A photograph of a pond surrounded by trees with autumn foliage. Several white swans are swimming in the water. The scene is peaceful and natural.

Achieving wellbeing after breast cancer: a survivor's story

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Foreword

If we believe patients are really to be 'at the heart of healthcare', as the Department of Health suggests, their views are vital in helping healthcare professionals to understand the patient's perspective and respond to it.

Patients' stories have been recognized (Patient Voices 2004) as making a significant contribution to understanding and acknowledging the patient's own unique experience of illness. Katherine's own story began as a quest for reconciliation and healing following her diagnosis and treatment for Breast Cancer, but it has become much more than this.

One of the hardest things in life is being able to put your anguish into meaningful words. Katherine has shown me how emotionally and physically painful - yet also rewarding - this challenge can be.

Using reflection and creative writing, Katherine has shown how she has been able to redress information gaps and stimulate dialogue and debate with professionals involved in her care and with herself. As such a professional, reading her personal account has led me to be critically reflective about my own practice and explore how I could apply her reflection to improve the information and care given to other current and prospective patients.

I would encourage patients to write and share their stories. The 'writing' and particularly creative writing can be an important part of the healing process. The story 'sharing' provides a 'humanising' influence on what could otherwise be seen as a clinical process and it supports health care professionals in delivering a service with patients at the heart of it. I recognise that an important element of writing in this way is that the patient engages with an attentive listener and that together we can make better sense of the patient's current and future healthcare needs.

Katherine's story has taught me one thing – that stories can be a persuasive form of communication. We listen to them because they introduce many dimensions to the subject and can interest and entertain: but when and if we listen carefully enough, they can also be powerful tools to (re)educate and inform.

Gail Williams
Oncology Nurse Specialist

Acknowledgements

At a conference held in April 2008, when I was at my lowest point following diagnosis and treatment for breast cancer from October 2006 to August 2007, I went to a workshop on digital story-telling, which demonstrated its value as a form of communication. I feared that my illness had robbed me of my ability to communicate effectively, but this workshop persuaded me to think again. It gave me permission to turn my thoughts, pieces of writing and diary notes into this story.

The 'journey' has involved many skilled and caring people, but I particularly wish to thank Dr. J Abraham, my Oncologist; Gail Williams, my Oncology Nurse Specialist (Breast Care); Sue Jones, my Physiotherapist; Dr Rob Jones, my GP; and Dr Jo Hampson, my consultant counsellor at the Chronic Pain Management Service, Velindre - who have all gone that 'extra mile' and made a difference for me, and have given their permission for me to name them in my writing.

I'm also deeply grateful to friends and relatives – in particular my Aunt Erika whose own cancer journey has been an inspiration to me, my friend Pam Baktis for her consistent support, and for all I learned from Rhiannon Bevan before she died from breast cancer.

I wish to thank all the people who have had sufficient faith in me to allow me to find my own solutions, reach my own conclusions and express my own opinions.

And finally, I would express my huge appreciation to Gail Williams, Mary Mahoney, Pam Baktis and Derith Powell and all those who took such care in contributing information, commenting on drafts, helping to shape my random thoughts into a coherent whole, and making me feel that retracing my steps along this road was worthwhile.

Section A: Introduction

Chapter 1: Introduction

Why I wrote this

This is a record of my experiences in discovering, being diagnosed with and treated for breast cancer, of recovering from treatment and achieving a new quality of life thereafter. I have written it with three distinct purposes.

Firstly, I wanted to make sense of a deeply traumatic experience for myself, my family and friends. This was part of the process of healing and moving on with my life.

Secondly, I thought other people might be helped by reading about a survivor's experiences – something I would have liked to have at the time.

Thirdly, I wanted to provide feedback to practitioners and those who train them, because in many ways I wasn't able to do this at the time and I believe that this could contribute to better future practice.

For myself

A young Carinthian friend told me that you carry your life experiences in your rucksack, but sometimes it gets too heavy. This story is about what is in my rucksack. I wrote it to lighten my load, by clarifying for myself what had happened to me. It helped me to explain this bewildering experience and to show me where I lacked the skills, capacity and information to support my best interests as a patient.

I have written this account in the form of a story because this was a way of keeping my experience of cancer in proportion and within the setting of the rest of my life. This enabled me to explain how I saw my position and how I felt about it. It helped me to feel that I was doing something positive to help myself instead of feeling helpless about my predicament. I was able to use diary extracts, letters, poetry, short writing pieces and pictures to illustrate my level of well-being and to set out some of the tools that I learned particularly through the recovery process. Writing this has not only helped in my healing, but has also given me the resources to address the uncertainties and frustrations of living with the aftermath of cancer treatment. I regularly use the materials in order to address problems, raise my spirits, or motivate me to make the most of each day.

