

a view from the front line



By Maggie Keswick Jencks

Foreword and Maggie's Centres: Marching On by Marcia Blakenham

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by Maggie Keswick Jencks, London 1995

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Preface

by Dr. Leong Che-Hung

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Contents

Preface	1
Foreword	3
A View From The Front Line	11
Maggie's Centres: Marching On.....	25



Preface

Dr. Leong Che-Hung

Having been in the practice of medicine for over 40 years I have had the opportunity to witness the joy of birth, the frustration of illness, the despair of being told to have cancer and the sadness of death. It has always been thought that Chinese are not willing to talk about, let alone accept deaths. Many years of involvement in the medical and elderly fields have led me to realize that culture and feelings have changed in the course of times. It is not death, nor illnesses, that are of primary concern, but it is the unknown of what you will be suffering from and the agony that you may have to face that make things unbearable. To patients with cancers, the possible pain associates with the diseases, the difficulties with communicating with their family, what might happen in the remaining days are all very demoralizing. The Maggie's Centre, the brainchild of Maggie Keswick a cancer sufferer herself, attempts to remove all these hidden frustrations. Within a purpose built cadre centre is provided an environment where cancer sufferers are explained in details their diseases, the treatment options and the possible outcomes. There will be ample reference literatures for them to do research on and find out the details. Most importantly they will have a chance to talk to fellow sufferers' to understand how others face up to the situation and also to realize that they are not alone. There are of course experienced counselors to help them with communications with their families and plan for the way forward. All in all this will facilitate the issue that 'While death is not the greatest worry, it is facing the unknown that is unbearable.'

HK has seen an upsurge of incidence of cancers, we will need more facilities not only to provide treatment but also centres for holistic care. I look forward to witness the success of this first Maggie's Centre as a role model for more facilities to come.

I congratulate the Keswick Foundation & the Hospital Authority and many other philanthropic donors in making the first such a centre a reality.

I look at this centre as a role model, and with further generous donations, other similar centres should be forthcoming.

Opposite: The temporary centre of Maggie's Cancer Caring Centre at Tuen Mun Hospital, Hong Kong



Foreword

by Marcia Blakenham

Maggie Keswick Jencks was diagnosed as having breast cancer in 1988, when she was forty-seven. She had a mastectomy, more or less forgot about it and got on with her life. Five years later, it returned. She was hurled into a maelstrom. Tests showed that she now had cancer in her bone, bone marrow and liver. She was told, kindly but baldly, that there was nothing to be done, and that she probably only had a few months to live. The weakness of her own body seemed to confirm this. Her husband, Charles, however, tried to find out all he could about her disease and whether there were any treatments that could help, even at this desperate stage. He telephoned and faxed doctors and institutions all over the world, and information poured in.

In *A View from the Front Line* Maggie described this period as especially difficult. She had reached a degree of serenity in which her mind had released its passionate attachment to life and was accepting the ebbing away of her body. She found herself reluctant to give up this relative and precarious tranquillity in favour of a confusion of treatment options with only a very dubious outcome. They had specifically been advised not to make these last months harder by vain attempts to prolong her life. On the other hand she had two teenage children, John and Lily. It seemed worth anything to try to gain extra time with them at such a crucial point in their lives. They heard of a trial for advanced metastatic breast cancer run by Dr Robert Leonard at the Western General Hospital in Edinburgh and they decided to fight.

It was during this defining period that she began to realise several key things which were to lead to the formulation of the Edinburgh Cancer Caring Centre of which she was the inspiration.

First and foremost, she saw in herself, despite her initial fears, how much better she felt when she began to take an active role in her own treatment. She came to believe that this quite deliberate move from passive victim to active participant was the single most important step she took in dealing with her illness. She was living, even if she was dying (as indeed we all are). Being alive means doing, as well as being done to, engaging and enjoying, as well as enduring.

Secondly, she saw that the profusion of alternative and complementary choices available to anybody who wants to take an active role in their own treatment, far from being a help, as she points out, actually feels like assault by information, without an authoritative person to help you negotiate it. There was no one place or one person to turn to. Each person with cancer has to find their own way along the precarious path of their illness, but they do need both information and reliable guidance.

Between June and August 1993, Maggie had continuous induction chemotherapy via pump and Hickman line at the Western General Hospital. During that time she talked incessantly to her medical team – her oncologist, Robert Leonard, her surgeon, Mike Dixon, and her oncology nurse, Laura Lee – about fulfilling what she felt were imperative needs for cancer patients, which could not be met solely by orthodox medical treatment. However good the treatment is, there is very little hospital time for the mental stress that comes with cancer, and that can be as hard to bear as the illness itself. Mike Dixon was so interested that he asked her to write a patient's perspective on the impact of diagnosis and recurrence, and on orthodox and complementary treatments, for a medical journal *The Breast* of which he was the Senior Editor. *A View from the Front Line* was Maggie's response.

It was written in 1994, during the eighteen month remission from the disease that she won with high-dose chemotherapy and stem- cell replacement. It describes, simply and lucidly, what it is like to be diagnosed with cancer and to cope with it. It also begins to explore ways of 'helping yourself'.

She describes the conventional and not so conventional treatments she explored. She was interested in diet, nutrition, nutritional supplements and boosting the immune system. These were her own ways of helping herself – she was not suggesting that everybody should do what she did. She did

believe that everybody could benefit from doing something for themselves and that they were likely to need help in finding the best way to do it. A good deal of Maggie's recovered energy went into crystallising her thoughts on what kind of help she and other people with cancer needed.

At first she had in mind a modest introductory hand-book called *Empowering the Patient*. She soon came to feel that yet another piece of text was not enough. What she and others needed was a welcoming place near the hospital, with an office and a library. The plan for 'Maggie's Centre' began to emerge. She looked into what little cancer-support provision there was in the UK. Accompanying her husband to Los Angeles where he was a visiting professor, she looked at the rather better services on offer in the US. She was particularly impressed by the Wellness Foundation in Santa Monica, and Harold Benjamin's model there served as a catalyst in the formation of her own ideas. Reinforced with what was by now a much clearer picture of the kind of place she had in mind, she persuaded the hospital administration at the Western General Hospital that they both needed and wanted a cancer caring centre.

In February 1995 an Edinburgh architect, Richard Murphy, was asked to produce a plan for converting a small stable building within the hospital grounds into a flexible space from which the centre could operate.

