

Emaciated but not unloved

Patients and carers need support to cope with the distressing effects of cachexia

→ Peter McIntyre

Images of gaunt, wasted bodies are shocking and often linked to feelings of shame, blame or guilt. When patients with advanced cancer begin to look this way, the problem lies with the cancer more than any lack of appetite. But if this is not well understood, friends and family can feel at fault, and cajoling the patient to eat can become a source of great tension. Timely advice can help.

“**Y**ou’re horrible looking... I would say you look like ‘Belsen’, the look of dying.” This cancer patient was using the word ‘you’, but talking about herself, grasping for imagery from the holocaust to describe what she felt was happening to her body.

Another patient described how the disease affected her very sense of identity whenever she looked in the mirror: “The face that looks back at me, it’s not me!”

Both were experiencing the effect of cachexia, a condition that affects many people with late-stage cancer and some other diseases, in which muscle and fat drop away, and the body develops a gaunt and wasted appearance. Their views were expressed through a recent piece of research from Belfast, Northern Ireland, which encouraged patients with late-stage cancer and cachexia and their family carers to talk about the psychosocial impact of the condition on both the patient and their family.

There is increasing awareness of the need to develop knowledge and expertise about cachexia

amongst health professionals and family carers. One aim is to reduce feelings of guilt and frustration in a family when a patient loses their appetite for food.

Love and nurture are closely bound up with food and nutrition, and a failure to eat or to thrive can easily spill over into feelings of guilt about an apparent failure of care. Although conditions such as nausea or mouth ulcers that affect people’s appetite can be treated, advanced cachexia is not responsive to nutrition alone, however lovingly given.

It marks a complex series of changes in the body which can lead to a 10%–30% loss in body weight. Anorexia causes the body to burn its fat reserves; cachexia causes loss of both fat and muscle, leading to extreme wasting. People with cachexia burn more energy at rest than other people – a tumour can consume large quantities of glucose – and the condition is often accompanied by severe fatigue. In his review of the biology of cachexia, Michael Tisdale, professor of cancer biochemistry at Aston University, Birmingham, UK, concludes: “Although cancer cachexia super-



officially resembles starvation, nutritional intervention alone is unable to reverse the condition.” Cytokines such as interferon and interleukin have been implicated in cachexia, but are not thought to be a sufficient explanation.

The name cachexia comes from the Greek words ‘kakos’ (bad) and ‘hexis’ (condition), a description that sums up the very poor prognosis for people with advanced cancer and advanced cachexia. It is itself the cause of many cancer deaths, and a contributory factor in others. However, in its early stages, cachexia can be missed, especially since it may not immediately lead to obvious weight loss, especially in patients who are obese or who have large tumours.

The European Palliative Care Research Collaborative (www.eperc.org) is devising a classification and assessment system leading to a decision-guiding tool for palliative cancer care of people with cachexia. Systematic reviews have been undertaken on factors that can distinguish patients with cachexia from those with other clinical

Rejection. When food is not wanted and can do little good, family carers may benefit from advice to show their love and support in other ways

conditions that cause decreased nutritional intake, and on eating-related distress. A cachexia assessment instrument for the palliative cancer care context is expected in the second quarter of 2009, after a pilot study and a Delphi process involving 18 international cancer cachexia experts. This ‘SIPP’ tool will help to guide the management of patients. SIPP stands for

- Stores (the amount of depletion in the body)
- Intake (the extent to which the patient is inhibited from eating)
- Potential (for cancer control and the extent of tumour activity)
- Performance (the patient’s physical functioning and the level of their distress)

Florian Strasser, head of Oncological Palliative Medicine at the St Gallen Cantonal Hospital in Switzerland, is leading the EPCRC work on

cancer cachexia classification and assessment. He has conducted clinical trials of fish oil, cannabis derivatives and the natural hormone ghrelin to see if these will help patients to take in and use nutrition. However, even where such approaches stimulated appetite, they have not yet shown widespread benefit for most patients with cachexia. One reason may be the previous failure to distinguish between different causes of weight loss and individual patient characteristics.

Strasser says that the extent of tumour activity as expressed by catabolic rate is now thought to be a significant factor in classifying cachexia and in guiding palliative care. “Five or ten years ago, we had this idea that if we increase the appetite through using drugs, then automatically the patient will eat more and will have less cachexia and more function. The new concept of classification tells us that pronounced inflammation or catabolism caused by tumour can cause involuntary weight loss – appetite loss is often not the main problem. It looks like the new classification has to move away from a simple anorexia syndrome to a cachexia syndrome where you have to take into account appetite and nutrition intake on one side and inflammatory tumour activity – measured by CRP (C-reactive protein) or tumour dynamics – on other, and the effect on muscle mass, muscle function and muscle strength.”

TAILORED ADVICE

He tailors advice to patients and family carers according to whether the main problem is lack of appetite or an inability to benefit from nutrition, and says that psychological counselling can be very beneficial in reducing eating-related distress.

