Chapter 1

Cancer: a journey of discovery
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Life is a journey undertaken on an ocean of experience. All human development, including the experience of illness and health, involves discoveries made on a journey across that ocean of experience.

Barker (2002: 43)

The aim of this opening chapter is to explore what is meant by the cancer journey in its many manifestations. An analysis will be made of the use of metaphors for discussing and understanding cancer, and consideration will be given to how their meanings have changed with social, technological and professional advances. The developments affecting cancer care over the last several decades will be examined, with an appreciation of the tremendous progress that has been made affecting a patient’s cancer experience. An examination will be made of how the notion of cancer and the cancer journey, from presentation to outcome, is different in the 21st century and the relevance of concepts such as victim, sufferer, survivor, hope, fear, courage and loss through the cancer journey.

Cancer

Once said, in terms of a diagnosis, the word cancer cannot be unsaid. The word hangs in the air with all its connotations that, in our culture at least, put fear, often abject fear, into the heart of even the most optimistic and knowledgeable individual. After the day of diagnosis, life is never quite the same. Whether, for whatever reason, the diagnosis is realised to be imminent, or whether it comes as some shocking cataclysm, the individual, now suddenly the patient, must seek to make sense of what this means and how it will affect not only the normality of daily life but any possible life aspirations. Questions without answers, or with answers wanted, tumble through the brain as the individual looks for meaning, moving from primeval concerns as to punishment for wrongs committed or to more mundane regrets over such as overexposure to the sun, the curse of nicotine addiction or that casually rejected environmental hazard.
Cancer as metaphor

In the search for meaning, humans look to metaphors to liken their reality to something which is perhaps more manageable and examinable. Metaphors, Lakoff and Johnson (1980) argue, allow the understanding of one thing in terms of another, giving illness such as cancer a certain symbolism. For most of the 20th century cancer has mainly been seen as a mortal disease, and a dreadful and dreaded disease to be fought, though not often beaten. The notion of cancer as a battle can give some order to the chaos of the diagnosis, as physicians, oncologists and surgeons share a common purpose and the ‘fighting spirit’ is encouraged. Reisfield and Wilson (2004) argue that war is an apposite metaphor with the enemy, the commander, the combatant, allies and an armoury of weapons to hand. Such a metaphor also implies vigour, hope and a serious purpose to offset the sense of hopelessness so ready to surface (Hammer et al. 2009).

Such a metaphor is still very potent and embedded in our cancer care language, but it has been much criticised in recent years. Sontag (2001), rejecting any cultural and societal value of such metaphors, argued that the body is not a battlefield and that such metaphors perpetuate stereotypes and stigma. It has to be recognised that Sontag held a particularly jaundiced, and arguably limited, belief that cancer sufferers were seen as victims of suppressed or failed emotions. She asserted that cancer is not a curse or a punishment and certainly not an embarrassment and that, as understanding of cancer causality and treatment advances, metaphors should become irrelevant. Perhaps what Sontag did not wish to acknowledge was that the use of metaphors is deeply embedded culturally, and energy should be focused on the sensitive and positive role that metaphors offer. The illustration of this can be seen in the widespread use of the metaphor of the cancer experience and trajectory as a journey.

Cancer as a journey

The metaphor of the journey is not exclusive to cancer or to illness, but is used in many challenges in life, from sport to intellectual activity. Life is acknowledged to be a journey, despite the abiding difficulty for many of confronting the endpoint. The journey for the cancer sufferer is not just linear, through diagnosis, treatment and the consequences thereof, but also an emotional rollercoaster. Not only that, the biology of cancer is itself seen as the transformation journey of a tumour cell (Kumar & Weaver 2009). The idea of serious illness as a journey has had its own potency. Davis (1963), addressing poliomyelitis, saw it as a form of crisis management from prelude and warning stages to the impact stage of diagnosis and the stage of treatment, and its corollary, which Davis described as the inventory stage. Despite its pervasive applicability, the journey defies a unitary description. As indicated above, it is not merely a linear journey through the stages, however real; each patient will travel in their own way. Reisfield and Wilson (2004: 4026) describe the journey metaphor as ‘quieter than the military metaphor’ but still having the ‘depth, richness and gravitas to be applicable to the cancer experience’. They then use the analogy of the cancer as diverting the individual from the freeway to consider the alternative byways imposed by cancer that bring with it the real concerns of
uncertainty, fear, anxiety, guilt, loss and anger. They also suggest, however, that these byways may also bring new meanings to life’s journey and new insights as to the nature of the traveller and those who care for and journey alongside the traveller. The journey metaphor, they argue, does not talk in terms of winning or losing, but rather of different roads to travel.