I also wanted to explain to the people closest to me - my family and friends – how I saw my 'cancer journey' and the effect the diagnosis, treatment and recovery processes had had on me without having to provide a separate version for everyone. I wanted them to appreciate that the diagnosis

wasn't the 'death sentence' that they feared and to show them how they could best help me in living a full life. I hoped that they would read the whole story. Those I have given it to have done so in different ways – some methodically reading a little or a lot each day; others dipping into different parts of the story. A few of them have been satisfied with what I have offered them; others have asked for more. Overall, it has been very helpful for my relationships with them, as they better understand me as an entity and are more able to accommodate to my needs.

For other cancer patients and their families

During the time of my diagnosis and treatment, I was desperate to find out about the experiences of other people. A very close friend had recently died of the disease, and although she told me a great deal about her experiences, I constantly wished that I'd paid more attention to and had better remembered her conversations with me. So one of the purposes of creating my own resource was to share it with other people who might want to know more about breast cancer, either because of a diagnosis, a family member or close friend's diagnosis, or in case of a future diagnosis.

Whilst everyone's cancer journey has its unique features, there are common elements – fear, uncertainty and sense of isolation – that are less of a burden when shared. I wanted to communicate some of the pitfalls that I experienced and how I responded to the challenges. I anticipate that this story will be read at different times and in different ways, but would suggest that patients at the start of their journey focus on the earlier sections and the information Appendix, whilst those people progressing beyond treatment may want to read sections C and D.

I have written very little about the effect of the cancer on my family and those close to me, although I acknowledge that my experience has had a profound effect on them too. By explaining the impact on me, this resource has helped them to appreciate that they have done all they can to support me in tackling the physical, psychological and emotional effects of my illness. Sometimes just 'being there' is the only way that you can really help.

For practitioners

I also wanted to offer feedback to practitioners and those who train them. As patients we are often too fearful or too ignorant to have a meaningful dialogue with the people who are trying to help us. As a result we do not ask the questions we really need answered, explain what we need or express our concerns. I believe that this story will be useful in making practitioners aware of the complexities of the cancer journey for many patients and the importance of and barriers to communicating information effectively. It should also provide some insights into why and how communications fail and the challenges of delivering specialist professional practice within what should be a seamless service.

In my writing I make the case for better information. Much of what I have written centres on my information requirements and the shortcomings of 'the system' in addressing them. It is based on my belief that everyone feels better if their information needs are better satisfied – which may mean having no information at all. It is a plea for more appropriately targeted information, available to people when and where they look for it, in a digestible format and media, and for practitioners to better understand why people need information, what they need, when they need it, how they use it, and where they go to find it. In each section I relate my information needs to what appeared to be available at the time.

I also wanted to state the importance of 'patient-centredness,' by which I mean an embracing, seamless service which is focussed on the needs of patients and gives them the support, confidence and encouragement to invest in themselves. This requires both the engagement and involvement of the patient and a clear understanding by practitioners of the holistic needs of the patient. Perhaps this requires more investment than it is realistic to expect in our target-driven world. Nevertheless, a patient centred approach smoothes the path to recovery and subsequent well-being and there is much evidence to demonstrate its value.

I would like to make it plain, however, that the dedication, care, skill, patience, support and sheer kindness of those treating me were the best available at the time and far surpassed what I could have expected. Nothing of what I have to say detracts from my thankfulness to them. I have unashamedly used the advice, skills and knowledge that they have shared with me to create this resource, a source of realistic hope for me, and possibly for others.

How I have written this

My story describes how I achieved my own way of surviving the journey from a cancer diagnosis, through the treatment to where I am now. It draws on diary notes, poetry and writing recorded throughout the journey and is written in the form of a chronicle. Because my account is long and detailed I have divided the text into short chapters within 5 sections each with an introduction, summary and some conclusions. After the information section (E) is an Appendix of useful references.

I have structured this report to reflect the various stages of my life before my initial diagnosis, the nature of my treatment, and what I felt I needed to do firstly to pick myself up from the treatment and then to achieve a quality of life and well-being thereafter. Many of these stages form overlapping strands, which I hope contribute to a coherent whole.

Chapter 2: Life before my cancer diagnosis

About myself

I am very fortunate to have a family that loves me, friends I value, activities that I enjoy, and a way of life that I have been comfortable with. I've had many opportunities, taken up challenges and I have generally enjoyed and appreciated good health and well-being.