“The cancer causes a decrease in the perception of appetite and the hyperglucocorticoid drive to tell the body it is hungry, and signals the brain ‘I am full – I don’t need food’. The patient understands that he has no hunger because of advanced cancer.

“He says, ‘Doctor, if I don’t eat, I am going to die,’ and I say, ‘Yes sir, that is the case because you have incurable cancer.’ If the patient has a nausea which

is bothering him, you may need to alleviate nausea. If I have a patient who has a lot of distress through having no appetite and is not receptive to understanding that his disease is too advanced for him to have appetite, I might give this patient a symptom-alleviating drug, which helps to stimulate the appetite. He will feel better, but I have to explain to him that he will have problems with muscle mass and loss of function.

“The hypothesis now is that if a patient has low inflammation and a stable tumour, then the patient might profit if you achieve increased nutritional intake by interventions like eating more proteins, giving supplements, and education about cognitive control of eating. I counsel the patient that he has a problem with the hypothalamus. ‘Try to eat every day 50 grams with two drinks of supplement.’ It reduces stress by helping him to understand the scientific base for what is achievable.”

But in advanced cachexia the body simply cannot convert extra nutrition to muscle or fat. These patients and their carers should not obsess about eating, says Strasser.

“You can summarise it as – eat chicken soup if you have low inflammation and the tumour is controlled. If you have a lot of inflammation and your tumour is exploding, forget about chicken soup and try to enjoy life through art or music or other means.”

In this Swiss Oncological Palliative Medicine clinic, Strasser’s multidisciplinary team tries to ensure that the main family carer is also present when a patient is counselled, after research at the clinic suggested that family carers are more distressed than the patient by a failure to eat (Strasser et al. *Palliat Med* 21:129–137).

“Often eating is a symptom of love, to express care and to advocate for the patient, but if you teach them about patients’ needs and other ways to express love and caring and advocating for the patient, then you can reduce the stress on both sides.”

A very similar message is revealed by research in Northern Ireland conducted by Joanne Reid, nurse researcher at the Unit of Nursing and Midwifery

“Inflammation caused by tumour can cause weight loss – appetite loss is often not the main problem”

“If you have a lot of inflammation, forget chicken soup and try to enjoy life through music or other means”

Research at Queen’s University and the Regional Cancer Centre in Belfast (J Reid et al. *Int J Nurs Stud* doi:10.1016/j.ijnurstu.2008.10.012). Reid interviewed 15 patients being cared for at home with advanced cancer and cachexia, and 12 family carers who were looking after them. She found high levels of distress on the part of patients and carers alike. They knew little about cachexia and received little help to learn about it.

Patients tended to see wasting as a sign of approaching death. One said, “I’m trying to get out with eating and all...but it’s doing no good. I know there’ll be no way out now. No going back, this will be it.” Another said, “I have it on my mind I’m on my way out and the weight loss is all to do with it.”

Carers were frightened by the weight loss, and some blamed themselves. “We were panicking because he wasn’t eating and we didn’t know

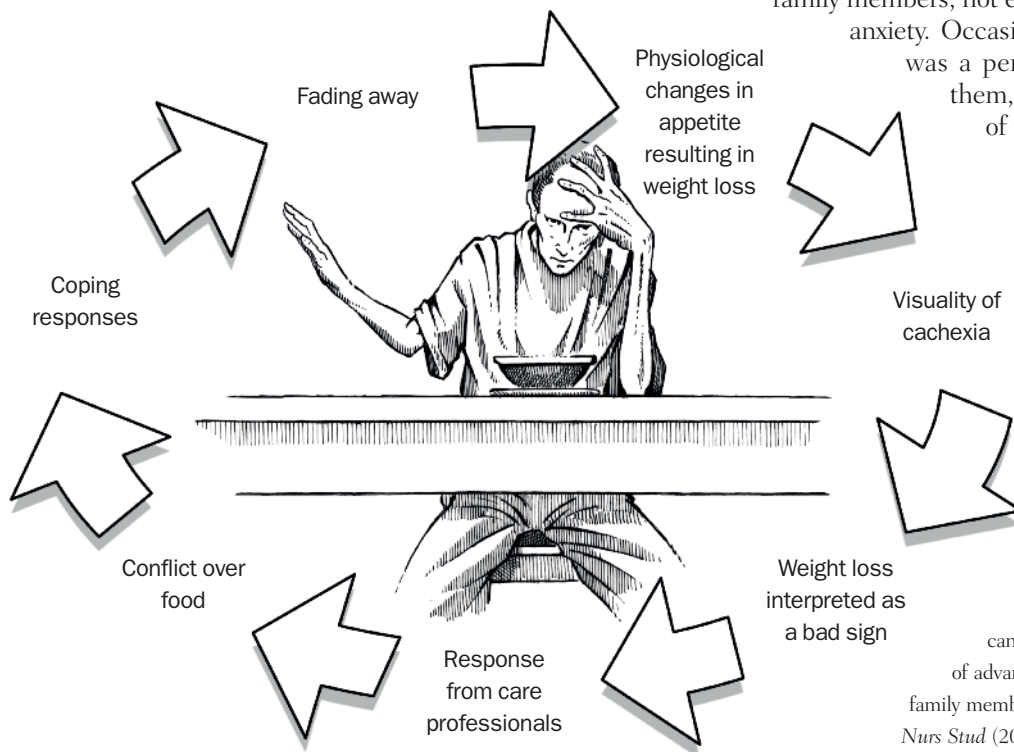
what to do...We felt it was our fault, because he wouldn’t eat and we couldn’t get him to eat.”