However, this author might part company with Reisfeld and Wilson at this point (to continue the analogy) as the whole notion of fostering hope and positive thinking, at least in the early stages of the cancer journey, is inextricably bound up with optimistic outcomes of winning and even, despite this metaphor, successfully defeating an enemy. Perhaps that is the mistake, and those who support and encourage the traveller on the journey should focus equally on the quality of the journey rather than where it will eventually lead them. While embracing the popularity of the journey metaphor, it must not be forgotten that people create their own metaphors of life and life changes, often reflecting their life worlds, for example, as their most demanding performance, their personal race for life, a labyrinth, or a game of chess. Lerner (1994: xiii) combines many metaphors and likens the cancer experience to ‘that of a soldier who is given orders . . . to parachute into a jungle war zone without a map, a compass or training of any kind’, and Rachel Clark describes navigating round cancer like ‘being dropped in a strange city, without a map or a compass. There are no landmarks and no familiar faces . . . no signs, no-one speaks your language’ (Clark et al. 2002: 1). Crane-Okada (2007), also using the metaphor of a compass, looking to helping patients on their journey, likens the features of a compass to the holistic support nurses can provide. Barker (2002) suggests a seafaring, ‘tidal’ metaphor for life itself, with crises such as cancer as piracy followed by the possibility of shipwreck before sea legs can be regained and the ship sets sail again. For those caring and in the caring professions, listening to patients’ narrative metaphors will provide insights into the unique journey and unique meanings for the many byways of their cancer journey (Skott 2002). For some, the cancer journey may remain real, but their search for a meaning is ‘not always tidy and neat’ (Quinn 2003: 170) and its meaning remains elusive.

The linear and rollercoaster cancer journey

It can be argued that the cancer journey is everyone’s journey in that its prevention, in terms of genetic makeup and lifestyles, is, or should be, part of the matrix of life. Leydon et al. (2003) argue that the cancer journey has no definitive starting point. However, in reality, the ‘presence’ of cancer in the psyche begins with the sense that something is wrong, often set against a pre-existing appreciation of personal risk. With this comes immediately the pervasive sense of uncertainty. Delay can occur at this stage if, for that individual, uncertainty may seem better than a certainty they do not want to face. The challenge of this is recognised in the Cancer Reform Strategy (DH 2007), which aims, not only to raise public awareness of risk factors and signs and symptoms of early cancer, but also to find effective means of encouraging people to seek help sooner. The journey has fully begun when investigations are carried out towards a diagnosis. The individual is now in the game and it is serious. The game is also new, and support is needed in terms of simple, clear and sensitive communications that meet both informational and emotional needs (McQueen 2009). Fallowfield and Jenkins (Fallowfield et al. 2003; Fallowfield &
Jenkins (2006) are not alone in their exhortations that, despite communication being the heart of nursing and medicine and a core clinical skill, patients, their families and carers still feel let down by less-than-ideal communication at a time when it matters most. The period of waiting for a diagnosis is arguably the hardest time, and often too long, when the person vacillates between hope and fear, bargaining and despair, not daring to accept optimism and fearing pessimism. Drageset and Lindstrom (2003) explored this in women with breast cancer, revealing anxiety that was hard to ameliorate by support mechanisms. Diagnosis can only serve to reinforce the emotions associated with uncertainty and waiting, emotions now replaced by certainty and decisions.

Reactions to a diagnosis are myriad in nature but Greer (1991) identified denial, fighting spirit, stoic acceptance, helplessness/hopelessness and anxiety. Greer argued that the particular responses can, in some cases, influence the course of their disease but in reality one person may move through all such reactions. Hickey (1986) and Hammer et al. (2009), in their respective ways, stress the primacy of ‘hope-inspiring nursing’ (Hammer et al. 2009: 1) to guard against the sense of hopelessness ever ready to push through and impair healing. Spiegel (2001: 287) looks at hope in relation to having the right attitude to the cancer journey, the ‘fighting spirit’, a kind of realistic optimism... determined to make the best of it’. Such an attitude is not to be seen as blind or false hope or an overburdening urge to be positive.

