

# MANAGING NEUROPATHIC PAIN IN END-STAGE CARCINOMA

Veronica Ngugi

This article describes the care of Kiwi, a 48-year-old man with an end-stage, cartilaginous carcinoma, who was admitted to a hospice because he was experiencing profound neuropathic pain. It explores the complexity of pain, highlighting social and psychological factors that influence the way in which pain is perceived by the sufferer. Methods of assessing pain objectively will be investigated, followed by consideration of some pharmacological and non-pharmacological management techniques. Recommendations for future practice will be made. The patient's name has been changed to maintain confidentiality in accordance with the nursing *Code of Professional Conduct* (Nursing and Midwifery Council, 2004).

## KEY WORDS

Chronic pain management  
Neuropathic pain  
Palliative care  
Terminal care  
Reflective practice

Cancer patients may experience several types of pain in different parts of the body simultaneously. Under-treatment of cancer pain occurs in many care settings. The commonest cause of poor pain management is inadequate assessment. This article explores the multifactorial nature of the experience of pain in relation to the care of a patient with end-stage carcinoma.

## Case report

Kiwi was a 48-year-old male, of African origin, suffering from chondrosarcoma, a malignant cartilaginous tumour. The tumour involved his right shoulder,

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scapula and axilla, with other local tissue involvement. The tumour had infiltrated the skin of the shoulder, affecting the blood supply to that area and giving rise to a fungating wound. Kiwi had been diagnosed with cancer 2 years before this admission to the hospice. He received palliative radiotherapy to the right shoulder, causing him to become highly fatigued. He then declined surgical debridement of the tumour, but later admitted that he had not understood the rationale for the procedure. He agreed to be admitted to the hospice for pain management.

On admission, Kiwi was weak and fatigued. He said he did not have any relations in the UK. Initially, he was reluctant to discuss his symptoms. However, he was openly concerned about his immigration status. He was a failed asylum seeker trying to avoid deportation. Hawthorn and Redmond (1998) state that patients worry that, if they describe their symptoms, they may be labelled a 'bad' patient. Kiwi admitted he feared being viewed as a 'problem patient' if he explained the nature and extent of his pain. His description of a problem patient was 'one who asks a lot from the nurses'.

Clearly, Kiwi needed to be made psychologically and physically comfortable before he would discuss

his symptoms. Before admission, Kiwi shared a room in a hostel with strangers. He was offered the privacy of a single room and was reassured that every effort would be made to control his symptoms. Provision of comfort is a primary intervention for the control of pain (Carr and Mann, 2000).

## Assessment of Kiwi's pain

Doyle et al (2004) state that pain occurs in 70–90% of patients with incurable cancer but that 80% experience effective pain control using proper assessment and drug therapy. Pain management at the end of life relies on accurate pain assessment (Carr and Mann, 2000; Duggleby, 2002). The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS, 2003) recommends that the history of pain should be recorded. Careful questioning will obtain information to identify factors that cause and influence pain.

During the assessment process, carried out by a palliative care nurse, Kiwi described shooting pains, affecting his right shoulder, radiating into his arm. He also explained that it felt as if his fingers had been pierced. He was unable to use his right arm because any movement of the limb caused increased pain. Kiwi stated that the pain was present at all times and that medication

did not provide him with any relief. At that point, Kiwi was taking oral morphine sulphate slow release 30mg twice daily, diclofenac 75mg twice daily and amitriptyline 10mg at night. Pain was affecting his mood. He had become anorexic, could not sleep and felt his quality of life was reduced because he was unable to care for himself. He was anxious and distressed.

Kinghorn and Gamlin (2001) state chronic pain experience is complex. It causes anxiety, depression, social isolation, physical disability, and has a detrimental effect on quality of life. Its multifactorial nature makes pain assessment and management complicated for the patient and clinician.