By April 1995 she knew that the cancer had come back again, for the third time. She set about her cancer caring centre with redoubled determination, knowing that this time she really did not have long to live. By May she had written a 'Blueprint' for the centre. It would offer information, psychological support, advice on nutrition, exercise and relaxation therapies. Each person visiting the centre would be helped to find his or her own best way of coping with the disease. There was to be no 'right way'. The centre was to be a haven, where the range of use would extend from a cup of tea you could make yourself in a friendly kitchen to attending weekly support groups led by a clinical psychologist.

She died on 8 July 1995, a year before the first Maggie's Centre was built, but she had done all the necessary groundwork for it, including putting in place much of the financing of the original building project. Her husband generously carried out her intentions after she died.

The cancer caring centre she imagined and planned, called 'Maggie's

Centre' for her, now thrives in the grounds of the Western General Hospital. A description of it follows Maggie's account of her diagnosis and illness, which was the crucible out of which the project was forged.

People who read her vivid account of her battle 'in the front line' and who come into the centre, full of warmth and life, and with such a strong sense of a particular personality to it, often feel curious about Maggie, whose presence seems such a part of it. Who was she?

Maggie was the only child of John and Clare Keswick. Her father's family was Scottish, and had a long tradition of trading in the Far East, and especially in China. Her mother's family was English, and Catholic. Maggie was born in Scotland on 10 October 1941 and during her childhood she travelled backwards and forwards between Shanghai, Hong Kong and Dumfriesshire, as Chinese revolutionary fortunes and the demands of her own safety dictated. There were long periods of separation from her parents, and she must often have been lonely. Nevertheless, she flourished on the long tap-roots she established in the two cultures she had grown up in, and in her mother's faith, Catholicism.

She grew up to be a vibrant and intelligent woman who made an unforgettable impression on anybody who met her. Fleet of foot, as if there were never enough time for all the things she wanted to see or do, she had an immense curiosity about everything and everybody she came across. She delighted in exploring new frontiers. She went to Oxford University, had a brief spell teaching at a convent school and then, with a friend opened one of the first boutiques in London, 'Annacat'. Having cut her design teeth on clothes, Maggie moved on. She joined the Architectural Association as a student where she met Charles Jencks, the designer and writer, whom she subsequently married. They had two children, John and Lily, for whom, when she became ill, Maggie fought her hardest to live. Maggie and Charles formed a highly creative partnership. They travelled exhaustively, looking at buildings old and new, meeting architects, academics and friends, giving lectures, going to conference and always, everywhere, talking and discussing, arguing and laughing. They embarked on ambitious schematic conversions of houses and gardens in Scotland, London and the US, of which the culmination is a large and astonishing landscape project in Dumfriesshire. Maggie designed an intricate system of lakes and causeways which disappear into the horizon. With the earth dug out from the lakes Charles designed a 55-foot double helix shaped turf mountain and a

winding snake rampart that curls around the lakes and into the distance. In a complete break with the English tradition of romantic landscape, these shapes are uncompromisingly man-made, closer in spirit to Neolithic tumuli than to Capability Brown or Repton.

Maggie's ideas about gardening were profoundly influenced by her love of Chinese landscape gardening and its philosophy. She had walked in many of these gardens with her father: the Imperial Gardens in Peking, the gardens of the literati in Suchow, and the great borrowed landscape valley gardens of the Imperial summer retreat in Jehol. Charles persuaded her that she should write about them. What she came up with was a scholar's classic on the subject, *The Chinese Garden*, which was published in 1978.

She describes Chinese gardens as cosmic diagrams, revealing a profound and ancient view of the world, and of man's place in it. She sees and writes about them as the background for a civilisation, for in them China's great artists, philosophers and poets wrote and worked. Her knowledge was such and she told her story so well that she was soon greatly in demand as a lecturer. She gave memorable lectures all over the world and she was consulted on the design of a Chinese garden at the Metropolitan Museum in New York and Dr Sun Yat-Sen's Classical Chinese Garden in Vancouver.

Though, like all the best writing, *The Chinese Garden* reads so lucidly and easily, Maggie struggled in mute misery against many a deadline for other things she wrote, such as the introduction to *The Craft of Gardens* by Ming Dynasty landscape designer, Jo Cheung. There were besides, always other parts of her life which needed her considerable energies and to which she could quite justifiably divert her attentions.

Her father had set up substantial charitable trusts in Scotland, and Maggie was very much involved in them. Under her guidance the Dumfriesshire trust initiated and supported projects to help young people deal with social problems in an area of frighteningly high unemployment. She worked particularly hard on a project to set up the first independent hospice in Hong Kong. Looking back one can see a consistent theme running through all the areas she became involved in. In each case, she was interested in exploring new ways to help people find their own way of helping themselves. She liked the idea of pilot projects. If these were a success they would be followed up and stand on their own feet. Meanwhile she would be planning the next project. Her considerable experience in these areas

was to stand her in good stead when she was working on her ideas for the cancer caring centre in Edinburgh. She was to need all her clear thinking and powers of persuasion to launch this particular little project on its way.

Family, friends, work, to all these aspects of her life, Maggie brought her huge appetite for living, and what seemed like a boundless energy. She loved life, and she lived it to the full, hectic but happy, on as many simultaneous fronts as possible. Cancer, first in 1988, then in 1993 and finally in April 1995 threatened to overwhelm her, but she was determined not to let it do so. She knew all too well how easily 'the joy of living could be lost in the fear of dying', but she managed to hang on to her joy, to the end. A performance of Simon Bocanegra delighted her, three days before she died. She sat bolt upright on her bed to describe it with as much passion as ever, eyes flashing, hands shaping the air for extra emphasis. The day before she died we sat outside in her garden, on a rare warm June afternoon. Face tilted up to the sun, she said, and meant it, 'aren't we lucky?'

*You ask me why I dwell in the green mountains;
I smile and make no reply for my heart is free of care.
As the peach blossom which flows downstream
and is gone into the unknown,
I have a world apart that is not among men.*



A View From The Front Line

by Maggie Keswick Jencks

Diagnosis

A diagnosis of cancer hits you like a punch in the stomach. Other diseases may be just as life-threatening, but most patients know nothing about them. Everyone, however, knows that cancer means pain, horrible treatments and – though no longer quite the unmentionable ‘Big C’ of twenty-five years ago – early death.