Fallowfield (2008), recognising the above, explores the world of the newly diagnosed patient and their family, the amount of new and possibly alien information to be absorbed, so needed (yet so undesired) and so potent for enabling decisions to be made and for future wellbeing. Nanton et al. (2009) argues that, by skilled and carefully tailored information and communications, not devoid of the gentle use of humour, healthcare professionals could reduce the distress of ongoing uncertainty. Although the emotional labour is recognised (see Chapter 10), if this is done well by both doctor and nurse in their respective roles (Dunniece & Slevin 2000; Quinn 2003), the journey to be faced can at least be cushioned by a trusting relationship with those who may seem at that time to hold their very lives in their hands.

The treatment journey

For a patient who has presented with distressing symptoms or for an emergency cancer treatment (whether surgery, radiotherapy or various forms of chemotherapeutic and other agents), treatment can be seen as a relief despite the diagnosis. However, for many who believed themselves well, or even ‘very fit’ before diagnosis, treatment makes them ill, often for some time, with spectres of nausea, vomiting, pain and fatigue fixing in the mind (see Chapters 7 and 8). In addition, as some patients find themselves screened for cardiac and renal dysfunction, there comes the realisation that a treatment may damage other organs that indeed, unknown to them or the healthcare professionals, might already be impaired. Even more potent is the reality, for many, of altered appearance, be it through surgical resection, iatrogenically induced loss of hair, weight gain or stress-induced weight loss, all of which can threaten the sense of self (Bredin 2000), and may be considered a form of ‘piracy’ (Barker 2002).
Decisions have to be made. No longer are such decisions made without close consultation with the patient and the family (DH 2007) but sensitivity on the part of the healthcare professionals is needed to discern just how much involvement is desired. Some family members and carers may find this added responsibility, in the absence of seeing in themselves any real expertise, an extra burden (Fincham et al. 2005). Others, who may have already avidly searched internet sources, value such involvement and appreciate the invaluable partnership when so much that is undesired seems to require acquiescence. Such involvement requires considerable support by the specialist team, particularly the nurse, whose presence is seen as being 24/7, i.e. they are always there (Leyden et al. 2003).

The stress of the cancer diagnosis and treatment journey can manifest itself in both psychological and physiological disturbance, and the coping strategies adopted will be varied (Smith & Fawcett 2006). In terms of giving support, particularly as a nurse, Frank (2002: 45) argues that ‘there is no right thing to say to a cancer patient because the cancer patient as a generic entity does not exist. There are only persons who are different to start with, having different experiences according to the contingencies of their diseases’. Some will seek out a new path and, temporarily at least, suspend their ‘other’ life. Others will look to retain their usual life, minimising any deviation from the norm wherever possible.

Kyngas et al. (2000: 11) found this tended to be the case with young people with cancer, where resuming their ‘normal life’ was seen as ‘a source of safety’. Miedema et al. (2007) also found the prevailing aim of young people with cancer was to achieve the ‘normalcy’ of their pre-cancer lives. This did not mean a denial of the disease; in order for such an aim to be achieved, optimal social, emotional and informational support was needed. For these young people emotional support often comes from the family, as indeed is so often the case whatever the age of the person with cancer.

Families and carers play key roles and they themselves must receive equal support as they travel this cancer journey. These informal carers often feel helpless and uncertain, possibly not knowing what help is available for them (Soothill et al. 2001). Supporting the crucial role of informal carers, family members or not, has to be a key partnership role of the community nurse alongside the specialist team (Wilson et al. 2002; Luker et al. 2003; DH 2007). Koldjeski et al. (2007) demonstrate how family-based oncology nursing can be essential for family wellbeing on the cancer journey. The support and supportive role of families may include children and young people whose needs are often difficult to express, as roles may seem suddenly to change and even to be reversed. Compas et al. (1994) found that the impact of a parent’s cancer diagnosis related more to perceived seriousness rather than to the characteristics of the specific cancer, and differed according to the age and gender of both parent and child. Adolescent girls of mothers with cancer were found to experience more significant distress. Thastum explored children’s coping strategies when a parent had cancer and, although finding they ‘seemed to manage rather well’ (Thastum 2008: 123), it did depend on how well the parent(s) were themselves coping and supported.