Using a visual analogue scale (VAS) to describe his discomfort, Kiwi graded his pain between 3 and 4. The VAS is part of the Palliative Outcome Scale (POS) (Higginson, 1998). The POS is a tool by which physical, psychological, spiritual, emotional and psychosocial symptoms can be assessed using a graduated scale, 0 (symptom free) to 4 (overwhelming). This assessment tool also makes use of a pain chart (Figure 1).

Pain assessment tools help determine the nature, intensity and cause of a patient's pain (Davis and Walsh, 2000; Nicholson, 2003). They are essential to achieve effective pain management (Carr and Mann, 2000). Pain is subjective and therefore tools must be developed to assess it objectively. Pain scale measurements are used for this purpose (Thomas, 1998). Walker et al (1987) note that use of pain charts promotes objectivity during assessment and monitoring.

Pain assessment is fundamental to the nursing management of cancer pain (Kinghorn and Gamlin, 2001). Carr and Mann (2000) report that inadequate pain management is associated with poor nursing assessment, highlighting that nurses have inadequate knowledge about pain and underestimate patient pain. In contrast, a comparative study found that nurses sometimes overestimate patient pain (Jandelli, 1995). This contradictory evidence

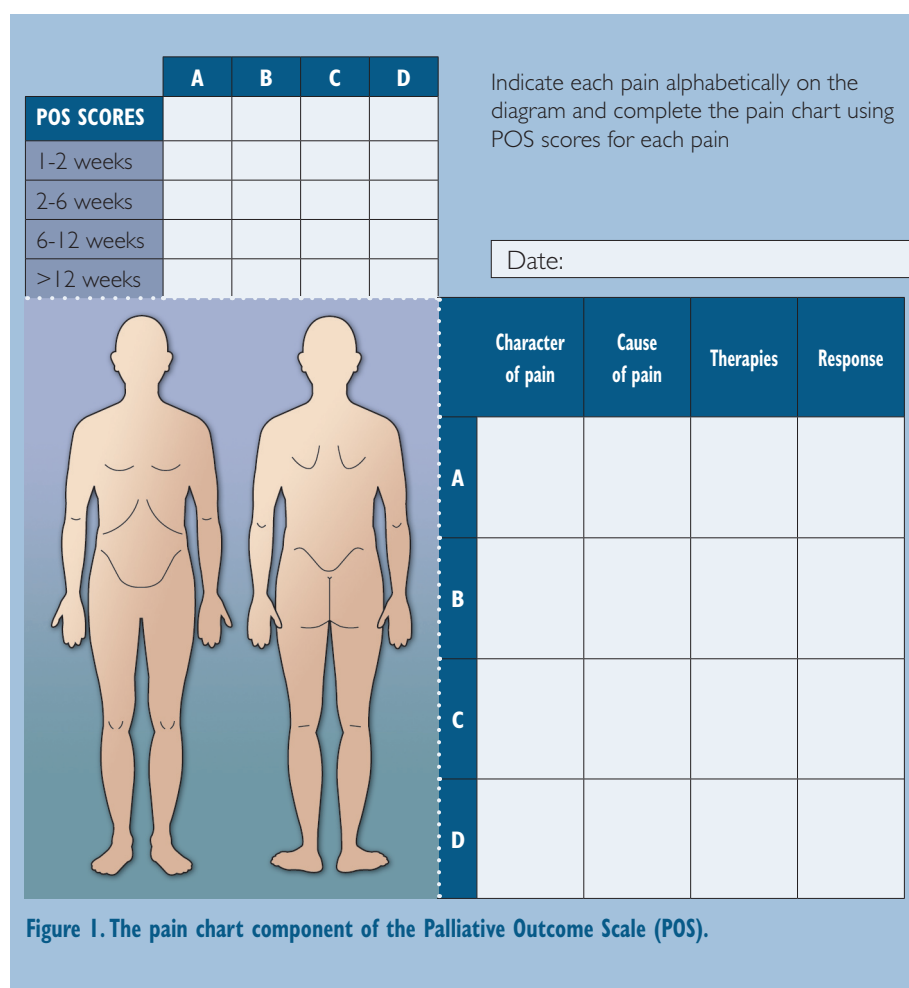


Figure 1. The pain chart component of the Palliative Outcome Scale (POS).

highlights the necessity for all nurses to be familiar with the various techniques for accurate and objective assessment of the subjective experience of pain. Melzack and Katz (1996) advocate the self-reporting of pain by patients and that the patient's report is the primary source of measurable information. Nurses should acknowledge that pain is whatever the sufferer says it is (McCaffery et al, 1994).

