they confirmed this they would not be necessary. They would be satisfied by internal review by the Pilgrims Research Facilitation Forum which took place.

PATIENT AND CARER FOCUS GROUPS

The patient and carer focus groups were set up to explore the patient’s relationship with food in terms of psychological issues and the effects of disease. This would require engaging with the patients on these issues. Many palliative care patients 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. To explore these issues would be better achieved by asking the patients and carers.

It was therefore decided that focus groups would be set up to obtain evidence from patients and carers themselves to explore:
• 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

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.

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 our 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 & 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. Their age range was 57 – 88, average 74. 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. The ratio of male female was 3:2.

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) was validated (Bauer et al 2002) 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.

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 we asked for responses 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.

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 FINDINGS OF THE PATIENT AND CARER FOCUS GROUPS**

The patients and carers designed a “Programme” based on the questions from the nutrition assessments we presented them with. (See Appendix 1)

The patients and carers 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 hospice 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.

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.

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?

There need to be clear criteria to prompt health care professionals to review the goals with the patient and carer. 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.

HEALTH CARE PROFESSIONALS FOCUS GROUP
The results of 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 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.

THE RESULTS OF THE HEALTH CARE PROFESSIONALS FOCUS GROUP
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 is taking place by email and face to face discussion with group members. 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 Appendix 2 for the current version of the Process Map at the time of publication).

The Process Map is 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.

CONCLUSION
The project leads acknowledge there has been no impact in practice at this time. Whilst the hospice movement has a very good reputation for providing quality of life in end of life care hospices do not have a formalised documentation of nutritional needs.

The Project Leads have presented the audit results at two conferences in Birmingham and Manchester organised by the Food and Nutrition Group from Help the Hospices. The conferences were delivered to an eclectic audience from the Acute and Palliative Care sectors of practice and research. A third conference took place in July 2010 in London. The patient, carer and health care professional Focus Groups’ findings were disseminated there. The Nutritional Assessment Focus Groups Programme was previously shared with one of the other hospices presenting at the conference. In their presentation they demonstrated how they have adopted the essence and the sequence of the Programme developed at Pilgrims in their revised Nutritional Assessment Tool and credited it to the Project Leads. Only this one hospice, is known to the Project Leads to be using nutritional assessment documentation. One of the reasons for this is that the MUST tool (Elia & Smith 2009) is not appropriate to palliative care and no alternative has been successfully introduced.
It is not possible to say at this stage when hospices will adopt a nutritional assessment tool which is why the Project Leads decided to design a Process Map to provide a stimulus to address nutritional needs first and from that to promote the idea of and eventually introduce nutritional assessment. Communication training is required to elicit patients unspoken needs that often is presented to professionals as their inability to eat. Conveniently, communication training at this level is currently being taught in the organisation as part of the “preferred place of death” initiative.

REFERENCES
www.bapen.org.uk
APPENDICES:

1. Nutrition Assessment Focus Groups Programme
2. Nutritional Management Process Map
Appendix 1

Nutrition Assessment Focus Groups Programme
Patients and Carers on Thursday 16th July 2009

Introduction
A Programme of Questions relating to nutrition needs was drafted to elicit useful information and to become the basis of a working relationship between the health care professional and the patient and their carer. This working relationship would be expected to be evolving and documentation would need to include questions that both initiate the relationship and are intended to facilitate periodic review.

The setting for this Programme is the initial introduction of the patient to the hospice which is normally referral at home but may be transfer from hospital to the inpatient unit. The Programme must be adaptable to the home, inpatient or day hospice situation.

The Programme includes a rationale and the intended outcomes from the questions.

Purpose
This Programme will be offered to the Palliative Health Care community as a contribution to the effort to make nutritional care more palliative orientated. It is intended to assist in providing nutrition to patients on their terms and hopefully in terms that are helpful to the relationship between the Patient, their Carer and the Health Care Professional.

The Programme
Rationale behind the Programme
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 opening questions
The first question 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.
Q1 Are you enjoying your food at the moment? (underlying question about food being a need or a want and the use of the word appetite).

Q2 Do you live to eat or eat to live? (what sort of eater are they?)
This question is likely to open the discussion.
The patients’ priorities may include:
- healthy eating - not junk or the wrong foods
- enjoying food
- being able to eat
- look forward to eating
- incentive to keep going
- eating with family
- balance between what is good for me and what I would like to eat
- Where does food fit, what is its importance in relation to other things – balance.
- being able to taste
- decisions about mealtimes – regular meals or "grazing"
- food as "fuel"
- timing food with medication

The carers’ priorities relate to the tension between the patients needs and the wants. Making a huge effort that might be wasted – feelings of rejection.

Q3. Are you on a special diet?
This would deal with any risks attached early in the discussion.

It would deal with hazards such as allergies or special diets such as diabetic or coeliac diet etc.

Cultural and faith issues would be discussed here.

It could also open a discussion on food preferences, likes and dislikes. (but see Q7 GOALS below, it could be in either or both places.

Q4. What are your Symptoms?
I have had the following problems that have kept me from eating enough during the past two weeks
- no problems eating
- no appetite, just did not feel like eating
- nausea
- constipation
- mouth sores
- things taste funny or have no taste
- problems swallowing
- pain; (where?) ...........................................
- Other” ..........................................................

Examples: depression. money, or dental problems
Food intake (with Symptoms)

Most of the next series of questions were taken from the questions extracted from a validated nutritional assessment tool and one that is used in a hospice in Essex which is “evidence based” (i.e. there is research evidence to support it)

As compared to my normal intake I would rate my food intake during the past month as:
- unchanged
- more than usual
- less than usual

I am now taking:
- normal food but less than normal amount
- little solid food
- only liquids
- only nutritional supplements
- very little of anything
- only tube feedings or only nutrition by vein

The “Weight” question

There was no difficulty in asking the patient’s weight so long as it was clear there was a reason and therefore what the benefit for the patient would be. It may not be a question of weight but muscle wastage. This would be asked with the symptom questions.