Treatments do not always progress smoothly. Side effects can be debilitating (see Chapter 8) and any necessary delay in the next stage of treatment can add yet further stress. The role of the cancer nurse specialist becomes paramount at such times, and the primacy of the therapeutic relationship with the patient and family can positively impact on the maintenance of dignity and wellbeing. Setbacks are hard and treatment decisions may
change and, alongside that, the means of coping. Barker (2000: 332) argued that such times can engender a sense of powerlessness, and all in the caring team need to recognise this and provide ‘the necessary human, interpersonal and intersubjective conditions for the development of a sense of security that the person not only seeks but needs to continue’, even in times of acute uncertainty. He continues that ‘maybe one of the virtues of caring is that it focuses the nurse’s attention on . . . awareness of the person who is the patient and in so doing fosters an increased awareness of the whole of that experience for the person’ (Barker 2000: 332).

Throughout the illness trajectory many decisions will be made as to treatments and their side effects, symptoms and their management where, as Shaha et al. (2008: 61) argue, outcomes are uncertain and ‘few guarantees of success are possible’. Uncertainty is multidimensional and as Barker (2000: 332) states, it is part of the human condition. If well supported with information and emotionally, he argues, people have the ‘capacity to grow through experience’. The worst of times, with both its certainties and uncertainties, can bring out the best in people.

In the late 1990s the first Cancer Caring Centre was opened in the grounds of Edinburgh’s Western General Hospital, the inspiration of Maggie Keswick Jencks, who died of breast cancer in 1995. Her vision was for an environment that would give emotional and psychological support, complementing, but also giving a respite from, the orthodox cancer treatment. It was to be an intimate setting where sufferers could both express, and be helped to manage, their fears and uncertainties, and a place where they and their families could just be themselves: husbands, wives, mothers, with lives to live. Such a setting could also offer means of helping relieve physical and emotional distress through relaxation techniques (Miller 2007). Maggie’s Centre, as it became known, offers something that perhaps cannot be offered by the health service, and its success has led to a network of such centres opening across the United Kingdom and even further afield (Miller 2007). The philosophy underpinning such centres can also be seen as facilitating the resilience so needed on the cancer journey by both patient and family. Addressing this notion, Jacelon (1997) identified how some individuals seem to possess resilience to cope with, and ‘bounce back’ from, life’s adversities. Resilience is seen as a ‘constellation of traits’ (1997: 128), some seemingly inherent in the individual such as a sense of autonomy, enthusiasm or humour; others may be more socially determined and arguably could be learned. Such resilience, if it can be fostered, can counter the sense of fragility and of strained personal resources that can occur on the cancer journey. Nurses and others in the caring team can be key in helping the cancer patient to achieve this or to detect where, on the continuum of response from vulnerability to resilience (Rutter 1985), the cancer patient might be at any one time.

**Life after treatment**

Following treatment there are new challenges to face as, to some extent, the treatment period, short or extended, provides a ‘cocoon’ of care that now, if all has progressed optimally, must be left behind. As the time from treatment completion lengthens, the concept of survivorship grows. One of most positive developments in recent years has been
that people can and do survive a cancer diagnosis and survivorship is a reality (Doyle 2008). This in itself has necessitated an exploration of what is meant by survivorship (the term first coined in the 1980s), when it begins, and what are the immediate and ongoing needs of those who can describe themselves as cancer survivors. Sontag (2001) was perceptive in her plea not to call those with cancer ‘victims’. Mullen (1985) described seasons of survival, beginning at diagnosis, as acute, extended and permanent, but this is a continuous process with needs ebbing and flowing as time passes. More conventionally, survivorship is seen as being disease-free for five years, after which, arguably, the risk of recurrence is less. Survivorship brings with it its own uncertainties and needs that must be specifically understood and provided for (Carter 1989; Vivar & McQueen 2005; Doyle 2008). This is an area for further research, and survivors’ needs, although recognised, are not yet fully met (DH 2007).