Ingham and Portenoy (2004) state the approach to symptom assessment and measurement should incorporate assisting patients to evaluate the impact of their symptoms on their overall distress level in relation to other concerns regarding their quality of life. This may help to clarify the interwoven nature of the experience of pain, placing it in the context of other concerns of the patient.

According to Wilkinson (1995), pain assessment can be achieved

using effective verbal and non-verbal communication skills. Effective communication is made up of various components, including language, paralanguage (inarticulate noises that punctuate conversation, i.e. 'uh-huh') and non-verbal elements such as posture, facial expression and touch.

Kiwi wanted to be involved in decision-making relating to his symptom control. This questioning made some team members view him as challenging and some even doubted the extent of his pain. Clamp (1980) notes that nurses' attitudes govern how care is administered, stating the commonest cause of poor care provision is inappropriate attitudes, such as making negative judgments regarding patient symptoms and experiences.

Patients experiencing pain are often not believed by medical personnel and are seen to be inventing or exaggerating their distress to gain

attention and sympathy (Thomas, 1998). Carr and Mann (2000) suggest that a trusting therapeutic relationship between the patient and the nurse is fundamental to pain management.

### Neuropathic pain

Kiwi's pain was assessed as being neuropathic. Up to 40% of cancer-related pain has a neuropathic mechanism (Back, 2001). Managing it can be challenging to the multidisciplinary team (Doyle et al, 2004; Hall and Sykes, 2004). Neuropathic pain is caused by pathological changes within the nervous system. Disease of central and peripheral nerves can cause neuropathic pain. It is differentiated from pain in general because it does not arise as a result of a correctly functioning nervous system, as in the case of trauma causing pain through normal, nociceptive neurological activity. Instead it results from neurological disease. Nociceptive pain is pain that arises from trauma, as opposed to neuropathology.

Kiwi's neuropathic pain resulted from compression and infiltration of the brachial plexus by chondrosarcoma of the right scapula with an associated mass in his right axilla. The brachial plexus is an arrangement of nerves (a plexus) running from the spine (vertebrae C5–T1) through the neck, the axilla and into the arm. Foley (1987) states that up to 85% of patients with brachial plexus tumour experience pain, weakness and sensory loss. According to Davis and Walsh (2000), pain resulting from brachial plexopathy affects the shoulder, scapula and interior chest wall, radiates into the elbow and the 4th and 5th fingers. Neuropathic pain is commonly associated with burning or stabbing sensations (Doyle et al, 2004).

Kiwi also experienced nociceptive pain, due to infiltration of tumour into cutaneous tissue. Multiple pain experience is common in palliative care patients (Doyle et al, 2004). Comprehensive assessment of pain requires that the complex nature of pain is understood (Hawthorn and Redmond, 1998). To help understand Kiwi's experience of his

pain, 'the gate control theory of pain' will be explained.

### The gate control theory of pain

The gate control theory, advanced by Melzack and Wall in the 1960s, suggests that pain perception is affected by experience and may be a learned process. It is not simply a result of the stimulation of pain-transmitting neurones. The theory suggests that pain may be moderated by the interaction of different types of neurones and the production of pain-relieving chemicals by the body (Melzack and Wall, 1962, 1965).

### Physiology of the gate control theory

Afferent nerves carry stimuli to the brain. They are made of different fibres. There are relatively thick, myelinated fibres for transmission of intense pain, smaller, unmyelinated fibres for the transmission of throbbing, chronic pain and large fibres that are non-nociceptive, or non-pain-transmitting. The gate control theory proposes that the effect of pain-transmitting fibres is mitigated by the effect of non-pain-transmitting fibres. All fibres pass through the same region of the dorsal horn of the spine that, for the purposes of the theory, is called the 'gate'. The action of the non-pain-transmitting fibres closes the gate to the effect of the pain-transmitting fibres and pain stimuli are blocked.

