

# Pain! The denial needs to end

Uncontrolled pain can blight the lives of cancer patients and survivors. But all too often, health professionals don't ask, and patients don't tell. **Simon Crompton** looks at why this is still the case, and what can be done about it.



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It isn't as if cancer pain isn't talked about. The need to manage cancer pain effectively has had a high profile since 1986, when the World Health Organization produced a three-step analgesic ladder as part of guidance aimed at bringing effective pain relief for the majority of cancer patients globally.

Since then, swathes of guidelines on treating cancer pain have been produced, including comprehensive ESMO clinical practice guidelines in 2012 covering assessment and management of mild, moderate and severe pain up to end of life. Opioids and other new pharmacological-based treatments are becoming increasingly available in European countries, as understanding grows, fears diminish and national laws and policy adapt.

But for all the profile of pain, is the experience of pain improving for cancer patients in the day-to-day reality of the clinic, hospital ward and home? The answer would appear to be no.

Cancer pain, according to WHO, includes pain caused by the cancer, pain related to the cancer (for example through lymphoedema) and pain related to treatment. But recent evidence suggests all types are undertreated.

An analysis in the *Journal of Clinical Oncology* concluded that one third of cancer patients do not receive pain medication proportionate to their pain intensity (JCO 2014, 32:4149–54). Another, in the *Annals of Oncology*, reviewing studies using pain management indices, concluded that nearly one in two patients with cancer pain is undertreated (Ann Oncol 2008, 19:1985–91).

“Despite increased attention to cancer pain, pain prevalence in cancer patients has not significantly changed over the last decade as compared to the four decades before,” said Johan

Haumann from the University of Maastricht's Pain Centre, writing in *Current Opinion in Supportive Palliative Care* (2017, doi:10.1097/SPC.000000000000261).

Mitzi Blennerhassett from the UK stands witness to the long – sometimes unending – journey into cancer pain. Patient advocate, campaigner, speaker and author of an award-winning book describing her experiences with anal cancer, Mitzi started experiencing pain from the cancer before her diagnosis 27 years ago. This continued with increasingly extreme pain through chemotherapy and radiotherapy treatments, and today she still suffers daily – and often unbearable – pain.

She remembers how her requests for better analgesia during treatment were ignored, and the level of pain she was experiencing was not acknowledged until a Macmillan nurse obtained dextromoramide and later diamorphine for her. Radiotherapy staff had told her there was nothing more they could do for it. “They looked at their feet and said they were sorry but the oncologist had told them that I couldn't be prescribed anything else.”

## “When treatment has finished they are left to cope with the side effects”

“I was trying to be stoic. I thought I was expected to just put up with the pain as there was no opportunity to talk about it. But it also seemed that health professionals were in denial about pain, particularly when it was caused by their treatments.”

She still finds it hard hold back the emotion when she remembers the pain she experienced during brachytherapy,

when the wall of the anal canal repeatedly went into spasm.

Today, talking to support groups and looking through online forums of cancer patients, she can't believe how – despite all the structural reforms to cancer services and the growth of multidisciplinary teams in the UK – health professionals still seem to be in denial. Many patients still aren't being told they might experience severe pain as a result of treatment, and still aren't being asked about pain on clinic visits.

“What stands out about most patients is that when treatment has finished they are left to cope with the side effects,” she says.

### In denial?

Why? With so much attention, resources, and guidelines focused on cancer pain, why is cancer pain still not being addressed? The guidelines are increasingly clear and specific about what should be happening – and increasingly take account of some of the anticipated barriers, such as uncertainty about the best drugs for different cancers.

Last year, comprehensive clinical practice recommendations were published in *Critical Reviews on Oncology/Hematology* on managing pain in people with head and neck cancers undergoing chemoradiotherapy (CROH 2016, 99:100–106). Severe pain is common in head and neck cancers, with half of all patients experiencing it before treatment, four out of five experiencing pain during treatment, and more than two thirds afterwards. The pain results from both malignancy and treatment, and the most frequent cause is chemo/radiation-related oral mucositis.