I was born in London in 1949, the eldest of five children. When I was young my parents travelled a great deal. By the time I was twenty three I had travelled to all 49 mainland states of America, across Canada, Mexico, most of Europe including the USSR and Eastern bloc, the sub-continent of India and Australia. I was at school in the US when President Kennedy was assassinated, and working in Australia when men first walked on the moon. My family is spread across the world – my parents live mostly in Austria, my twin sister in New Zealand, my brothers live in the US and sub-Saharan Africa and my younger sister in London. Because we were such a scattered family our parents encouraged us to write letters to each other. Writing is a great therapy for me.

My parents were great role models for us, encouraging us to strive to achieve our potential. As a result, we've all taken responsibility for ourselves, family, friends, colleagues, and the wider community - and tried to make a difference where we could. None of us is willing to accept passively what life throws at us. Two events have had a particular impact on me. The first was being part of a working party in Bangladesh in 1973, where after 10 minutes training, I inoculated people against smallpox in the old City of Dakkha as part of the World Health Organisation programme to eradicate the disease – I saw the dignity with which the women eked out their meagre existence, making me realise the triviality of many of our strivings in the West. The second was to discover, after my Grandmother's death in 1968, details of some desperately harrowing experiences; despite these, she never gave up her faith, her belief in the goodness of mankind or the hope of a better future. These things I have carried with me throughout my adult life and they have strengthened my resolve never to give up lightly and to make the best of circumstances.

I came to South Wales to study in 1971, and stayed because I needed to put down roots somewhere. I met my partner, Dick in 1987 and happily took on the role of 'Mum' to his two daughters, Vicky and Kate (then 5 and 3), whom I adore, and who have given me years of happiness and fulfilment. As far as we can, we enjoy a simple life, enjoying the garden and conservatory, walking, the countryside, music, and 'being' together.

I have kept up with friends from primary and secondary school and from both universities, whom I see at least once a year. In 1979 I met Pam Baktis, then an undergraduate at Cardiff University, and we have been friends ever since. She is my confidant and has been a real stalwart for me throughout.

In my working life, I've been fortunate to find work that was worthwhile, in the main with congenial colleagues, with a network of support for when things went wrong. Having been the Director of the Welsh Consumer Council for 17 years, I set up my own research consultancy in 1994. As an economist, social researcher and town planner, I have learned to acquire, assess and use all types of information, including published and unpublished research data, statistical analysis in areas ranging from social policy to human sciences, and material available on the Internet. The Internet is a hugely valuable tool in the right hands, but it is not accessible to or meaningful for everyone.

In 1998 a friend asked me to help her as Assistant Editor of the International Journal of Consumer Studies; I was intrigued, but not confident that I could help. Three months later she was diagnosed with cancer and within 10 months she was dead. I accepted her dying request to take it over as Editor; and it has thrived.

In the early 1990s I started work as a trustee for a voluntary organisation, an interest that has expanded. In 1998 I joined the Caerphilly Ladies' Choir and practice every Tuesday evening in the local school. This, together with walking and photography have become my hobbies and sustained me over the years.

I've tried to look after myself well. I hurt my back in my early thirties and was off work for many months. Since then I tried to eat sensibly, drank alcohol only rarely, took regular exercise, and did not smoke. Each year I've taken a good summer break in St Urban in Carinthia, Austria where my parents live, and I've had the opportunity to unwind ready for the winter ahead. My first real illness was in my late 40s: I had a hysterectomy in 1999 and became even more determined to maintain my good health and well-being. I regularly had health check-ups – eye tests, dental check-ups, and had my last mammogram in 2005 (including being recalled to a Breast Test Wales for what appeared to be an irregularity in the x ray). In 2005 I broke a tooth, which my dentist did not treat properly and which led eventually to a severe infection, and left me with vertigo. Although this has been kept under control by my homeopath, there were several months during the chemotherapy that it bothered me – and still does when I'm tired.

In 2001, Rhiannon Bevan, one of my closest friends, was diagnosed with lobular breast cancer. She was devastated by the enormity of the diagnosis. Twelve months later secondaries were found. In the four years that followed, she and her husband researched all manner of ways of addressing the impact of her advancing illness. As a home economist and excellent cook, she was able to pass onto me an understanding of nutrition and its impact on well-being. She and I enjoyed a lot of time together during the last months of her life: we used to walk every couple of weeks along the Penarth headland, followed by tea at her house. I learned a lot about cancer, its treatment and the impact it had on her. She died in May 2006 and I was still grieving her loss, when I was diagnosed with lobular breast cancer four months later.