Doyle (2008: 507) emphasises the need for all nurses to deepen their understanding of cancer survivorship needs and to take a leadership role in ‘influencing theory, research and practice’ around this ‘dynamic concept’. What is recognised is that survivorship has both positive and negative effects. The joy of surviving is tinged with the fear of recurrence, the irreversible and/or ongoing effects of treatments such as body image changes, pain and fatigue (see Chapters 7 and 8). The restoration of ‘freedom’ may be spoiled by feeling cast adrift from the support of healthcare professionals, who for some may have been like a second family (Rowland 2008). Some will express a sense of growth and new awareness (Barker 2000), but others may remain bitter at having had cancer at all and be unable to move on (Rowland 2008). Yet others sense that, in some ways, though no longer a cancer patient, they do not truly feel a survivor (Doyle 2008). Alongside remain the family and/or the carer who, in many ways, mirror the survivors as they too learn to incorporate this as part of their lives. As normal life resumes, Stott (2008: 61) wonders if the complexity of being a survivor is seen as such, commenting ‘Cancer and its effects cast a long shadow’ and it must not be assumed that ‘patients can just resume their lives as though cancer was just an unfortunate interlude’.

**Cancer recurrence**

Survivorship can also embrace those who are not disease-free but who, despite treatment, have not seen the cancer eradicated, or for whom it has since recurred, to the same part of the body or spread to other parts of the body as metastases. Reaction to the return of cancer has not been much researched but Griffiths et al. (2008), looking at oral cancer recurrence, identify heightened vulnerability revealed in a mosaic of responses. These were not all negative, and included new-found coping mechanisms and improved relationships. It is undeniable that the return of cancer poses yet further challenges for its clinical and emotional management by the healthcare multidisciplinary team, but with advances in cancer care, many more now live with cancer, rather than see it as immediately mortal. Although the term ‘chronic’ now has its own critics, cancer can be seen as a chronic illness where, although cure may no longer be possible, quality of life can be maintained for a considerable time in a way that was inconceivable as little as 25 years ago.

Managing metastatic disease is not the same as managing a chronic condition such as diabetes mellitus, and the philosophy of the treatment alters, with the aim of gaining the
best control over the cancer whilst not inducing a toxicity that detrimentally affects daily wellbeing. For many, further treatment may require hospital care where the oncology nurse, as a key member of the team, once again guides patients through the decision-making process in relation to the possibilities and realities. Increasingly, however, it is possible for treatments to be based at home (Marsé et al. 2004). Fitch and Maxwell (2008) maintain that nurses are often the most appropriate healthcare providers in supporting patients and their family at home, helping them to understanding their therapy, often able to act as intermediaries in communicating the needs and concerns of patients to their physicians. The patient and family have to acknowledge that some form of treatment will now be a fact of life, for the most part, for the future, however long it may be. Whittemore and Dixon (2008), though not looking specifically at cancer as a chronic illness, explored how people with a chronic illness integrated this reality into their lives. Despite effort and motivation this was found to be hard as they struggled to live life rather than live illness. Such research serves to demonstrate that success in managing formerly life-limiting disorders brings its own challenges for both the participants and all who care for and about them. At this stage of the journey, what might matter most is the ability of healthcare professionals, and particularly the nurse, just to acknowledge a shared humanity and the capacity ‘to presence oneself’ alongside the patient and family (Benner & Wrubel 1989: 13).

The end of the survival journey

Palliation of symptoms and quality-of-life issues become increasingly the overarching concern for those whose cancer journey moves inexorably towards its end, and where the hope for cure is replaced by a hope for continuance of life. It should be remembered that, for at least 20% of individuals, there is a desired quality of life until the very final days (Lunney & O’Mara 2001). However, for many cancer patients the complexity of physical and emotional symptoms requires specialist clinical, interpersonal, humanitarian and spiritual skills expressed so ideally in the hospice philosophy of care and ‘the twin pillars of mind and heart’. Such care is achieved by exquisitely competent symptom management, combined with ‘open, compassionate conversations’ (Lunney & O’Mara 2001: 277) with the patient, family and, indeed, close friends. Lunney and O’Mara (2001) suggest that the end-of-life experiences are not entirely new but rather are different expressions of those previously encountered. Hope remains but its complexion has changed. The skill of such care at the end of the journey is explored in several chapters in this text, particularly in Chapters 5, 7, 10 and 12.