Cancer does kill of course – but fear, compounded by ignorance and false knowledge – is a paralysing attack in its own right. The myth of cancer kills as surely as the tumours.

I am a sanguine character and for forty-eight years my life was exceptionally easy – so easy that for me breast cancer seemed almost like a payment of dues. After lumpectomy, a further incision to the margins and finally mastectomy, I decided against having an implant because it seemed false to pretend it hadn’t happened. I also didn’t like the idea of a silicone sac sewn into my body for appearance’s sake: since it couldn’t have any feeling in it, what was the real point? And perhaps I was also relieved (and here I am conscious of how lucky I am in my marriage) to find I could survive amputation and not feel diminished: my Amazon chest is a battle scar, an affirmation.

I was amazed and touched by how much my friends and family minded about my having cancer. Recovering from surgery and radiation I was cushioned in love and thoughtfulness, and the moments I had of panic, though violent, were brief: thousands of women have primary breast cancer, are treated, and that’s it. My cancer, on the inside of the breast, was an aggressive type, but none of the lymph nodes under my arm showed any malignancy.

I had six weeks of radiotherapy, then took Tamoxifen for two year. There were no side effects.

Metastases

It took five years to return. I had put cancer so far behind me I didn't recognise it. The pain in my back, which sometimes, when I was alone, reduced me to sobs, felt much like an old herniated disc playing on my sciatic nerve. The increasing exhaustion was presumably due to pain, with maybe a bit of anaemia? or menopause? My doctor did a few blood tests, they showed nothing special. I asked for a CAT scan; there was a question over whether some speckles up and down the spine needed watching. I was told to return in six months. I accepted that. Such is denial, such is ignorance.

It helped us later to be told by an American oncologist, that an earlier diagnosis of metastases would have made little difference; 'If only...' is a lousy thought to deal with.

Eventually, in Scotland with my mother, I felt so ill we took my temperature. It was 103.5. The cancer had spread to my liver, bone and bone marrow. A compassionate local consultant who saw me told my husband not to haul me round the world looking for treatments, since we could gain no more than a brief extension of life with increasing loss of quality. How long have we got? The average is three to four months ('and I'm so sorry, dear, but could we move you to the corridor? We have so many patients waiting...').

Treatment

However, through our local hospital's weekly cancer clinic we also heard about a trial in advanced metastatic breast cancer run by Dr Bob Leonard at the Western General Hospital in Edinburgh. I fitted the criteria for treatment with high-dose chemotherapy and stem-cell replacement. Dr Bill Peters at Duke University, North Carolina, had already treated several hundred patients with a similar regime and the average length of remission for his patients after treatment was then eighteen months. It seemed like a lifetime.

The preliminary three-month course specified weekly Adriamycin and continuous 5FU via a Hickman line. My cancer proved chemo-sensitive. But, strangely, I found that the process of deterioration which my body had now begun had also affected how I thought about death: in running down, my body had in some way prepared my mind to accept the ending

of my life. Eventually, the most difficult thing was deciding to give up the certainty of death for the uncertain prospect of a stay of execution: if I got into fighting mode, and it failed, would I ever get back again to this precariously balanced acceptance?

Conventional and unconventional alternatives

My husband read and rang everything and everybody who knew about breast cancer, in America, in Britain, in France and in Germany. I found this quite exhausting but also that it was necessary to him as his way of dealing with my illness. Friends rang us with news of remissions achieved by the administration of shark cartilage, carnivorous plant extracts, laying on of hands, hydrotherapy, diet, regimes of pills, oxidation. In his extremely well-balanced book *Choices In Healing*, Michael Lerner likens cancer to a parachute jump, without a map, behind enemy lines. There you are, the future patient, quietly progressing with other passengers towards a distant destination when, astonishingly, (Why me?) a large hole opens in the floor next to you. People in white coats appear, help you into a parachute and – no time to think – *out you go. Aaaiiiieeee!*

If you're lucky the parachute opens. You descend. You hit the ground. You crawl upright. You are surrounded by a thick fog through which a crowd of dimly discernable figures call and gesture 'Here! This way!'. But where is the enemy? *What* is the enemy? What is it up to? Is it here, behind this bush? Over there? Near? Far? And which way is home? No road. No compass. No map. No training. Is there something you should know and don't?

The white coats are far, far away, strapping others into their parachutes. Occasionally they wave but, even if you ask them, *they don't know the answers*. They are up there in the Jumbo, involved with parachutes, not map-making.

It is true that recently some of the parachute-makers have been asking new questions which my revolutionise the process: monoclonal antibodies; oncogenes; vaccines; DNA – all this research may lead us someday to a cure or cures, or at least delays and surer remissions. But can you promise me the magic parachute in a year? In two? In five?

Meantime I am down here in the war zone, trying to figure out my map.

Responsible doctors are rightly fearful of charlatans preying on vulnerable patients, but intelligent patients start reading and soon realise that the track record in orthodox treatments in most cancers is itself not altogether reassuring, and the Scientific Method not as disinterested as it likes to suppose: it is legitimate to feel that a sum of various supports to the recommended therapy may boost one's chances. But how is the patient – utterly unequipped to deal with this barrage of suggestions and faced with doctors who, at worst are downright anti any additional therapies and, at best supportive but sceptical – to proceed?

Guerrilla warfare

In *Bully For Brontosaurus* the scientist Stephen Jay Gould described the rare cancer, abdominal mesothelioma, he developed in his thirties. The scientific literature at the time described it as incurable, with a median mortality of eight months after diagnosis. Reading this soon after surgery he sat, stunned, for fifteen minutes. Then, into his mind came a great and stately procession of Bahamian land-snails – with whose small-scale evolution, treated quantitatively, he had been working for some year. 'I am convinced,' he wrote, that this 'played a major role in saving my life', for the knowledge of statistics he had acquired from the snails allowed him to realise that *median* does not have to mean *me*. 'Knowledge' he wrote, 'is indeed power, as Francis Bacon proclaimed'.

Counting up the reasons why he was unlikely to be at the high point of the statistical curve he stopped panicking: his chances, as a young, well-educated scientist with a strong will to live, were much better than the median. Mentally he began to push himself down the bell-curve and along into the tail. With a new warmth towards snails, we too set out to educate ourselves in cancer, and to see if there were complementary therapies – I thought of them as guerrilla tactics supporting the parachute jump – that might do the same for me.