The gate control theory explains how external stimuli that only activate non-nociceptive nerves, for example, massaging an injured area, block the effect of nociceptive nerves and thereby reduce perceived pain following injury. It also suggests that painful stimuli cause the release of opioid chemicals in the body capable of closing the gate, enabling control of the perceived pain. It is by this means that acupuncture and electrical analgesia are thought to have their effect (Melzack and Wall, 1962, 1965, 1996; Taylor et al, 1983; Doody et al, 1991).

The theory also incorporates psychological, cognitive and emotional elements of the experience of pain. The central control of the brain is

significant in the gate control theory because cognitive and higher brain centres influence the pain perception. Anxiety, excitement and anticipation cause neurological activity that can open the 'gate' and thus increase pain perception. Melzack and Wall (1996) state that alleviating fear and anxiety reduces the perception of pain. For example, cognitive activities, such as distraction and relaxation, can close the 'gate' and decrease pain perception (Carr and Mann, 2000).

This aspect of the gate control theory may explain Kiwi's experience of his pain. His anxiety and distress could have limited his ability to 'gate out' pain stimuli, resulting in the intense experience of his pain. This is sometimes called 'total pain', a concept developed by Dame Cicely Saunders, the founder of the modern hospice movement. There is a link between the social, physical, spiritual and emotional elements of the experience of pain (Saunders 1972, 1976).

### The pain-management process

Kiwi stated that he omitted to take analgesia before admission because he wanted to retain control of his senses and morphine made him drowsy, limiting his ability to care for himself. The omission of analgesia contributed to his uncontrolled pain. According to Thomas (1998), pain assessments should take place regularly, be unhurried and not be part of the drug round. Patients should report their pain at the time it occurs.

A multidisciplinary team approach was adopted to achieve effective pain management. Assessment and management of Kiwi's pain was ongoing, as advocated by Bruera and Watanabe (1994). The multidisciplinary team included nurses, the social worker, physiotherapist, chaplain, occupational therapist, junior doctor and consultant, who met regularly to discuss Kiwi's symptoms and assess the effectiveness of his treatment.

According to the NCHSPCS, no patient should experience pain without assistance to reduce it (NCHSPCS,

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2003). Hunter's (2000) view is that, if a patient is not experiencing adequate pain control, the multidisciplinary team may be deemed morally negligent.

Randall and Downie (1999) acknowledge that a multidisciplinary approach is essential to meet the needs of palliative care patients. The multidisciplinary team explained the medication regime to Kiwi, providing a written explanation of the rationale for individual drug use. This communication gained Kiwi's co-operation and minimised misunderstanding (Lindon and Lindon, 2000).

### Pharmacological management

The World Health Organization (1996) analgesic ladder is a guide for the use of analgesia. It is a three-level ladder system (Figure 2). By this standard Kiwi was at level three where the use of opiate, non-opiate and adjuvant drug therapies is advocated. Studies claim that 80% of cancer pain can be managed using the analgesic ladder (Zech et al, 1995; Mercadante, 1999), although a separate review suggests there may not be enough evidence to prove or disprove these claims (Jadad and Browman, 1995). Patients who do not experience pain relief with opiates alone should have access to supplementary analgesia that may be in the form of a non-steroidal anti-inflammatory (Doyle et al, 2004).

Kiwi was unwilling to take morphine via a syringe driver. This method of administration was advocated to provide continuous pain control. Kiwi associated morphine with addiction and death. After clear explanation, he realised that his view of morphine, in this context, was a misconception. He therefore agreed to opiate treatment.