The cancer care journey: then and now

So much has changed since Susan Sontag first wrote Illness as a Metaphor in the 1970s and openly discussed the association of cancer with death and the sufferers as victims. She believed that when cancer was finally understood, so would the language change and metaphors be rejected (Sontag 1978). Sontag was right in that, as knowledge and scientific
understanding has burgeoned and outcomes improved, cancer is more openly discussed and metaphors, if not rejected, have changed, as discussed above, from that of victim to that of survivor on a journey. However, as Mullen (1985) observed, there is no denying that life is forever altered by the experience of cancer and the word still instils fear into most people as the ‘diagnosis . . . hits you like a punch in the stomach’ (Keswick Jencks 1995: 1). Even at the end of the first decade of the 21st century, cancer is perceived as seriously life-threatening and, in the unexplained symptoms in the ‘worried well’, it is often what the individual is fearing but avoids voicing (Wick & Zanni 2008). People now expect that the National Health Service will deliver the best and fastest treatment available to save their lives or the lives of those they love, should cancer occur. The current picture in the United Kingdom, however, is not as encouraging as might be believed, comparing poorly in terms of five-year survival with Germany, France and Sweden (Verdecchia et al. 2007). Despite this, the road travelled since the 1970s is worth considering in terms of the cancer experience and the remarkable progress made.

In the 1970s the word cancer was largely taboo; people ‘whispered about or alluded to the disease indirectly’ (Mayer 2007: 481). In the 1970s, the diagnosis was often missed or made too late, compounded by reluctance of the person to present with the feared symptoms. Diagnostic techniques and treatment were hugely variable between, and even within, different areas of the country. Waiting times for treatment were so long that patients could die before treatment had begun. In terms of treatment, there were few options beyond surgery, usually carried out by generalist surgeons and where, if this did not resolve the problem, life expectancy was limited. Patient and treatment outcomes varied considerably in terms of survival. The concept of specialist services was as yet embryonic. A significant breakthrough for cancer patients’ experience occurred with the work of Dr Vicki Clements, based at St Bartholomew’s Hospital in London. She herself, diagnosed with ovarian cancer, sought to bring cancer ‘out of the closet’ and by 1984 had founded the British Association of Cancer United Patients (BACUP) to provide the crucial information, practical support and help that patients and their families so needed. Clements argued that patients deserved honest communications as to their condition and prognosis. Her drive and determination led to what at the time was quite a radical development: that of collaboration between progressive clinicians and patients, with patients recognised, perhaps for the first time, as having their own expertise.

Other major technological advances were occurring in the early 1980s. Computed axial tomography (CAT) was introduced: a scanner allowed a series of cross-sectional scans to be made along a single axis of a body structure or tissue to construct, for the first time, a three-dimensional image. Alongside this, surgical techniques were steadily improving and emerging knowledge of the biological basis of cancer suggested exciting possibilities for the future. Research into the use of radiotherapy and chemotherapeutic agents in the management of cancer was also advancing, although at that time the side effects were significant and hard to alleviate. Nausea and vomiting was an inevitably miserable side effect of most chemotherapeutic agents until the 5HT3 receptor antagonist was researched (Marty et al. 1989), developed and introduced in the late 1980s. The drive to improve both cancer prevention and cancer care, in terms of screening equipment and services and specialist centres, gradually gained momentum from both healthcare professionals and the public, and in 1985 led the Minister of Health, Kenneth Clark, to commission an
expert working group chaired by Sir Patrick Forrest, to look at breast cancer screening. The Forrest report, published in 1986, recommended breast screening for all women over the age of 50 years (DHSS 1986). The success of this report was reflected in its implementation in full by 1988. Despite these obvious advances, the United Kingdom compared badly with many of its European counterparts in terms of the percentage of gross national product (GNP) spent on health. The computed tomography (CT) scanner was a major and amazing breakthrough, allowing clinicians for the first time to see exactly where a tumour was within the body. It revolutionised detection, diagnosis and subsequent treatment, but this key development was never rolled out by the government, and money for this vital equipment depended on charitable donations and other money-generating appeals.