In some cases this led to conflict over food. “I made dinner, made what he liked, what he always liked...He said he didn’t like it, didn’t want it, which I was quite angry at.”

Patients often felt pressured to eat. One said, “I do my best to eat, to please them.” Another urged her husband to lie on her behalf and tell the rest of the family that she had eaten earlier.

Food was closely bound up with feelings of care and love between partners. Often women would try to tempt their ailing husbands with buttery cakes or cheese, while men caring for their wives tended to encourage them to eat steak and other high-protein meat dishes.

Reid said, “Patients felt that the provision of food by the family members was a sign of their love. For family members, not eating was a real source of anxiety. Occasionally they felt that this was a personal rejection towards them, as opposed to a rejection of food. That could have led to feelings of anger. They



Understanding cachexia.
This schema was developed for patients, families and health professionals by a nursing research team; however, knowledge of the condition remains incomplete, and there are no guidelines either for assessment or treatment

Adapted from The experience of cancer cachexia: A qualitative study of advanced cancer patients and their family members, by Joanne Reid et al. *Int J Nurs Stud* (2008)

may also have felt guilt because their loved one's condition was continuing to deteriorate and that might have been seen as a reflection of them failing to provide adequate levels of care."

Patients and families felt lack of support from healthcare professionals. One family carer said, "We were in limbo...nobody cared. We couldn't turn to anybody...nobody seemed to help us...we just had to cope on our own."

For this reason, Joanne Reid and her team are extending their research to discover the experience, understanding and perception of healthcare professionals about cancer cachexia.

SUPPORTING PATIENTS AND FAMILIES

"The main outcome we would like to see in Belfast is the establishment of a supportive healthcare intervention for patients with advanced cancer who have cachexia, and their family members. We feel in order to do that we need to get healthcare professionals' perspective on the challenges of managing cancer cachexia in clinical practice," she said.

PhD student Claire Millar will spend six to eight months asking nurses on the ward, specialist palliative care nurses, dieticians and junior and senior doctors about their experiences with advanced cancer patients who have cachexia. The team will then match what they find from professionals with the data from patients and carers to design and test a healthcare intervention.

Reid says that cachexia is under-researched compared with other conditions of end-stage cancer. "Perhaps one reason is that cancer cachexia is a very silent symptom of advanced cancer, when compared to pain or shortness of breath, and that may lead to its importance being underestimated and therefore underdiagnosed, and in turn undertreated.

"Pain scales and pain management techniques are much more developed, whereas we don't have a clear definition of cancer cachexia and I feel our current understanding of its pathogenesis remains

incomplete. Due to this, we don't have clear assessment guidelines and the optimal treatment for cachexia in patients with advanced cancer has not been uncovered yet.

"A lot can be done in advising patients and families at an early stage of advanced cancer about the weight loss that will follow, giving them the opportunity to explore what that means for them, and setting up a situation where patients and their families can express their fears and concerns. They need to be very clear about the difference between weight loss that is associated with starvation and weight loss that is associated with cancer cachexia."

There is a high degree of consistency between the conclusions being reached in St Gallen and in Belfast. Both Strasser and Reid would advise patients who can benefit to eat little and often, but also advise families caring for someone with advanced cancer and cachexia not to make food the cornerstone of family love and concern.

They both have similar approaches also to the extreme fatigue that is often part of this condition. In Belfast, Reid advises an individual approach for each patient. "It is about planning your day – if people are planning activities, they may want to ensure they have time to rest to be able to do the things they want to. Unfortunately, for a lot of people who have a high degree of fatigue, it does not matter how much rest they get, they still feel constantly tired. It is a very individual situation."

Strasser agrees. "I counsel my patients to 'talk to their muscles'. Gentle exercise is a good way to maintain, or bring about a slower decrease of, muscle function. Patients are taught energy preservation (doing less with the energy they have), restorative activities, good sleep, and at the same time to perform physical activities.

"A key point is to balance expectations to reality, in other words, not to pressure patients to achieve unreachable physical goals, and not to give patients the misconception that they should not move or burn precious calories."

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at an early stage about the weight loss that will follow”