Thomas (1998) states information regarding treatment and its effect counteracts unhelpful and inaccurate beliefs, facilitating informed choice. In this case, Kiwi's misunderstanding was reduced. He also accepted that his fungating skin lesion should be treated using 10mg of topical diamorphine once daily. This proved to be highly successful. According to Twycross and

Wilcock (2001), topical diamorphine is useful when treating pain associated with skin ulceration.

To treat Kiwi's neuropathic pain, he was prescribed 10mg morphine sulphate, orally, every 4 hours, with 10mg doses prescribed to limit breakthrough pain within the 4-hour period, as necessary. Morphine sulphate is effective in controlling pain because it mimics the action of endogenous opioids (the body's natural opium

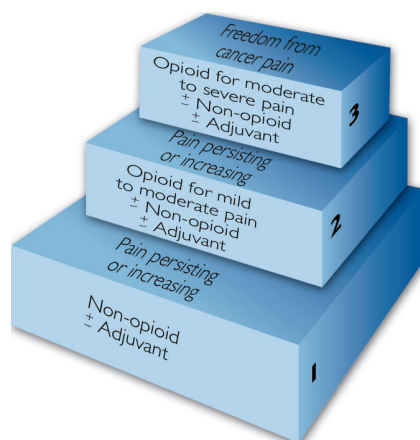


Figure 2. The World Health Organization analgesic ladder (World Health Organization, 1996).

produced in the brain). Lipman and Gauthier (1997) state that there is no maximum, safe dose of morphine, but that it should be titrated to meet the needs of the individual patient. Its action is explained in Table 1.

Kiwi was also prescribed gabapentin, 600mg twice a day, which was to be titrated against his pain. Gabapentin blocks excitatory calcium channels in the dorsal horn of the spine, thereby inhibiting the neurological activity causing neuropathic pain (Dworkin and Breitbart, 2004). It also has an anticonvulsant action. Gabapentin is commonly used to treat neuropathic pain (Bennett and Simpson, 2004). Wiffen et al (2005) state that gabapentin has a role in the treatment of shooting pain. Studies of gabapentin as an adjuvant to opiates found that a combination of anti-convulsants and opiates is effective in controlling neuropathic pain (Twycross and Wilcock, 2001; Bennett and Simpson,

2004; Caraceni et al, 2004; Dworkin and Breitbart, 2004).

Kiwi's pain was assessed every 4 hours to determine the effect of his pain management. His morphine sulphate and gabapentin were titrated against his pain. Back (2001) acknowledges the importance of titrating drug doses until pain relief is achieved. Accurate documentation was kept to build up a complete picture of Kiwi's pain. Wilkinson (1995) states that documentation of patient pain experience should be maintained.

Kiwi was also advised to take diclofenac, a non-steroidal anti-inflammatory drug (NSAID), 75mg twice a day. As a result of thermal, mechanical or chemical trauma, cells release chemicals resulting in pain. It is suggested that NSAIDs inhibit the action of these chemicals bringing relief from inflammation and pain (Doyle et al, 2004). They are also effective for the relief of bone pain arising as a result of metastatic disease.

Hall and Sykes (2004) state that it is common practice to prescribe

### Table 1

#### The action of morphine

Morphine is an exogenous opiate. It is a  $\mu$  ( $\mu$ ) agonist that activates the  $\mu$ -opioid receptor, inhibiting neurones from passing pain impulses, thereby producing an analgesic effect. ( $\mu$  is the 12th letter of the Greek alphabet.) The  $\mu$  is a neurological receptor site. The  $\mu$ -opioid receptors are neuroreceptors situated in the central and peripheral nervous system and the gastrointestinal tract that are normally activated by the body's natural opioids. An agonist is a chemical or substance that mimics the body's naturally occurring chemicals. When taken into the body, agonists produce the same effect as the naturally occurring substance they mimic.

proton pump inhibitors (PPIs) or histamine-2 receptor antagonists to counteract the gastrointestinal side-effects of NSAIDs. Use of PPIs has been shown to reduce gastroduodenal damage by 40% (Raskin et al, 1996). Kiwi was prescribed the PPI lansoprazole 30mg, once daily.

