

'Integrated Cancer Care'

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Introduction

The holistic approach to care for patients with cancer or other illness aims to mobilise their own self-healing powers rather than using extraneous treatments to combat their disease. This entails energising and balancing the 'whole person' - body, emotions, mind and spirit. Interventions include diet, complementary therapies, healing and psychological and spiritual counselling, combined within an individually tailored package. The approach is mainly offered in the private and voluntary sectors, with a large self-help element. Input from oncologists or liaison psychiatrists has been very limited; indeed there has been some hostility from orthodox professionals at least until recently. Whether the holistic approach improves survival from cancer is a controversial question on which the evidence is conflicting. However there is evidence for improvements in quality of life, symptom control and patient satisfaction. A selection of quotations, mainly from the book 'Integrated Cancer Care', will be used to illustrate the approach. Experience with a group programme, CHRYSALIS, to introduce it to patients and staff within an NHS setting, is described.

(Introductory slides: a series of relaxing scenes of New Zealand mountains and fjords, followed by the erupting volcano, White Island, as a metaphor for the shock of cancer diagnosis)

The diagnosis of cancer

One woman writes: 'Having cancer is a deeply traumatic experience, a descent into fear, despair and powerlessness; in brief, into a state of emotional turmoil which health professionals - who need to protect themselves from personal involvement in their work - can hardly imagine and which most sufferers dare not discuss. A sharp animal fear in the pit of the stomach, heart stopping then speeding up with a downward lurch, a great need for air, clammy hands and paper-dry mouth. Then numbness, the world switching to slow motion, followed by a blast of icy loneliness, the sense of being cut off from the cancer-free part of humanity, like a mediaeval leper banished from the community and underneath it all, profound dread. It is at such moments the patient would need help. Instead: a doctor who is 'brief, correct and ice-cold', a cheery remark from a nurse and a sense of being sucked into a vast impersonal system that has taken over one's destiny.'

The importance of 'breaking bad news' in a sensitive way, and supporting newly diagnosed patients through their adjustment reactions is in fact already well recognised in orthodox cancer care settings, if not always put into action. But the other aspect of the approach I am going to describe, the holistic approach, is very different from that of mainstream oncology or liaison psychiatry. I became interested in this during the last few years of my own career in psycho-oncology through meeting a few inspiring individuals who appeared to have transformed their own lives after being diagnosed with cancer, and in many cases making remarkable recoveries from the cancer itself.

What is the holistic approach?

One dictionary definition of holistic is 'characterised by understanding the parts of something to be intimately interconnected and explicable only by reference to the whole; holistic medicine characterized by the treatment of the whole person, taking into account

mental and social factors, rather than just the symptoms of a disease'. The approach is not new – the same principles were followed in the healing temples of ancient Greece – and the word itself is derived from Greek *holos*, meaning a whole greater than the sum of its parts. It advocates balance between body, emotions, mind and spirit for the individual, and connectedness with others and the environment. The aims of a holistic programme for cancer, and other illnesses, can be simply stated as follows: to feel better, exercise some control over one's situation, live better and possibly live longer. Such a programme includes various specific complementary therapies, combined with changes in attitude. The best-known UK venue for its promotion has been the Bristol Cancer Help Centre but it is found in many other settings including self-help groups and some mainstream hospitals. In some ways it complements and even overlaps with more conventional approaches, and in other ways conflicts with them. For me, the results of exploring this approach included my editing the book 'Integrated Cancer Care' on which today's talk is based, developing a group programme called "Chrysalis" at the Churchill Hospital in Oxford and introducing selected elements into my NHS clinical work and teaching. So my emphasis was the integration of the holistic approach with conventional care, rather than viewing it as 'alternative'. This presentation is descriptive, including direct quotations from patients' and colleagues' contributions to the book. I'd especially like to acknowledge Sally Baldwin, Beata Bishop, Thurstan Brewin, Alastair Cunningham, Camilla Connell, Rosie Daniels, Pietro Pizzo, Heather Goodare, Laurence LeShan, Tony and Ann Neate, Robert Ross and Leslie Walker.