Dealing with stress

The diagnosis had been as hard on my family as it was for me. For oneself it is possible to accept anything; not so for those one loves. Seeing the suffering of my husband, mother and teenage children affected me physically. At one time I could not sit, or lie, or stand, listen or speak coherently because my shattered mind vibrated so violently through my body I felt I might disintegrate. Later, yoga helped me re-establish some

equanimity. Counselling helped me think more calmly about my children's future.

Nutrition

The area, however, that sprang first to my mind as we looked for ways to encourage remission, was diet. If you ask your oncologist, 'What should I eat?', ninety-nine per cent will answer 'Whatever you like! Eat well, keep up your weight!' because they know the awful effect of cachexia. In America the Gerson experience scuppered nutritional therapies for cancer for more than twenty years; diet became 'alternative' and 'unproven' rather than 'complementary'. In Britain some medical professionals grew wary as a few stories circulated of anorexically thin patients obsessed with avoiding many categories of food, under the influence, so it was said, of the Penny Brohn Cancer Center's original – but now carefully reassessed – diet programme.

In our own experience, the husband of a cousin had died of a perfectly curable cancer while trusting exclusively to a macrobiotic diet; in the end, it seemed, dying sooner of malnutrition than he would have of the cancer he so feared. A woman friend died quickly of cancer because, too frightened of the treatments suggested by her doctors, she turned exclusively to diet as a cure.

My current remission is due to extremely powerful chemotherapy; without it I would certainly not be writing this now – so I am not for nutritional therapies on their own. But equally it makes no sense to me to be told that, while a diet restricted in fat, salt, and sugar and strong on fruits, fibre and vegetables is widely accepted as cancer *preventative*, once you actually *have* cancer you should be eating anything, everything, you fancy – fat, sugar, barbeques – anything!

In the months before my metastatic diagnosis I developed crazy cravings for sugar, chocolate (which I had never much liked before), and cakes and biscuits of all kinds. My skin also got drier and drier, till getting into a bath was impossible because I prickled all over as if rolling in a nest of hedgehogs. No creams or potions made the slightest difference. Since I gave up all sugar, anything to do with hoofed animals, salt and the known carcinogens like smoked-cured foods, I have settled into a comfortable weight of around nine stone (somewhat higher than my weight at 40), all these nasty symptoms have disappeared and I feel terrific. I am perfectly

aware that the scientifically trained physician may respond: ‘But that has nothing to do with it! You feel terrific simply because your chemotherapy worked, and you’re in remission!’ But I believe I feel better than I have for years – from long before the cancer could have affected me – and that nutrition has been a major factor in this.

However, had someone *told* me to follow such a diet, I would have been appalled. (Life with such miserable meals! You must be joking!) I am not a natural vegetarian. I adore meat – roast lamb for Sunday lunch is my idea of caviar with trumpets; roast beef with yorkshire pudding makes my heart sing. I love dripping, brains, and kidneys, liver and bacon, pork crackling, sausages, croissants, unpasteurised brie, mayonnaise, French sauces, double cream, sponge cakes and black ginger cake lathered with butter. I don’t miss any of them.

Carolyn Katzin MS, a Los Angeles-based adviser on nutrition to the American Cancer Society, advises cancer patients ‘ideally, to restrict the intake of *all* fats to three tablespoons a day (including salad dressings, oil for stir-frying and other below-conscious-level fats) and eat the recommended minimum of five servings of fruit and vegetables daily – but,’ she stresses, ‘don’t get frantic about food. Follow these guidelines eighty per cent of the time – and twenty per cent indulge a little.’ That was a life-line. At home we eat a cancer-discouraging diet and – tens of vegetarian cookbooks later – our food is delicious. But we continue to go out to restaurants, to travel abroad and to eat with friends without panicking. If you know you can indulge it’s remarkably easy to do so only moderately.

A lot more work needs to be – and is now beginning to be – done on the effects of nutrition on cancer, but, as Michael Lerner points out, there is, in fact, more in the existing scientific literature – albeit somewhat obscured and un-coordinated – than most doctors realise. Until we know more, no responsible doctor should brush off a patient’s inquiry about food with an unqualified ‘there is no evidence linking nutritional therapies to cancer cures’, without explaining that what he means is an *absence* of scientific study, not a *negative* assessment based on fact.

Perhaps even more important than the actual effect of dietary restriction is that this is an area where patients can most easily take control of something tangible they can do for themselves.

Even supposing nutrition makes no difference to mortality or quality of life, helping an interested patient to take charge of such an important aspect of their lives has powerful psychological implications.

Supplements

To my diet I added some homeopathic drops and megadoses (way over RDA levels) of vitamins A, C and E, selenium, chromium, potassium, and digestive enzymes to maximise absorption of nutrients. For a month I also took weekly injections to boost the thymus (thought by several alternative cancer physicians to be affected by cancer) until it was over-boosted and I developed a violently itchy reaction. I have no idea whether they helped me or not.

Supplements are controversial even among complementary practitioners. Some think it simply a waste of money, others that real harm could result. Michael Lerner warns that research on rats fed with vitamin B12 showed powerful liver tumour *enhancement* and zinc has been shown both to retard and enhance – probably by its known antagonism to selenium – tumour growth.

Blood-tests or hair analyses for deficiencies is expensive and takes time, but in cancer patients they commonly show an inversion in potassium / sodium levels and lowered zinc and selenium. Notable vitamin A, C and E deficiencies are common in patients undergoing surgery, radio-and chemotherapy. Could these deficiencies not account in part for patients feeling so ill during and after treatment?

More precisely, a study in the *New England Journal Of Medicine* 312: 1060 (1985) showed that sixty-nine per cent of chemotherapy patients who took supplements of 1600 IU dl alphetocopheral acetate (vitamin E) for a week before, and then all through, their treatment with Adriamycin, avoided losing their hair. That seems to me worth trying.

I had not read this at the time, and my hair did fall out. Since I was expecting it, however, I was rather interested to see how it would feel to be a Buddhist nun, and friends gave me a couple of hats in which I felt very cheerful. I got tired, suffered briefly agonising mouth ulcers, and twice missed a week of treatment for low blood counts – but, except for desperate bouts of worry about my family, I felt remarkably well all through, kept up my weight, and slept easily.