Kiwi also found it difficult to sleep. He was prescribed 25mg of amitriptyline at night. Amitriptyline is a tricyclic antidepressant with a mild tranquillising effect. In view of Kiwi's symptoms, it was chosen for its analgesic and antidepressant properties. He was also advised to take senna at night to avoid constipation as morphine has been found to cause constipation (Doyle et al, 2004). Following implementation of this drug regime, Kiwi stated that his pain was controlled and his sleep had improved after the first week.

### Non-pharmacological management

Wells et al (2003) consider that successful management of cancer pain relies on patients' willingness to discuss their discomfort. Kiwi was encouraged to speak openly by being offered reassurance that the investigation and control of his pain was a nursing priority. It was also made clear that he would be given assistance in order to resolve his problems with the immigration authorities. When patients exhibit fear and anxiety, nurses must provide information in order to achieve a reduction in distress. They must assist patients to understand their situation and allow them autonomy regarding their care (Thomas, 1998).

### Psychological pain

Kiwi was deeply anxious regarding his failed asylum application. He was educated and spoke English. He made it clear that he understood his illness and his immigration status. Refugees face unique difficulties and require access to culture-sensitive health services. They find it difficult to access health service information (British Medical Association, 2002). Many refugees who have failed asylum status live an itinerant life, for fear of

detection by the authorities. Prolonged uncertainty about asylum decisions causes anxiety and ill health (British Medical Association, 2002).

Patients experiencing cancer pain tend to have increased anxiety and are concerned about loss of independence (Monroe, 2003). As previously stated, anxiety and depression can affect pain perception (Bennett and Simpson, 2004). Communication between Kiwi and the nurses was ongoing. A trusting nurse-patient, therapeutic relationship is fundamental to pain management (Carr and Mann, 2000). During conversation, active listening skills were utilised. Kiwi was prompted with open questions, designed to encourage him to voice concerns, rather than give one-word answers. His main concerns were fear of opiates and injections. Other routes of administration were explored and an explanation of opiates was given. It was emphasised that he would be closely monitored and the drug regimen would be changed if he experienced unpleasant side-effects (McCaffery et al, 1994).

To alleviate his distress, Kiwi was reassured that a social worker was presenting his case to the Home Office to obtain an extension of residence. He was assured that he would not be deported and the Home Office was reviewing his case on humanitarian grounds. (Kiwi died before this matter was resolved.) Kiwi was also referred for music therapy. He stated music made him happy and relieved his pain. Biley (2000) states that music reduces pain by distracting the sufferer, focusing cognitive processes, activating inhibitory synapses and making use of gate pain control. After discussion with the music therapist, Kiwi was provided with recordings of music to his taste.

Kiwi could have been offered complementary therapy in the form of massage or transcutaneous electrical nerve stimulation (TENS) for analgesia and relaxation but these options were not explored. This should be considered as a failure to some extent. It will be borne in mind during future

practice. Despite several discussions about spirituality, Kiwi did not express the wish to see a spiritual adviser.

For the remainder of Kiwi's admission his pain was controlled satisfactorily. Kiwi deteriorated rapidly and died, 3 weeks later, while sleeping.

### Conclusion

This case review has highlighted the complex nature of the pain experience and the importance of the multidisciplinary approach to pain management (Kingham and Gamlin, 2001). Although the final outcome of the case reviewed was positive, lessons need to be learnt in order to improve future practice. Kiwi's case highlighted the problems nurses can encounter when assessing pain intuitively. Misunderstanding the pathology of pain and the negative emotions and social concerns of the sufferer can lead nurses and other health professionals to wrong conclusions about pain.

Objective pain assessment tools have been shown to be of use to develop understanding of the subjective experience of pain. Education is a powerful tool that can change practice and challenge ideas (Thomas, 1998). Kiwi's lack of understanding of medication and the reasons for its use made him appear 'difficult'. He began to feel that he was unpopular and troublesome. Open communication and good listening skills, combined with the creation of a physically and psychologically safe environment, reassured Kiwi and generated the spirit of concordance, enabling a regime of palliative care to be developed that led Kiwi to a comfortable death.