Theories of cancer causation

Patients will question why they have developed the disease; holistic theory attributes cancer (and indeed all other diseases) to energy imbalance at the level of body, emotions, mind and spirit. The multi-factorial model is acknowledged, with physical factors including genetics, environmental pollution and diet all playing a part. As regards psychological factors, many patients recognise themselves in the so-called Type C personality - bottling up emotions, pleasing others and unaware of their own desires. Said one patient, 'I did far too much, was permanently exhausted and survived on willpower. People turned to me and I spent most of my time trying to help them, often neglecting my family and my own needs'.

There is some evidence that chronic depression predisposes to cancer and it is striking that all three of the patients who wrote detailed chapters about their illness had had psychiatric treatment for depression before their cancer was diagnosed but have had no depression since. A symbolic significance may be discerned in the primary site of the tumour. For example, one patient linked her cervical cancer with psychological conflicts about whether to have children. However, the huge emphasis which holistic theories place on psychological factors in cancer causation is not really backed up by conventional research findings. For example, a role for life event stress is not well supported by evidence, but many patients believe it anyway. Said one, 'we cancer patients 'knew' that our emotional histories had contributed to our illness'.

I shall describe some of the interventions that make up the holistic approach. Broadly speaking these are arranged in the order of body, emotions, mind and spirit, although all four aspects are closely interwoven.

Relationship with the body

(Slide: painting by Cranach the elder, of Adam and Eve)

This image is suggestive of shame towards the physical form. Patients' relationship with their bodies had often had been bad even before the illness. The body was ill treated, disliked or ignored and disregarded as a 'kind of flesh-and-blood taxi'. Cancer changes body image in a way which may lead to further self-rejection, and it is important to address this: 'Self-hatred must be dispelled. An organism which keeps getting messages of loathing and rejection is unlikely to heal well'. Touch can be helpful, whether as part of the therapeutic relationship (in contrast to mainstream psychotherapeutic teaching) or through complementary therapies such as massage and aromatherapy.

Complementary therapies

Acupuncture, aromatherapy, herbalism and homeopathy are used to raise energy levels and to relieve specific symptoms. 'They inject hope, comfort and physical and spiritual healing into the most dismal situations. Beyond immediate benefits they also have a deeper purpose; by involving the patient in therapeutic activities they awaken what Albert Schweitzer called the wise healer in us all'.

Dietary factors in cancer have recently been better publicised. The general recommendation is for plenty of fruit and vegetables, preferably organic, while avoiding meat and dairy and processed foods. Vitamin and mineral supplements are usually recommended too. Radical dietary change can have profound psychological and social effects. One system, the Gerson therapy, is a vegan regime including freshly squeezed organic juices every hour supplemented with coffee enemas five times daily. Most of the patient's life is taken up with the regime and help is necessary. Astounding successes are described for individuals on this diet but it has not been formally evaluated and relatively few patients choose to adopt it. 'No diet will provide positive benefits if it creates emotional stress due to resistance...some patients have said quite openly that they would sooner die from cancer than eat what they describe as rabbit food.'

Relaxation, meditation and visualisation

This group of techniques have a role in both the emotional adjustment to cancer and in control of physical symptoms such as pain and nausea, which are often exacerbated by anxiety. (Some variants are of course widely used in mainstream medicine).

'One of the biggest obstacles I have faced to healing has been the stress I have experienced from fear, since I was diagnosed with metastatic cancer. I found that this fear manifested in a number of physical symptoms: tightening in my chest, abdominal discomfort, headache and sleeplessness. I believe that prolonged anxiety affects the ability of my immune system to function, and that the more relaxed and peaceful I feel, the easier it is for my body to heal. I also found that this fear affects my emotional state. It sometimes leads to feelings of sadness, disappointment, anger, resistance and helplessness. The spiritual work I do helps me in both the physical and the emotional realm. It has helped me to focus outside of my body and physical state on something bigger than myself. It has given me hope that my life can have purpose, even if my physical abilities are diminished. It has helped me reach a still, tranquil state of mind, which is useful in dealing with fear. I have learned to accept the range of emotions that come up, and to let them come and go, rather than getting stuck in the related emotional and physical states. I think this is probably better for healing, as the physical effects of stress are reduced'.