Aware that pain is often underestimated and undertreated in this group,

an Italian multidisciplinary group of head and neck specialists reached an expert consensus on pain management. Their resulting recommendations impressively addressed not just pain management principles, but practicalities – setting out not only what should be done when, but also which health professional has responsibility at which stage.

**“Patients think the professional will ask if they are interested. And the professional thinks, if the patient has pain, they will tell us”**

It seems a significant step forward from the World Health Organization’s (now much debated) simple three-step approach, which just recommended a mild to strong order of drug administration.

Yet one of the authors, Carla Ripamonti, Head of Supportive Care in the Cancer Unit at Fondazione IRCCS, at Milan’s National Cancer Institute, is surprisingly realistic about the impact these pain guidelines – and any others – are likely to have.

“There are many valid pain assessment tools,” says Ripamonti, who also co-authored the ESMO clinical practice guidelines on cancer pain management. “But only pain specialists seem to use them. In general, too many oncologists and other physicians don’t take the time to talk to patients about pain, or use the assessment tools.”

She has noticed that oncologists

seem to be far more knowledgeable about guidelines on nausea and vomiting than pain – possibly because they are symptoms that are likely to appear sooner than pain during treatment.

Many other key figures in cancer pain are aware of the difficulties of converting guidelines and good intentions into action in the clinic. Wendy Oldenmenger, a nurse who coordinates oncology nursing research at Rotterdam’s Erasmus MC Cancer Institute, has studied in detail the barriers to good cancer pain management. Her analysis in the *European Journal of Cancer* identified knowledge deficits, inadequate pain assessment and misconceptions regarding pain as the most common obstacles (*EJC* 2009, 45:1370–80).

“We have so many guidelines, from the WHO guidelines in the 1980s onwards, but still oncology pain management isn’t as it should be. There are patients with complex pain problems, and they will always be a challenge, but there’s also a problem with treating basic pain on a day-to-day basis, particularly in outpatient clinics. Most of the time, nurses and physicians think they know the guidelines, but actually they don’t know how to use them in daily practice.”

Many nurses and physicians still have the same misconceptions about pain and analgesics as the general public, she says, fearing addiction and side effects. The problem is no longer that opioids aren’t available, it’s that professionals don’t give them, patients don’t take them, or there’s not enough explanation of how to use them.

“Communication is a really big issue,” says Oldenmenger. “Patients are afraid to talk about pain – they don’t want to distract the physician from effective treatment. They think that the professional will ask

them if they are interested. And the professional thinks, if the patient has pain, they will tell us.”

Though practice varies considerably from clinic to clinic and country to country, the problem of implementing good pain management is widespread across Europe. Norway, for example, is often cited as a world leader in palliative care. But a study published last year indicated that cancer pain control in Norway did not improve at all between 2008 and 2014, with prevalence of cancer pain among inpatients at 53–55% and among outpatients at 35–39% (*Support Care Cancer* 2016, 24:2565–74). An earlier study showed that 30% of patients with severe pain did not use opioids, and some of these did not receive any analgesics at all.

### The oncologists must ask

Stein Kaasa, Head of Oncology at Oslo University Hospital, Norway, and Director of the European Palliative Care Research Centre, believes that inadequate cancer pain control is an issue at all stages of cancer – primary diagnosis, treatment and long after treatment. Even the basics, such as the use of oral morphine, are often not followed, he says. At the core of the problem is oncologists’ focus on the tumour, not the patient.

“During short outpatient visits between the patient and the oncologist and the surgeon, I believe that physicians don’t investigate pain systematically,” he says. “It’s well documented that pain is under-reported in consultations because it’s the physician who sets the scene – and if they focus on the tumour, then patients don’t feel it’s appropriate to raise the issue of symptoms. It should be the responsibility of the healthcare

## “People don’t want to hear”

Cordelia Galgut, a registered counselling psychologist from London, was diagnosed with bilateral breast cancer 13 years ago. Her pain started after surgery, and became more widespread and complex through radiotherapy and four years of the hormone treatment with Zoladex. Today it continues to affect her arms, abdomen, hips and legs.