Non-Western approaches

Since I grew up in Hong Kong it was natural, when we began the map-making, to think of Chinese medicine. Although it works on principles so different from Western scientific medicine that there is no real dialogue possible between them, most of my Chinese friends find both helpful. I expect the same is true of Indian Ayurvedic therapies. In my case we consulted Dr Li Ting-ming who runs the Institute of Chinese Medicine in London. Trained in Edinburgh in Western medicine, in Beijing in Chinese herbal medicine, and a cancer survivor herself, she believes powerfully in the part played by the mind in overcoming cancer. She gave me good, stern advice on the importance of the cancer patient's mental attitude, and PSP capsules from a mushroom used therapeutically in China for at least two thousand years. Recently subjected to trials in Hong Kong and China. PSP has proven value in minimising the side-effects of chemotherapy and radiation, and in preventing weight loss. Its problem is that, as the mushroom exists only in remote mountains in the wild, the capsules are prohibitively expensive.

I also began a twenty-minute practice of Qigong exercise (which I still do) every morning before breakfast, and weekly sessions of reflexology. At first my feet were as if dead – I could feel almost nothing. Gradually, as I had more treatments, they began to reawaken. The sessions were both relaxing at the time, and energy boosting afterwards. Reflexology and aromatherapy are probably the most widely-practiced support therapies for cancer patients in Britain. We found that many nurses had taken courses in them to add to what they could freely offer their patients. In America, reflexology is almost unknown, but acupressure and acupuncture for pain relief are widely praised and practiced.

Hospitalisation

In hospital for the stem-cell replacement I did unusually well until hit by an internal infection (it turned out to be pneumonia) which knocked me out for some weeks. I lost – partly because of the revolting hospital food – about 33 lbs (two and a half stone). A month later I had a painful second bout of pneumonia. When eventually I flew to Los Angeles where my husband was providentially teaching – I was weak enough to need a wheel chair. I added still higher doses of vitamins. Within three weeks, on my diet, Megace, these supplements, and in the California sunshine, I was bicycling up the beach.

Boosting the immune system

About this time we also heard about an immune-boosting ‘soup’. Developed by a Chinese bio-chemist at Yale, Dr Alexander Sun, for his mother, sent home to die with stage IV large cell adenocarcinoma of the lung. The soup appeared to have arrested her disease: six years after her ‘final’ diagnosis she is alive and tumour-free in New York. Other patients, and a small trial with thirteen participants in Czechoslovakia have shown good results in a variety of different cancers, some with metastases in the adrenal gland, bone or brain. It seemed worth a try. I began taking a tub of Sun Farm Vegetable Soup every morning for breakfast. By the time we got back to Britain three months later, I had so much energy I needed tethering to the bed.

Just before discovering the soup, we decided to take an AMAS – Antimalignin Antibody in Serum – test developed by Oncolab in Boston, to monitor any malignancy still active after my treatment.

In sera sent across the country the false negatives are seven per cent and the false positives five per cent: one out of the three markers in my results showed active malignancy, at a low but still measurable level.

Six months later when we were in Boston in August, we had the test done again. On blood tested within twenty-four hours of being drawn, AMAS is ninety-nine per cent accurate. All three markers were now negative.

I realise this may be due to a delayed effect of the chemotherapy or a build-up in hormone therapy, (Megace at first, and presently - since at the moment I currently prefer spots and hot flushes to fat – Tamoxifen). But it could also be the soup. The energy – which I still find remarkable remembering my total exhaustion after treatment – I believe is due to the supplements and reflexology as well as the remission itself.

Cancer and the mind

Since then I have become more consciously interested in the part played by the mind in cancer remission. Stephen Jay Gould, writing from experience and what he calls ‘my old-style material perspective,’ is strong on the idea that attitude matters in fighting cancer, suspecting that mental states may feed back upon the immune system. The two best books I have found on

cancer agree: Michael Lerner, from the perspective of a knowledgeable and experienced cancer-carer, and the Australian cancer survivor Ian Gawlor (*You Can Conquer Cancer*, Hill Of Content publishers, Melbourne, Australia) both place the sufferer's mental state at the heart of successful outcomes.

Above all they emphasise the importance of the patient's own involvement with their treatment, something born out by Bernie Siegel and the Simontons' findings, that 'difficult' patients do better than passive ones. By now most cancer professional must be aware of the psychiatrist David Spiegel's discovery (so surprising to himself) that, among his breast cancer patients at Stanford University, those who took part in group therapy lived some eighteen months longer than those who did not. Although not yet duplicated in other trials, from down here on the battlefield the results look pretty interesting. In California I went to a weekly group and found it reassuring. I like the exchange of information, the concern that quickly grew for each member, the mutual support. Yoga, Qigong and guided relaxation all helped me during my treatment, but since then I have also spent ten days at a retreat learning Vipassana meditation, a technique that, by passing the mind continuously down and up the body while observing dispassionately all its sensations – 'as they are, not as you would like them to be' – can bring the practitioner into a remarkably positive and relaxed state of equanimity. Though not very experienced and a hopelessly intermittent practitioner, I have found it greatly helps my confidence: when hit by fear or despondency, I have something to fall back on.

Improving the system

What might one gather from all this, a single experience, not yet concluded? Some things are certain, others may be pointers to how better care – and I believe, better outcomes – might be offered to the patient.

Firstly, no patient should be asked, however kindly and however overworked the hospital staff, to sit in a corridor without further inquiry, immediately after hearing they have an estimated three to four months left to live. But even after the less devastating diagnosis of primary breast cancer, most people need adjustment time before going home to do the washing up. Doctors need better training in how to break bad news. However bad the prognosis, it will still help the patient to know that the median may not be the message. And, given the real, well-validated

phenomenon of spontaneous remissions in cancer, telling it as it is should never cut the patient off without leaving a chink of hope and some area of manoeuvre.

Waiting areas could finish you off

In general hospitals are not patient-friendly. Illness shrinks the patient's confidence, and arriving for the first time at a huge NHS hospital is often a time of unnecessary anxiety. Simply finding your way around is exhausting. The NHS is obsessed with cutting waiting time – but waiting in itself is not so bad – it's the circumstances in which you have to wait that count. Overhead (sometimes even neon) lighting, interior spaces with no views out and miserable seating against the walls all contribute to extreme mental and physical enervation. Patients who arrive relatively hopeful soon start to wilt.