Various relaxation techniques are used. Visualisation of a relaxing scene is helpful. Symbols with spiritual significance may emerge, or 'glimpse of a higher dimension beyond normal ego consciousness'.

(Slides of Bowen Falls, Stirling Falls, New Zealand)

Waterfalls are a popular image chosen by patients undergoing radiotherapy or chemotherapy to symbolise washing away of cancer cells and cleansing of the self. The Simonton type of visualisation is more controversial, as it consists of images of the tumour being conquered by the body's immune defences. The imagery session concludes by visualising oneself fit, active, happy. 'Being invaded is what many patients experience...the imagery has a touch of Star Wars about it, for they see the tumour as a hostile alien intruder, an enemy from some outer space, determined to destroy its host'. Patients are encouraged to choose their own imagery, whether highly militant or gentler.

Healing

(Slide of painting by Duccio: Jesus opens the eyes of a man born blind)

Healing, sometimes called spiritual healing, is often misunderstood as promising a miracle cure of the kind shown in this painting. Reputable healers do not claim to be able to achieve this, although remarkable physical recoveries do happen occasionally. It is often said that 'healing is a process not an event'. Ann and Tony Neate, from the College of Healing, Malvern, write: 'Healing is the channelling of universal energy to a patient by thought processes to bring about an overall state of energy balance and harmonisation on all levels, thus stimulating the body's natural defence system to deal with disease'... as healers, we endeavour to release and transmute the misplaced energy that stimulates the growth of the cancer cells...healing does not need the faith of the patient and does not conflict with any other therapy...healing is not about curing...it can be helpful in relieving pain...above all, it can transform the attitude of the patient towards the illness, enabling them to accept it in a more positive and creative way'.

Changing attitudes

Key words regarding changes of attitude include patient choice, self-responsibility, as opposed to self-blame, and self-expression. 'Now you can begin living', said one patient, referring to the period following diagnosis. Another said, 'every crisis brings its opportunity. The crisis of cancer can lead to renewal, to changing things in life that are unsatisfactory and to find ways of living more creatively. What I have learned over the years is that the indispensable first step towards healing is to make a major change in some area of life. Something must have been wrong in one's existence to allow serious disease to strike. It is almost immaterial which of the available changes the patient starts with – as long as a start is made by a no longer helpless active player'.

As an example of breaking the pattern, one patient who started with improvements to her diet naturally progressed to cutting out smoking, drugs and alcohol, practising meditation, taking stock of her life and revising relationships which had been sapping her energy.

One patient, a 'previously squeamish man who had spent a lifetime avoiding all forms of human confrontation' resolved to reinvent himself, to 'try to beat cancer by the application of humour – if you can laugh at something you take away its power'. Examples of his humour are often rather black. For example, he says it is a lasting

source of amusement to continue getting his social security benefits for terminal illness. He says he doesn't go so far as to call cancer a gift (although a few patients do) but does report that the five years since its diagnosis have been the best of his life, 'living positively and creatively, one day at a time'. He points out that talking of losing the battle with cancer has become a cliché, but most patients do not actually fight.

Counselling and psychotherapy

Many patients become their own therapists; others seek professional guidance. A contributor who called her chapter in the book 'Patient Heal Thyself' describes how counselling helped 'to free myself from the crippling weight of my previous emotional history, the break-up of a first marriage, depression and religious upbringing. Another recovered patient turned psychotherapist says that 'under the impact of serious illness some choose to come to grips with some non-physical factor they suspect has contributed to their ill health. It may be something that has lost all relevance long ago, yet which left behind pain, guilt or repressed anger, or else a life trap – a situation which seems intolerable and unalterable with serious illness or even death as the only honourable way out – such as a miserable marriage which can't be ended because of the children'.

Conventional psychotherapy is not always well received. 'I visited a Jungian psychotherapist and explained that as I might only have three months I did not want to explore what could have happened in the woodshed, but wanted to make the best possible use of the remaining time. He asked me how I got on with my father and when I explained that he had been a great support he said that showed deep denial and that there were years of work to be done. When I said I found spiritual things a great solace he told me to come down off the ceiling and charged me £300 in advance'.