“Here I am, 13 years on, seemingly cancer free, and in more pain than ever. It gets worse. It’s related to my treatment, but it’s very seldom acknowledged. You talk to the doctors about it, and it’s swept under the carpet.

“My arms are hugely painful on both sides, and it radiates down to hips and then the legs, so I have problems walking. The scar tissue seems to have more and more effect over time.

“After my initial surgery, nobody talked about pain. The nerve pain was terrible. I was just given a load of basic painkillers, but on some level I accepted it because it was so soon after the event and I was happy to have survived. That goes on for a year or so.

“I have three very large scars. They tightened after surgery, causing more pain and abdominal tightness and affecting my diaphragm and arm mobility. I’ve raised the symptoms with my surgeon, oncologist, radiotherapist, and GP, and though they acknowledged that there was pain

caused by the scars tightening, the attitude was: ‘You’re lucky to have survived’ – that was all that mattered.

“And the pain has got worse, but that attitude has continued. It’s as if they think: ‘Conventional wisdom is that the pain shouldn’t get worse, therefore it doesn’t. It’s either in the patient’s head, or something I don’t need to acknowledge because the main thing is we’ve kept you alive for 13 years.’ People don’t want to hear, therefore they don’t hear.”



system – and the physician specifically – to put symptom management on the agenda.”

So how does pain get onto the daily routine – not just in centres of excellence, but for cancer patients throughout Europe? The hard option – and one frequently suggested when it comes to putting pain on the map – is to engrain it by making it a more intrinsic part of health professionals’ basic education.

Wendy Oldenmenger estimates that on average in Europe, medical and nursing training provide just two to three hours on pain management. In some countries, medical schools include nothing at all on symptom management. This may result both in a lack of confidence in treating pain, and an implicit message to physicians that treating pain can’t really be that important.

“If you aren’t trained in pain, and

don’t know what to do about it, then you probably don’t ask about it,” says Stein Kaasa.

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In Norway, palliative cancer care is now included in the medical curriculum, and the curriculum for medical oncology and radiotherapy includes developing skills in symptom management. But bringing such a fundamental national change takes time and investment.

It isn’t the only option. There may be simpler paths to bringing cancer pain management towards the centre of day-to-day clinical practice. Several commentators believe that major progress could be made by providing new incentives and simple measures to embed pain assessment into routines. And simply communicating about pain in a different way could bring change.

Carla Ripamonti’s disappointment that guidelines are not better used is balanced by her belief that it would be relatively easy to get them more widely implemented.

“We need to find a different approach,” she says. “ESMO publishes pain guidelines in the *Annals of Oncology*, but if you look at other cancer journals, they only publish research articles. There needs to be more diffusion of the guidelines, translated into more national languages so that all physicians can easily access them.”



Somehow, she says, oncologists need to be made to talk about pain in consultations. She acknowledges that oncologists often don't see patients for long periods, and pain often arises after symptoms such as nausea. But if oncologists always raised the subject there would be less chance of longer term pain problems associated with treatment toxicity, for example, being missed. Patients could then be referred to supportive or specialist pain units.

### Part of the routine

Wendy Oldenmenger, however, believes there are simply not enough resources to refer more than a few cancer pain cases to specialist services. A study she carried out at two Dutch outpatient oncology departments, and published in the *Annals of Oncology* last year, showed that around 40–45% of patients reported pain and

12% registered their current pain as moderate to severe (*Ann Oncol* 2016, 27:1776–81). So she believes the issue has to be addressed within these clinics. And the most practicable way is to make pain assessment part of their whole outpatient clinic routine.

**“You have to assess pain in the same way you would assess a tumour, with a scan before a consultation”**

Oldenmenger proposes a system of patient pain self-assessment. As part of a multidisciplinary group, she trialled a new approach to pain at the two outpatient oncology departments. At each visit, patients were asked to register their pain intensity on a

touch screen computer, and this was incorporated into medical records. Cases of untreated pain could be flagged to physicians. Patients were also provided with web-based information, to increase understanding and expose misconceptions about pain.