This could not continue and, by the 1990s, senior clinicians’ voices were increasingly heard in the United Kingdom. In 1994 the Chief Medical Officer, Kenneth Calman, chaired the committee that led to the Calman Hine Report in 1995 with the recognition, arguably very late, that something must be done for cancer services (DH 1995). This report proved to be the major catalyst for change, leading to the development of cancer specialist centres, where cancer surgery would be performed only by specialists. Resources and priorities were to be so directed that waiting times would be markedly reduced, there would be no socioeconomic disparity and there would be equity of services across the regions (DH 1995). A period of optimism followed as the report impinged on the professional roles and priorities of healthcare professionals and their patients but (although not debated here) the incidence and prevalence of cancer continued to rise and the United Kingdom remained low in the European league tables. In 1999 a group of key cancer experts met with the Prime Minister, Tony Blair, to develop a national cancer plan, and a cancer ‘tsar’ was created in England to oversee the plan and ensure that resources were in place to improve patient outcomes. In addition to the continuing issues of screening and waiting times, there was to be increased investment into new treatments, the workforce was to be expanded and the infrastructure strengthened (DH 2001). The aim was that by 2010 the picture of cancer survival was to be at least on a par with that of the leading European countries. However, data take time to collect and collate, and the analysis by Verdecchia et al. (2007) still showed a disappointing picture. Mayor (2009) reports that the NHS cancer plan has achieved a tentative increase in survival at one year for many types of cancers but that, until further data are available, such a result should be viewed with a degree of caution.

However, good news is established for breast cancer, where survival rates have been improving for more than 20 years. The estimated relative five-year survival rate for women diagnosed in England and Wales (and other parts of the United Kingdom demonstrate a similar picture) in 2001–3 was 80%, compared with 52% in 1971–5 (Coleman et al. 2004) and the estimated 20-year survival rate has gone from 44% in the early 1990s to 64% for the most recent period (Office of National Statistics 2005).

In 2007 the Cancer Reform Strategy was launched (DH 2007) looking to establish the kind of service seen elsewhere in Europe. It was clearly recognised that many more lives could be saved if the outcomes of the United Kingdom were brought up to the standards of the best countries in Europe and there was little dissent as to what needed to be done. Was this enough to meet the goals? Great credit was given to the involvement of patient groups in
this reform strategy, something that would not have been considered or thought possible in the 1970s (DH 2007). Scotland, which continued to have one of Europe’s lowest rates for cancer survival, followed a year later with its new cancer plan, entitled *Better Cancer Care*, which aimed to reduce the number of cancer deaths in Scotland (Scottish Government 2008). The common purpose continues to be to improve cancer prevention, detection, treatment options and care and meet head-on the challenges that persist.

**Cancer journeys: stories and narratives**

Understanding cancer can be seen not as one journey but rather as many different forms of journeys, of suffering, of care and of emotion. There are also the journeys of scientific discovery in the field of cancer, to which this chapter has not done due justice, and journeys of a more sociopolitical nature as to how cancer care has been, and is, seen as a political priority. However, it is the journey of the patient which is the foremost concern of this chapter. Of course, understanding how this journey is experienced depends, to some extent, on understanding the other forms of life journeying. Considerable insight can be gained from the stories that patients, and those who care for them, tell. Many cancer patients feel the need, verbally or in written form, to give a personal narrative of their illness experience. Calman (2000) stated that stories ‘help us make sense of the world and able to bear some of the burdens which we face. They give meaning and structure to our daily lives’ (Calman 2000: 17). Although the terms are often used interchangeably, ‘narrative’ looks to go beyond the actual ‘story’, attempting to capture, investigate and draw out the truth behind the experience for that individual in time, space, personhood and relationships (Clandinin & Connelly 2000).