Relationships with people

Many patients had put others' needs before their own to a rather excessive degree (ignoring the last word of the commandment 'Love your neighbour as yourself'). 'Forgiveness was very important especially towards myself, and avoiding feeling guilty at the slightest opportunity'. Patients may need to become less people pleasing, more assertive, and learn to set boundaries. One 'challenged the medical establishment in ways never before dreamt of' in relation to the patient-led criticism of the statistically flawed research study carried out some years ago on the Bristol Cancer Help Centre.

New lifestyles

Serious illness often forces patients to retire or change jobs, in some cases providing them with an opportunity to find their true path in life – in the words of Laurence LeShan, to 'sing their own song', often in a field involving more self-expression and creativity. The man who cultivated humour became a playwright. The woman who had previously worn herself out by attending to others wrote, 'I found creative things inspiring and music was especially healing...painting lifted my spirits ...I kept a taped daily diary...I also experimented with colourful vegetable and fruit dishes and started compiling a healthy cookery book...a good haircut helped, and occasional visits to the opera or theatre were a great treat'.

Creativity

Creative expression can take many forms, as well as the traditional ones of writing, music and art. Many patients do these by themselves, others with a trained therapist. The benefits come from self-expression. The need for talent and technical skill

is a side issue, though many patients understandably do not realise this and decline such therapies because they would be 'no good' at them.

One patient wrote, 'I believe art therapy saved my life by giving me the opportunity to get in touch with my authentic self...in art therapy my mind was not in charge. It did not control the paint or the glue. The materials would have their say, be whatever they were, show their qualities and I would make a connection, engage with them. Images emerged from an inner world that I had lost touch with. It was here that I discovered my values, my priorities and came to understand that I had sacrificed them for the more urgent demands of life...these fragmented and lost parts appeared week by week on the paper...art therapy is not for producing a picture for anyone else, it is about being spontaneous, allowing something deep inside to express itself, to make its mark. I believe that the body knows how to heal itself, redress the balance. Feelings are processed and expressed without the involvement of the ordinary mind'.

Spiritual growth

Serious illness provides an opportunity for spiritual exploration and growth. This may involve a formal religion or be experienced in more general terms. Revival of joy in living can come through taking time to appreciate the beauty in nature or music and the uplift these provide. Patients reconsider and honour their core personal values, finding a sense of meaning and purpose in life. Many remark that worldly status and possessions have come to seem less important.

(Slide of Cape Reinga)

This shows the northernmost tip of New Zealand, close to a place called Spirits Bay, through which, according to Maori tradition, the spirits of the dead will pass on their journey back to their homeland in the Pacific. An essential part of the spiritual journey must concern personal beliefs about death and dying. Although most patients will strive their utmost towards recovery, I believe the acceptance of mortality forms part of the holistic approach to cancer, as it does in the more conventional approaches of palliative care. This can conflict with the interpretations of the 'fighting spirit' approach found in some oncology units, which can involve the denial of death and persistence with aggressive anti-cancer treatments to the end.

The following quotes are from participants in the 'Healing Journey' spiritual programme developed by Alastair Cunningham and his colleagues in Canada.

'When I was first diagnosed, I think that I had very little understanding of my own spirituality. I saw God as something separate from me and outside of myself. This allowed me to blame him and accuse him of punishing me. It also allowed me to question the existence of a God. If there were a God, why would he let this happen to me? Because I was not sure about my beliefs, I was able to use this time as an opportunity to discover what I believe. In the process of exploring my faith I have been able to identify with my spiritual self and give thought to what the meaning of my life is. I think the inner resources I have discovered have played a major impact on my healing and enabled me to find a peace in my life which I never felt before'.

'I think that one of the greatest gifts I have received from my spiritual journey is the realisation that my spirituality can encompass all of my life. It is not something that belongs in a special compartment, separate from the rest of life. It has to do with a basic sense of what life is all about. Life has to be about more than an exercise that leads to death and decay in a grave. Life begins with breath and ends with breath. With the beginning of the first breath, spirit and body are connected. When our physical self dies, our spirit moves on. It is this faith and belief that helps me to have an inner sense of

wholeness and peace, even if my body is not perfect. Developing, growing and maturing in my spirituality helps me to understand that the death of my physical body is not the end of my spiritual self. A healed person is not necessarily a person without any physical disease'.