Waiting time could be used positively. Sitting in a pleasant, but by no means expensive room, with thoughtful lighting, a view out to trees, birds and sky, and chairs and sofas arranged in various groupings could be an opportunity for patients to relax and talk, away from home cares. An old-fashioned ladies' room - *not* a partitioned toilet in a row – with its own hand basin and a proper door in a door frame – supplies privacy for crying, water for washing the face, and a mirror for getting ready to deal with the world outside again. There could be a tea and coffee machine (including herb teas) for while you're waiting, and a small cancer library, as well as BACKUP and other leaflets, for those who want to learn more about their disease. More ambitiously there could be a TV with a small library of cancer-informing tapes and, to cheer you up, a video laughter library. Norman Cousins' book, *Anatomy of an Illness*, makes a good case for laughter not only as escape but as a therapy to relax the patient physically, leading to less pain and better sleep.

At the moment most hospital environments say to the patient, in effect: 'How you feel is unimportant. You are not of value. Fit in with us, not us with you'. With very little effort and money this could be changed to something like: 'Welcome! And don't worry. We are here to reassure you, and your treatment will be good and helpful to you'. Why shouldn't the patient look forward to a day at the hospital?

Information eases fear

Mentally, a simple information pack with, (especially if treatment is to be in a large NHS hospital), a hospital plan, plus, say, the names of the doctors and specialist nurse, the telephone numbers and a friendly introduction to BACKUP, Macmillan Cancer Link, and other support organisations, including local self-help groups would help a lot. So would the addition of a simple sheet, (with space to write the answers, and a pencil) called 'Questions you may like to ask your doctor,' – not just for the information itself, but because the act of a nurse or carer giving me this would have indicated a support-system out there, ready to help. Feeling alone, as if set adrift in a leaky boat on a violent and hostile sea, numbs the mind and lets in despair.

But it would have been helpful practically too. Few patients hear anything much the doctor says after the word 'cancer'. Nor do the family or friends who have come with them for support. The next doctor's appointment may be a week or more away and meanwhile ignorance breeds fear. Information is what most cancer patients cry for – at many different levels. A guide to some questions you might want to ask your doctor could liberate those who are too timid, too conscious of taking the doctor's time or too fearful of the answers to ask, and indicate an openness on the physician's part to let the patient participate actively in their own treatment.

Every individual makes their own map, but cancer is exhausting. Even telephoning BACKUP for the first time maybe too much both emotionally and physically. Finding complementary therapy, even supposing you have the money to pay for it, is usually pretty random – via a friend who heard that such and such or so and so helped someone known to a friend of theirs – and an overview of what other patients have found helpful (and where it's available locally) would give patients a chance to weigh more easily the merits of these different possibilities for themselves.

Even better would be if their doctors themselves could, as the homeopathic physician George Lewith suggested in 9 July 1994 issue of the BMJ, 'learn the language of (complementary therapies such as) acupuncture and nutritional medicine, (so that) they have a much larger breadth of medical models through which to approach a patient' – and through which to enter into a dialogue with the patient on how to proceed, together. We need our doctors to take an intelligent interest, and have some understanding of, the

complementary therapies we may be drawn to.

Obviously a great deal more research needs to be done on nutrition and supplements in cancer care. My hunch, based not only on my, but other patients' experience, is that actively improving diet and rectifying deficiencies caused in part by cancer treatments, definitely improves the patient's well being. Trials on high-dose supplementation would seem to me a high priority.

Empowering the patient

Above all what matters is not to lose the joy of living in the fear of dying. Involvement in ones own treatment is a empowering weapon in this battle. I believe it will be proved in time to make a difference in mortality, but meantime there is a reasonable body of evidence to suggest that patients who eat healthily, keep active and take steps to deal with stress and fear, feel fewer symptoms and less pain even in the final stages of their disease. At a complementary cancer care conference at Hammersmith hospital, a young girl spoke of how her mother had continued aerobic and dance classes to within a few weeks of her death, delighting in remaining fit and virtually pain-free – 'She was,' said her daughter with real happiness and pride, 'so well when she died'.

I have no deep illusions of long survival. My chemo-remission, if I perform according to the median, is likely to end in about six months. As the surgeon who put in my Hickman line reminded me, early warning of further metastatic activity is not known to prolong survival. But if the next AMAS test shows positive again and the map we've made so far no longer works, there are still other things to try – and most of them work maybe twenty percent of the time. Choosing the less expensive (no point in bankrupting my family), those that least disrupt how we want to live, and as many of them as possible , I mean to keep on marching, down the tail of the statistical curve and on, into the sunset, and then, when eventually I must die, to die as well as possible.



Maggie's Centres: Marching On

by Marcia Blakenham

The first Maggie's Centre, at the Western General Hospital in Edinburgh opened in 1996, just 100 yards from the oncology department.

At first glance it looks reassuringly familiar, a small rectangular stone stable-block with a pitched roof. Then you look again: what is going on here? People wondering whether to come over can easily recognise and identify with the small scale and shape of the building. On the other hand the big windows and bright colour of Richard Murphy's vibrant conversion are completely unexpected and create a curiosity about what is going on inside. It gives visitors a taste of what they will find when they do venture in.

Maggie's Centres are places where people feel at home and cared for. At the same time, the lively imaginative atmosphere encourages people to dare to explore, and stimulates them to want to do so. The aim is clear. The object is to encourage people who feel frightened and anxious about coping with cancer to feel better by developing their sense of confidence and resourcefulness. What they discover at a Maggie's Centre may help them put a different perspective on what is happening to them and make a profound difference to their experience of living with cancer.

Richard Murphy has designed an environment for the Edinburgh Centre which helps achieve this. The building is full of zest and life and colour. Light floods in from a ridge roof-light. The interior space is flexible, with dividing sliding doors. From the large entrance space it is possible to understand what is going on in all the other areas of the building. There are no intimidating closed doors with specific labels on them. As one visitor noted 'the bright modern building is as informal as a private home. Nobody is obviously in charge, nor is anyone too busy to greet a recent arrival or hear the latest news. The atmosphere is hard to pin down, but it is far more coffee morning than cancer ward'.