Repede (2008), telling the story of one woman’s journey through metastatic breast cancer, sees such stories as a means of conveying meaning for the reader and healing to the teller. Gaydos (2005) describes the listener or reader as being drawn in and giving their own interpretation, in light of their own unique experiences, which allows the story to become ‘a resource and a memory for the listener as well as the narrator’ (Gaydos 2005: 256). Gaydos (2005: 257–8) also considers that, as part of the art of nursing, nurses can, through their own skills of ‘mutuality’, be ‘co-creators’ of the narratives whereby a shared and more profound meaning of the story is elicited. However, more familiar are the personal accounts read as ‘blogs’, articles or books. Rachel Clark, in her poignant account of her experience of cancer at the age of 25, speaks directly to healthcare professionals so that they can learn from her words (Clark et al. 2002). In the same vein, Maggie Keswick Jencks gave her inspiring and feisty ‘view from the front line’ (Keswick Jencks 1995). Lance Armstrong’s story is one of the courage and determination of a winning sportsman, with all its metaphors, but it speaks equally for all to hear, of how, for that time in his life, cancer consumed his thoughts before he could once again, with his own altered perspectives on existence, celebrate being alive (Armstrong 2001). Gloria Hunniford, telling the story of her much loved daughter’s journey through cancer, writes as a mother walking, not always easily, alongside her daughter, herself also a mother (Hunniford 2005). All such stories speak to everyone but can offer much to healthcare professionals who, despite Gaydos’s ideal of being a co-creator of narratives, do not always have the privilege of this opportunity.
The journeys of those who have experienced cancer and who also work as healthcare professionals has a particular poignancy if, as well, their work was in the field of oncology. This was the case for Peter J. Morgan who, about to begin work as an oncologist, was diagnosed with advanced cancer. From that day, continuing his work until his death, he kept a diary, parts of which were made into an educational video (Chabner 1997). His personal narratives and reflections provide a compelling account ‘of the survival of the spirit that would not succumb to the “chaos” of cancer’ (Chabner 1997: 206) while also relating what in his life was most precious. ‘His work as a physician was at the top of his list’ (Chabner 1997: 207). Peter J. Morgan epitomises what can be seen as the work and care of a ‘wounded healer’.

Wounded healers and the cancer journey

The notion of the wounded healer has its origins in Greek mythology where the centaur, Chiron, was wounded by Herakles’s poisoned arrow, a wound that was not to heal and left Chiron in perpetual suffering. Chiron was able to transcend his own suffering and transform it into the capacity, as a wounded healer, to heal others (Conti-O’Hare 2002). The notion of the wounded healer can, to a significant extent, be seen as inherent in all healthcare professionals who, in order to fully ‘heal’, must have recognised and been immersed in the suffering of others, so much part of the emotional labour of caring. Learning to cope with the inherent stress of others’ suffering and transforming it into positivity can then form the basis of a truly healing relationship with the patient (Conti-O’Hare 2002; Dunning 2006). It is not intended to mean that all true ‘healers’ must themselves have been overtly ‘wounded’, but many healthcare professionals will attest that only when they had shared similar experiences and become a patient did they fully appreciate, as an insider, the world of the sufferer (Morgan 1984; Dunning 2006). Morgan (1984) argues that as wounded healers, any ‘physician or other healthcare worker who . . . had extended hospital care is in a unique position to act as an intermediary between the needs and sensitivities of hospital patients and the rigidities and compulsions of care givers’ and ‘would have the trust of the patients and the respect of the staff’ (Morgan 1984: 1336).

DeMarco et al. (2004) and Picard et al. (2004) explored the world of nurses as cancer survivors and described both the particular vulnerability that insider knowledge gave them and also, despite a sense of role ambiguity, how, as a ‘wounded healer’ it had deepened the compassion they felt for their own patients on their journey with cancer, acknowledging ‘a willingness to accept the vulnerability of both practitioner and patient’ (Conti-O’Hara 2002: 33). Mayer (2008) urges nurses as cancer survivors to use their own stories and journeys to enhance the education, interdisciplinary working and research in the field of oncology.

Reflections on the journeys

There cannot really be firm conclusions to a chapter such as this where explorations have no endpoint. The author has looked to illuminate the primacy of the journey as perceived and presented by the traveller. How its stages are perceived, the ‘inscape’ of the cancer
sufferer, before setting out on the road or at journey’s close, will depend on many others: journeys by those who care on a personal or professional level, or both; emotional and spiritual journeys; journeys of scientific understanding; journeys of political will. To be human is to journey, and the cancer journey with all its twists and turns, light and shade, is unique to each cancer patient and survivor. For Maggie Keswick Jencks, even in her most difficult times and near the close of her own life, it was that ‘above all what matters is not to lose the joy of living’ (Keswick Jencks 1995: 13). Surely, for all who participate in and care for those on the journey, we cannot but share the aspirations embedded in this sentiment.

References