Combining therapies

Many patients combine orthodox and holistic therapies. Three years after successful treatment for acute myeloid leukaemia, one woman wrote, 'I believe my recovery was thanks to several threads at work throughout the illness. I was fortunate to have an outstanding haematologist. The prayers, love and confidence of friends and family were, and still are, of help beyond words. When I had finished with the chemotherapy, I underwent a monthly regime of acupuncture. I still have acupuncture and aromatherapy and imagine I will continue to do so into the future. The aromatherapy oils that are rubbed into one's skin are clearly a huge assistance. The regular relaxation and feeling of well-being from a positive and gentle massage cannot be overestimated'.

Evaluation

Evaluation is quite challenging because this is not a standard package but relies very much on patient choice and motivation.

The RCT can be applied to individual complementary therapies, though the best design would take account of patient preferences. It is more difficult to devise trials of full-scale holistic care, which has so many components, including internal changes of attitude besides the administration of therapy techniques. Patients who feel committed to the approach may not take kindly to the constraints of a trial protocol. They want to choose their own path and to try everything that might help. 'I had homeopathy and a number of other treatments including applied kinesiology, vega-testing, osteopathy and cranial osteopathy, reflexology, acupuncture, electrocrystal therapy, radionics, dowsing, hydrogen peroxide, ascorbic acid, essiac, royal jelly, herbs (Western and Chinese), an ozone generator, plus a radiTech bar and crystals for geopathic stress. We decided to explore every approach however bizarre'.

Integration and obstacles to integration

Several centres have developed services whereby specific complementary therapies (rather than the full-blown holistic approach) are available in NHS hospitals. Palliative care units have led the way with, for example, aromatherapy, acupuncture, art and music therapy widely available. At Sobell House in Oxford, we introduced patients to Cocoa, our first PAT (Pets as Therapy) Dog.

Such initiatives have been generally well received. However, there are also arguments for keeping the holistic approach separate from mainstream medicine. One doctor wrote, 'yes, if it means that medicine accepts the validity and otherness of complementary therapies and tries to understand but not swallow them up, for as separate and independent disciplines they have much to offer that modern hi-tech medicine lacks. Let each side do what it can do best, and communicate across the necessary gap that separates them'. He goes on to say, 'it sounds more positive and friendly to integrate but...there is a tension in our nature between logic and magic. Basic human nature and current cultural trends seem to need both, but perhaps it's best they're kept a little apart'.

(Slides: painting of 'Two Dancers on the Stage' by Degas, and Maori poi (raffia ball) dance enacting the journey to New Zealand in the seven canoes)

This is perhaps a far-fetched metaphor, but among my slide collection I happened to have two pictures showing very different forms of dancing and it struck me how much would be lost if they were combined.

About five years ago I introduced the Chrysalis groups to the clinical cancer centre in Oxford, being a series of four open group meetings to introduce some principles of holistic cancer care. They included plenty of time for discussion besides a short talk with slides, taped relaxation, visualisation sessions to music and short exercises for example based on 'angel cards'. Mostly these groups were well received. Patients' written feedback included, 'very welcoming and peaceful...unthreatening...space and time for tears! Useful advice from professionals and support from peer groups...very comfortable, comforting experiences...gave me insights into my condition... well organised sessions and each person was given an opportunity to contribute, or not, just as they wished...it reassured and clarified things I had heard about visualisation and guided imagery. Showed how one can still value oneself even after considerable mutilating and scarring (mental and physical)...it gave me the impetus to explore what I could do for myself, especially mentally. Orthodox treatment often tends to give the patient the impression that they are powerless in the face of cancer and that only surgery, radiotherapy and chemotherapy can do anything for them. The evidence is mounting that patients' attitudes and mental outlook are very much more powerful than any of these treatments...it was well worth the long journey. Probably the most therapeutic of all the so-called treatments to which I have been subjected and the one most likely to result in any extension to my life expectancy. Why? Because the lessons I learnt continue to work inside me and give me strength whereas everything else was simply a nightmare to be endured. The brutality of cancer 'treatment' must be revisited and reconsidered unless it can somehow be balanced by sessions such as Chrysalis as part of the prescription. It's a great pity this type of approach isn't more widely available'.