The original intention was just to build this one small haven where cancer

patients at the Western General could help themselves get back on their feet. However, almost as soon as the doors opened, Maggie's was asked to provide similar places for other cancer hospitals across Scotland, England and Wales. It met such an obvious need. Hospitals are stretched to their limits. Doctors want to be able to give their patients more time. They like their patients to be well informed, and to be able to participate in their treatment options. They know that most people who hear the word 'cancer' for the first time freeze and take in very little else of what their doctor is saying. They know that when it comes to helping people cope with the impact of having cancer, they and the hospital environment are part of the problem and not the solution.

They need partners outside the medical hierarchy to help their patients get the best out of their medical treatment and tackle the major upheaval in their normal lives.

The initiative for new Maggie's Centres comes principally from doctors and consultants who have seen how important this synchronization of medical care and support is, and how well it works at a hospital which has a Maggie's Centre operating nearby.

Maggie's was asked to provide a centre at the Western Infirmary in Glasgow. Page and Park undertook an intricate conversion of a Grade II listed gate house at the entrance to the hospital. The little red brick tower at the centre of the building now acts as a light-well. They have slotted a horizontal cube onto the side with a large window looking straight into the trees of Kelvingrove Park.

Ninewells Hospital in Dundee offered a wonderful site on the edge of the hospital grounds opposite the oncology unit, looking out over the river Tay. We didn't know how much we were asking of him, when we suggested to Maggie's friend Frank Gehry, that he might design the Dundee Centre pro bono. Frank, like the wonderful man that he is, did not hesitate. He loved Maggie. He will only take on a project if he believes in the client, and Maggie was still his client even though she was no longer there. He made a dizzying series of models each one more exciting than the last before metaphorically throwing them all in the bin. He said that he had a dream in which Maggie chastised him for being too fancy. She, and the people who would be using it, wanted something much simpler. The main block of the little white rendered building with its' small watch-tower could,

just about, be another Scottish croft. What makes it dance is the pleated aluminium roof which gives it a joyous wackiness and reflects the sky.

He is now designing the first Maggie's Centre outside the UK, which will be built in Hong Kong.

What Richard Murphy, David Page and Frank Gehry proved to us beyond any doubt is that place and space do make a considerable difference to how people feel. An imaginative environment is liberating. The purpose of Maggie's is to help people who are feeling as if they have been kicked in the stomach by a cancer diagnosis get on with their lives again. The buildings set the scene for them to do just that.

A building has done a good job if it even lifts your spirits for a brief moment. If it creates spaces which make it easier to be with other people, by creating a comfortable balance between public and private, which make you feel safe but at the same time stimulate your imagination without you even noticing that such a thing is going on, then it has done even more.

The Maggie's architectural brief is a demanding one. We have learned to be more ambitious about what we ask for. We want more than functional spaces. A building which has quality makes you feel valued. We believe that kindling curiosity and imagination is fundamental to feeling alive, and we want this spirit embodied in our centres. We choose architects who have the imagination, the confidence, the ability and the understanding to respond to such a brief.

Page and Park designed another building for Maggie's, at Raigmore Hospital, in Inverness, this time a new-build. David Page, and Charles Jencks as landscape architect, worked on an unusual scheme in which building and landscape share a symbiotic relationship. Charles' landscape forms twist in to David Pages' interior spaces making a single entity of the inside and outside, giving an unmistakable footprint to the project, which sits in front of a vast horizontal wilderness of hospital buildings and car parks.

Zaha Hadid, who designed the Maggie's Centre at Fife, has given us a building which seems to erupt out of the car park. The pyramidal / dart-like shapes of her folded angular building appear to be clad in a dark sparkling asphalt. The building has considerable presence. It is perched on

the edge of it's own oasis, a bowl of trees. You walk in to a surprise. The long glass wall-window which faces you looks straight out into a green wilderness. You catch glimpses of more sky and trees through the triangular openings which stud the wrapping walls as you sit at the kitchen table.

I hope a theme is coming through about these buildings... each is original, surprising, full of light and the atmosphere which they create inside them is informal and even light hearted.

There is nothing haphazard about this informality. At the heart of Maggie's Centre philosophy is the recognition that each person is 'in charge' of their own disease as they are of their own life. In many cases people will feel immeasurably better, as Maggie did, for becoming an active participant in their treatment. If other people feel more comfortable in a more passive role, nobody at Maggie's Centre will push them to do otherwise. The professionals in the centre listen and if asked, advise and guide, but they do not instruct. There is no single right way of helping yourself and the uses that somebody with cancer will make of the centre will vary enormously. Some will use it as a nice place to pause and rest, others to meet and chat. Others again will want something more specific.

A typical first time user may have cancer or be a friend of, or care for someone with cancer. They may 'drop in' either because they like the look of the place, which they can see from the oncology department of the hospital, or because a nurse or doctor has suggested they might like to do so. Once inside they can take a look, sit down, have a cup of tea, browse through some of the literature, and if they wish to, talk to somebody about whatever they want to. The 'somebody' will be a professional. The atmosphere is friendly and informal, but there is a clear professional structure to the kinds of help on offer.

There are three main components.

The first area in which a Maggie's Centre offers help is in providing useable information. Maggie knew that ignorance fuelled fear and helplessness. She also knew that most people diagnosed with cancer know very little about the disease. All that they are likely to know is that it is potentially life-threatening and that treatments are horrible. She, too, had been overwhelmed by 'information' and by helpful and unhelpful advice. It is difficult to know what questions you want to ask, difficult to know who to

ask and where to go to find answers and difficult to gauge the accuracy and usefulness of the information you do access.

At Maggie's Centres people are helped to find out what they want to know about their illness, and their treatment. They are advised about ways of minimising side-effects, should they arise. They can find out practical information about benefits. There is a lending library, there are videos, there is access to the internet, and there are regular courses to join.

The second approach to helping yourself is a programme of relaxation therapies. Anxiety aggravates physical symptoms. If you are anxious, you are more likely to have sleep problems, to be more sensitive to pain and to be less resilient psychologically. At Maggie's Centre you will have a range of well researched options to choose from, to help you learn to relax. You can book an individual relaxation session or join a t'ai chi or meditation group.

The third approach provides psychological support both individually and also in weekly support groups, which are led by a clinical psychologist. It is all too common for people with cancer to feel vulnerable and painfully alone. Meeting other people in the same predicament helps people who are feeling isolated to see that they have hopes and fears and experience in common. It helps to put problems which may have seemed huge and unique into a shared context and exchange ideas about how to deal with them. It helps to learn, sometimes, that there are things you can laugh about, and that you can offer support to other people as well as be supported by them.