By the end of the six-month project, most patients reported that when they scored their pain as moderate to severe, their physician discussed these results with them. The percentage of patients with moderate to severe pain decreased from 12.5% to 8.5% over the period.

“We should integrate supportive care and pain management into oncology,” says Oldenmenger. “I think we must use the new communications and technology possibilities before patients even get into their consultation.”

Stein Kaasa agrees that routine collection of patient reported pain scores before a consultation is the direction to take – and that new

technology such as mobile phone apps offers huge potential.

“You have to assess pain in the same way you would assess a tumour, with an MRI or CT scan before a consultation,” he says. “Then it can be incorporated into the consultation and into the decision-making process.”

At the same time, he says, it is important to recognise that complex and long-term problems of pain may require referral elsewhere. Different and specialist approaches may be required for those who have been cured of cancer but suffer chronic pain as a result of surgery or radiotherapy – because long-term opioid prescription may not be possible.

“If a patient is cured but still having pain, and the oncologist doesn’t know how to handle it, there should be an automatic referral to a pain team or cancer survivorship clinic.”

### From guidelines to practice

So if solutions are becoming clearer, how are they to be made to happen? Kaasa believes that health systems need to provide the structures to make pain management an ‘essential’ rather an ‘added extra’. Economic incentives can be an extremely effective way to bring change.

“We know that it’s challenging to change behaviour in complex health systems,” he says. “In countries which use diagnostic related groupings (DRGs) to determine how much to pay for a patient’s hospital stay, you could say that in order to get full payment you have to follow symptom management guidelines with specific groups of patients.”

Another option is to include pain management in cancer plans – comprehensive national policies designed to reduce cancer cases and

deaths and improve quality of life. Josep Borràs, professor of public health at the University of Barcelona, and one of the authors of the European Guide for Quality National Cancer Control Programmes, developed as part of the 2014 European Partnership for Action Against Cancer (EPAAC), says that pain policy needs a new emphasis.

He says that although cancer pain has been on national and international agendas for more than 20 years, the emphasis has invariably been on providing pain resources – for example changing legislation to ensure that opioids are accessible, or building palliative care teams and units. These have been the focus of most cancer plans, including EPAAC’s.

“Now we need to focus more on qualitative issues and less on the quantitative approach,” he says. “We need to expand the use of tools for pain management from palliative teams to clinical teams in surgical oncology, medical oncology or radiation oncology.”

Currently, he knows of no national cancer plans that include these day-to-day aspects of pain management within their targets or quality measures. “It’s something we need to do in the future,” he says.

One model to follow might come from Ontario, Canada, where a statutory but independent cancer quality council, set up in 2002, monitors and publicly reports on cancer system performance within the province. It then makes recommendations for targeted quality improvement to ministers. Among its quality indicators are patient symptom screening, including pain, and the patient experience with symptom management.

An even greater political commitment to pain management came in Italy in 2010, when a new national law was passed, “to ensure access to palliative care and pain

therapy”. This requires that physicians record type and intensity of pain, analgesic therapies and clinical results.

It also encourages the availability of opioids in pharmacies, the development of pain education programmes for health professions, the growth of regional palliative care networks and quality standards for the networks. The overall impact of the law on day-to-day practice is still to be determined.

## “We need to expand pain management from palliative teams to clinical teams in surgical, medical or radiation oncology”

There is no doubt that managing pain in cancer patients has achieved a high profile – and in some cases the highest political priority – over the past decade. But throughout Europe there remains the fear that policy, targets and guidance will only go so far. Something has to happen on the humdrum and human level if cancer pain is to be conquered. For Mitzi Blennerhassett it comes down to basic principles: start the conversation with the patient, and listen.

“Some patients may require palliative care from the day of diagnosis,” she says. “We need more patients on the groups that draw up pain guidelines – people who really know what it’s like to go through. We need more articles for clinicians which describe what it’s like for patients. And we need to break through this damaging idea that you mustn’t talk to patients about pain because you might frighten them. The denial needs to end.”