### Recommendations for practice

There was some feeling that Kiwi was exaggerating his pain for ulterior motives. This may be a common occurrence. It is recommended that nurses attend in-house teaching sessions with particular reference to the pathology of pain, the gate control theory, effective communication skills and pharmacological and non-pharmacological pain management.



It is important that nurses grasp the concept that pain is what the sufferer says it is. It is also recommended that nurses are familiar with the particular difficulties that asylum seekers face when trying to access health services.

It is the author's experience that nurses tend to report that a patient is 'complaining of pain'. They remain unaware of the pejorative overtone of the word 'complain'. Patients are often afraid to be thought of as complaining. They may be reluctant to speak about their symptoms if they feel this will be regarded as a complaint. Therefore, nurses need to alter their language to encourage communication. It may be beneficial to use phrases such as 'the patient is experiencing' or 'the patient is describing', i.e. language that does not have negative connotations. **EOLC**

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## Key Points

- ▶▶ The experience of pain is complex and is influenced by psychological and social factors.
- ▶▶ Effective communication is the key to the success of pain management.
- ▶▶ Neuropathic pain is caused by pathological changes within the nervous system.
- ▶▶ Pain assessment tools have been shown to be beneficial in developing an understanding of the subjective experience of pain.

## CASE ASSIGNMENT

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## REFLECTIONS ON CREATIVITY

**Nigel Hartley** Director, Creative Living Centre, St Christopher's Hospice, London

Many people think of creativity as something given as a gift. It is often bad experiences at school, or at some other stage in life, with music, painting or writing, that cause people to feel distanced from art. These experiences are sometimes so unpleasant that people do not attempt to create artistically for the rest of their life. It is intriguing then, that while so many people are disconnected from art for the majority of their life, it is possible to encourage those same, ordinary people, at the end of their life, to create works of art of real value and meaning.

Daisy, for example, was 89 years old and coming to the end of her life in a care home. Her husband had died some years previously and she had no other immediate family. A community nurse specialist had visited Daisy at the home and, although she was able to help with alleviating Daisy's pain and other unpleasant symptoms, the nurse was concerned that Daisy remained withdrawn and depressed. The local hospice arranged for Daisy to be visited by a musician.

Within a few moments of the meeting, Daisy, who was sitting in her wheelchair in her room, became very energetic and lively. She announced that she wanted to write a song and asked the musician to take down the words. She would call it 'Why worry?' It was a song for her husband. The words came out almost in their completed form and, with a few 'nips and tweeks' from Daisy and the musician, the lyrics were completed. Daisy then sang the melody she wanted for the song and the musician was able to pick it out on an electric keyboard. He also added some chords to complete the song. Daisy acted as musical director. She knew exactly what she wanted. A recording was then made of Daisy singing the song with the musician accompanying her. The lyrics are as follows:

Worry, why do I worry?  
Everybody wants to know why worries come and go  
Worry, why do I worry?  
I could worry most of the day  
In the most depressing way

I love you, Oh, how I love you!  
And I know you love me too  
I knew that we could be happy  
And I gave my heart to you

I miss you, Oh, how I miss you!  
But we will meet again,  
I know now that when I worry  
I cannot bear the pain.

Worry, why do you worry?  
Everybody wants to know why worries come and go  
I love you, oh, how I love you!  
I hope you really know  
How I love you so!

This song was put together in the space of an hour. Daisy explained to the musician that she was very surprised by the quality and structure of what she had created. She asked the musician if he would make sure the recording was played at her funeral. He did so a couple of weeks later.

Creativity offers many motivational and inspirational possibilities. When people are offered the means to express themselves artistically, in the right way and at the right time, they can produce results that are moving and surprising. Art can be used therapeutically, allowing people to express abstract and difficult emotions in a way that they never thought possible. This is particularly useful at the end of life, when powerful and overwhelming emotions are evoked.