However, only a tiny minority of patients or staff took up opportunities to attend. Doctors, although showing some theoretical interest and paying lip service to the potential of such an approach, were especially reluctant! I do not know why so few patients came. Despite our marketing efforts, many obviously did not know about it. Others were probably deterred by practical factors such as clashes with physical treatments or living some way away. They may not have wanted to spend any more time at the hospital than they had to already and, if they did choose to explore holistic approaches, perhaps would rather do so in a quite separate setting. No frank opposition came to my notice, rather to my surprise. But I know some patients and staff do object, often due to ignorance and fear, and there are also a number of valid objections apart from the lack of clear evidence of benefit.

When used in the alternative rather than the complementary sense, patients are deprived of conventional treatments that might have cured them. Some of the therapies can have unwanted physical effects, occasionally serious ones, which is especially likely if the combination with conventional treatment isn't taken into account. An example would be a high-fibre vegan diet together with radiotherapy to the abdomen, or interactions between herbal medicines and prescribed drugs. Psychologically there may be concerns about making patients feel guilty for getting cancer, or giving them false hope of cure, although neither seem to be common problems if the therapies are presented in a sensitive way. Of course there are always some 'quacks' that are poorly qualified, doing it for the money, or set against conventional medicine.

Conversely, conventional healthcare professionals can hold unhelpful attitudes. I have witnessed very dedicated and highly trained oncologists tell patients there is nothing they can do for themselves, that nothing is known about diet and cancer, while

persisting with expensive and toxic chemotherapy for dying patients rather than acknowledge the reality. Patients themselves have some robust things to say about this. 'The individual's self-healing ability and inner being is ignored in a medical setting where the Cartesian principle of body-mind split still rules. This neglect means wasting a potentially powerful healing aid that costs nothing, has no harmful side effects and can work amazingly well...doctors and nurses tend to value patient compliance above all else and resent self-help initiatives from lay people. My infinitely caring and dedicated consultant assured me there was nothing I could or should do to speed up my recovery after major surgery, except to take it easy and leave the rest to him...he urged me to resume the life I had lived before my illness and get on with it as if nothing had happened. He meant well, but he was wrong, for I followed his advice and had a recurrence one year later...no staff member suggested changing diet, attitude or lifestyle. Few acknowledge openly that cancer patients may play any role in their own healing. Doctors have no right to play God by extinguishing hope. Had I passively accepted my doctor's death sentence I would have died years ago, another victim of sophisticated Western-style voodoo. What do I require from my doctor? First of all, the recognition that I have a mind. The patient requires the doctor to provide a glossary, map, phrasebook and signposts. It is the patient who has to make the journey and choose the exact route. The cancer journey is an adventure. It is possible, even desirable, for some to join the guided tour (i.e. conventional medicine). But for those who wish to find their own path, doctors have a vital role in helping to make the process easier. Listen to the patient, don't dismiss their ideas; they may be right, but even if they are unscientific, they may be part of a therapeutic search for meaning. Offer loving support, without stigma, rather than too-ready psychiatric referral. When death approaches, don't regard it as a defeat...the doctor who can accompany the patient and not push for useless and unpleasant treatments will be honoured and respected by the whole family. *Don't just do something – be there*'.

Key concepts in the approach I have outlined are: self-responsibility, making active choices, willingness to change and the belief that a serious illness even if initially devastating may turn out to hold some positive meaning or be a catalyst for spiritual development. My last few slides show that life and growth can sometimes flourish unexpectedly in inhospitable settings.

(Closing slides of: safe haven for a tiny fishing boat at the foot of a cliff in Milford Sound, Gannets' nesting colony on White Island, the explosive volcano Mount Cook with the lily Ranunculus Lyalli flowering on the high mountainside)

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