Blood tests

The value of blood tests was discussed relevant to the nutritional status of the patient. Like the “weight” question it is entirely appropriate if there is a benefit for the patient which there could be in terms of their mineral levels. Blood tests may need to be taken periodically and link this to appropriate treatment.

Do you experience taste changes?

Are cold or warm foods generally better tolerated?
- Loss of normal taste?
- Excessive metallic taste
- Excessive bitter taste?
- Excessive sweet taste?
- Excessive saltiness?

These questions are more or less straightforward.

Q5. Provision of Information and Care Plan

Information on nutrition, diet, what can be done/can't be done, ideas about food preparation, presentation, fortifying foods, supplements such as are available to the Hospice Catering Managers. What is the content of products, how to tell their nutritional value?

Access to dieticians.

Leaflets about what is needed e.g. blood tests and in what circumstances. This may have to be tailored to each individual patient.

The health care professional could develop a Care Plan, particularly with the Carer on the variety of information needed and available to assist with nutritional requirements. The patient and carer keep the Plan.
The Care Plan/Information Pack could include tips, FAQs (Frequently asked questions), websites, leaflets and helpful organisations.

This would also seek to address the area of potential conflict between the patient and carer over each of their perspectives and anxieties in the patient’s relationship with food. The Patient and carer as far as possible would be involved together in the food “shopping list” and the preparation of food such as choosing the content of a “smoothy”. Opportunity for communal eating and how to gain the benefit of the social experience as far as this is possible.

**Q6. Activities and Functions**

Over the past month, I would generally rate my activity as:

- normal with no limitations,
- not my normal self, but able to be up and about with fairly normal activities,
- not feeling up to most things, but in bed or chair less than half the day,
- able to do little activity and spend most of the day in bed or chair,
- pretty much bedridden, rarely out of bed

**Q7. What are your own goals to improve nutrition?**

i.e.  
(1) To lift mood,
(2) to be able to enjoy food,
(3) to eat with relatives and friends.
(4) Other........................................................................................................
(5) What are your Likes .........................................................
    Dislikes.................................................................

The goal was defined thus: “the ability to obtain a degree of nutrition that is appropriate for both the patient and carers given a set of variables”. The variables depend on the varying state of health of the patient, their needs and how these affect their nutrition. These variables refer back to the first two questions.

**Review**

There need to be clear criteria to prompt health care professionals to review the goals with the patient and carer. 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.
Appendix 2

NUTRITION ASSESSMENT MANAGEMENT PROCESS MAP

RATIONALE
Some patients, not all, have nutritional issues. Mostly these are related to anorexia or cachexia but some may have problems for example of weight gain due to steroid use. Not being able to eat, smell or taste can be distressing symptoms for the patients. They may not want to eat. On the other hand their carers may want them to eat causing conflict. Other members of the family may get involved putting pressure on the patient which may become intolerable. There are social issues too around eating with others or eating alone.

Eating and drinking is an existential issue because our survival depends on nourishment. When a patient says they cannot eat it is difficult to deduce whether they mean they don’t want you or their family to persuade them to eat or it may be they are using food to express underlying feelings and fears. This may be manifested in other ways such as apathy, low mood, questioning the meaning of continued life. They may have difficulty understanding their own feelings and expressing them to you. This must be born in mind when making the early assessments of patients/carers nutritional needs.

The following process may help you address nutritional issues and potential conflict that may be overt or hidden. To do this you may have to look for the triggers that indicate whether the patient really does not want to eat or has an underlying question that needs to be expressed.
THE PROCESS
△ Obtain a Baseline Indication of how the patient is managing food
△ Their likes/dislikes
△ Is there an issue; for whom (patient/carer) and in what way?

WHAT DRIVES THE PATIENT?

NUTRITIONAL ASSESSMENT (INITIAL AND ONGOING) (see attached “Programme” of questions and comments from the patient/carer user group 2009)

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>CARER</th>
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| Symptoms
What is the meaning of the symptoms for physical/psycho-social and spiritual intervention? What you see on the surface belies what is underneath. Need to interpret the words of the patient so that underlying nutritional signals are identified and acted on | Issues
How to resolve potential conflict issues. Failing to acknowledge the conflict and address it runs the risk of it festering. The balance needs to be struck between addressing the conflicts and leaving the home with more anxiety than when you arrived. |
Look for messages from the patient and/or carer that trigger the concern in your mind that the rejection of nutritional needs hides other issues and bring them to the multi-disciplinary team to highlight potential resolution or to clinical supervision for reflective practice.

![Diagram of multi-disciplinary team referrals]

### Referrals
- CNS
- Catering
- Speech & Language Therapy
- Dietician
- Social Worker
- Chaplain
- Occupational Therapy
- Counselling

### Interventions

<table>
<thead>
<tr>
<th>Practical</th>
<th>Pharmacological</th>
<th>Education Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment</td>
<td>Medical treatment of mouth sores</td>
<td>How to manage change in expectations – 4 meals a day</td>
</tr>
<tr>
<td>Food presentation</td>
<td>Effect of steroids on weight gain/loss</td>
<td>Ways of dealing with symptoms e.g. crushed ice pineapple</td>
</tr>
<tr>
<td>Size of plate</td>
<td>Medications for appetite/taste/smell</td>
<td>Caring with Confidence Healthy Living; Stress Reduction</td>
</tr>
<tr>
<td>Likes/dislikes</td>
<td></td>
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<tr>
<td>On LCP</td>
<td>“Why won’t he eat?” leaflet</td>
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