It is crucial to the confidence of anybody using the centres that they should do so knowing that they are not going 'behind the back' of their doctors. Any way that they choose to help themselves at a Maggie's Centre will have the full support and approval of their medical team. The medical team will know that any service offered at a Maggie's Centre will have been approved by a Professional Advisory Board.

A Maggie's Centre is fully independent, both financially and administratively, from its sister hospital, but shares the closest possible links with it. This autonomous relationship with the hospital is important. Maggie was far from being the only person who finds a hospital environment unhelpful to a sense of well-being. She hated the word 'patient'. She saw it as a word with all the connotations of enduring and

suffering which she found least life-affirming. In hospitals people are patients, and hospitals depend on their behaving like patients, otherwise the huge bureaucracies which run them could not operate. A Maggie's Centre is not just another hospital department. It is small and separate enough for the people who use it to identify it as their own place.

If you can reduce your anxiety levels you will feel better. You will also feel pain less severely and be less distressed by any side-effects of medical treatment. This obviously greatly improves your quality of life. Common sense alone tells us this, but it is confirmed by scientific trials. A lot of research now shows that people who can access support over and above their medical treatment enjoy a better quality of life.

Maggie had a strong hunch that these benefits would also eventually be found to improve the outcome of medical treatment - that you would live longer. The medical world is more cautious. There is as yet no conclusive evidence of improved cancer regression or survival following what are called in the jargon 'psycho-social interventions'.

There were two interesting studies, one by Fawzy published in 1993 and one by David Spiegel in 1987, which suggest that it is possible that psycho-social interventions do increase your chances of living longer. Common sense again tells us how powerful a part hope and will-to-live have to play in life. Whilst it would be quite wrong to say 'you will live longer if you can feel less anxious and more positive', it would be equally wrong not to support those who hope that it is true. There is an increased interest in the effect of psycho-social support on illness and cautious optimism even in medical circles. It makes it particularly important that there should be a continuous evaluation of the work that is going on at the centres, both to see which 'interventions' or ways of helping people are most effective, and also to find new ones.

When Maggie died in 1995 Richard Murphy's first set of plans for the conversion of the stable building at the Western General Hospital were on her bed. She had written a blueprint and a constitution for the project, which detailed how it would be run and what it would do. It would be for anybody who wanted help in dealing with cancer: friends and family as well as those who had cancer themselves. Maggie knew how hard it was to be close to, and look after someone with the disease. No financial restraints should stop people from using the centre. All its services would be free of charge.

Her medical team at the Western General Hospital became her champions in the early days of the project. She developed a particularly strong relationship with Laura Lee, who was her oncology nurse. From the very first days when they talked about it Laura caught Maggie's excitement and saw that this was a project, which could make a huge difference to how people lived with cancer. When Maggie died Laura took over the fledgling project. She was the Edinburgh Centre's first programme director, and is now chief executive of the expanding family of Maggie's Centres.

Laura was joined by many people who loved Maggie and believed in her idea. Her husband Charles gave a substantial sum of money which allowed the stable building to be converted and ensured that this first centre should have time to gain its own financial feet. Friends and fellow patients devised schemes to raise more money. A decade on Maggie's Centre in Edinburgh thrives. It has a very personal, loving feel about it. Those who never met Maggie talk about her when they come in. One woman told Laura that she never visits without offering Maggie a silent thank you for the new life that the centre has given her.

There are now five Maggie's Centres up and running, in Edinburgh, Glasgow, Dundee, Inverness and Fife. There are interim Maggie's services running in Oxford, Swansea and in Hong Kong until the new centres there are built. The Richard Rogers Partnership has designed a centre which is under construction at the Charing Cross Hospital in London. Richard Rogers and his partners have been wonderfully generous to Maggie's both in waiving their design fees and in providing a home for the team of people working to expand Maggie's into new areas in the UK. We are enormously grateful to all the architects who have given Maggie's so much. There are campaigns under way for centres in Cheltenham, Nottingham and Newcastle, as well as Swansea and Oxford. Capital and revenue costs have to be found.

The longer term plan is to make sure that anybody with a cancer diagnosis in the UK can access help from a Maggie's Centre wherever their treatment is taking place. It should be a normal adjunct of your medical treatment. Each new centre will share the same core philosophy, of encouraging self-reliance and confidence as the best way of improving wellbeing. It will have the same autonomous relationship with its' sister hospital that Maggie's Centre in Edinburgh shares with the Western General. It is hoped that each new centre will be housed in a building which will foster its users' curiosity

and imagination, at the same time as making them feel comfortable and looked after.

We know that we must stay on our toes as we grow, not get lazy and doze our way in to becoming the very institutional behemoth the first Maggie's Centre was built to get away from. We must be alive to changing needs. How and where people are treated by the NHS changes all the time, and we must be flexible to these changes. Different cultures have very different attitudes to illness. The Charing Cross Hospital in Hammersmith London sees people who speak two hundred different languages, which will set interesting challenges for the Maggie's Centre which will open there later this year.

Many people who come to Maggie's come at a time when the possibility of death has made them look at their lives and ask questions of themselves which they have never faced before. One of the people who works for Maggie's in Edinburgh, says that what inspires him each day is how incredible the people are who walk through the door. People are amazing, and never so much as when they are facing an enormous challenge and feeling at their most vulnerable.

More and more people are walking through the door. More people are living longer with cancer. More people can expect to live longer with cancer. The question is, what kind of lives do they want to live? What can this shocking confrontation with the possibility of death add to their lives?

We know that what makes Maggie's different is a certain atmosphere and 'attitude' shared by those who work for Maggie's, an alertness to other people, and a respect for them, an ability to recognize qualities and strengths in people which they may not recognize in themselves, a desire to grow as people ourselves. Only if we stay alive and passionate are we going to be any use to anybody else. It is a demanding job description but a valid one. It is a privilege to meet people who are courageous enough to come into a Maggie's Centre at such a critical moment in their lives and ask for help. We must meet them with equal honesty and try, at least, to ask as much of ourselves as being 'in the front-line' is asking of them.

If we can live up to such ambitious standards and stay true to this attitude, Maggie's will flourish.

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maggie's

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