The last three years has been a time of change for me. The trauma of the diagnosis and treatment, and acknowledgement of its implications, have all had an impact. I take much less for granted; I actively seek to enjoy each day more; and I am more appreciative of the kindnesses of others. I feel

that my being has been assaulted to its physical, emotional, spiritual and intellectual limits, taking me on a new journey of discovery, to places that I did not know existed.

I wrote this poem about myself in March 2009.

Who am I?

Interested in the world around me, how it works and how people think
Curious to know more, impressed by things I cannot comprehend

Detached and not easily involved

Like to plan things, start them, get them done

Averse to rushing or being rushed

Attracted by new challenges

Distracted by having to prove my worth

The barrenness of busyness

Judgmental of myself and others

Forced to be more patient with myself and others

Frustrated by lack of time and energy

Loved by my children and family

Love my friends, who've helped me on my way

Guilty that I need to be alone from them

My route through life a silver thread unique to me

Grateful to my parents for all they gave me

Glad not to know what's around the corner

Need calmness and tranquillity

Need music, kind words, encouragement

I love the stillness of the countryside

Sounds of birds singing

Silky air on a late Spring day

The excitement of the wind

The shapes of gnarled trees

The colours of autumn leaves

The crunch of snow underfoot

The eerie silence of the world eclipsed by the sun

Seeing deer in meadows and under trees

Watching butterflies and bumble-bees

Walking alone with my thoughts

The reflections in the lake

Wild flowers in the meadow

I fear the unknown

Anger and aggression

Chaos

Despair

Injustice

Loss of independence

Loss of dignity, integrity and hope

Loss of sense and senses

Being unable to meet others' expectations

Not being able to manage my pain.

Section B: My journey through the healthcare system

Chapter 3: The diagnosis

How it came about

In summer 2006 I went as usual to Austria for my summer break. I relaxed, swam, walked, enjoyed the food and sunshine, and had my friend Pam to stay. After she left I remember thinking how tired I was, like an engine needing a service. I thought no more about it and returned in September to South Wales to resume my life there.

In late September, I returned home from a meeting of one of my voluntary groups. I was tired. It had been a full day and as I had a busy week ahead, thought I'd have an early night. I put on the bedside lamp and got undressed, when I noticed a little ripple and slight reddening of the skin around the nipple of my left breast. A cold sweat came over me, but I told myself not to panic. I had a meeting with a colleague the next morning and tried to act normally, but I was terrified. I went for an emergency appointment that afternoon with a GP whom I had never seen before. He said that he could feel a lump and that he was making an urgent referral to the Royal Glamorgan Hospital, there being a 17 week wait for the Cardiff and Vale Trust. I regarded myself as extremely fortunate in going to the Royal Glamorgan, which was only 20 minutes away by car, 5 years old at the time and had a very good name.

I was fitted into a clinic in the Llwynypia Hospital a week later. I saw my surgeon for the first time. He was reassuring, telling me that nothing could be done until various screening tests had been carried out – mammogram, ultrasound, and biopsy. The mammogram and ultrasound showed nothing, but I had a biopsy and was told a week later that it contained lobular cancer. Ten days later a MRI scan revealed that I had cancer in both breasts – one was 60-70mm and the other 13mm – and that my lymph nodes were affected.

I knew from my friend Rhiannon's experience that lobular cancer (about 15% of breast cancers) behaves somewhat differently from the more frequently occurring 'ductal' cancer in that it spreads like ivy and is less dense and more diffuse. Because of its structure and behaviour, it is only rarely detected on a mammogram and often goes undetected. Although the tumour area in the right breast was very small, I decided to have a mastectomy on both breasts. I was offered immediate breast reconstruction, which I readily accepted even though my mother and Dick, my partner, thought I was crazy and still blame this for the pain that has resulted.

I was booked in for the surgery in late October, six days after the MRI scan, and in the meantime I had the results of the biopsy on the right breast, underwent the pre-operative assessment, and met the breast nurse and surgeon. I arranged a locum for my journal, negotiated new project deadlines

with my clients, revised my will, brought my company accounts up to date, and communicated with my family and friends. My family, equally traumatised, offered me their undivided attention; Dick, my partner, took me to old haunts along the English border, we took family photographs and we had a wonderful day in the Brecon Beacons in the autumn sunshine.

Getting myself emotionally prepared

At times of crisis I find it very hard to share my thoughts and feelings with others. You just focus on what you have to do. Discussion is diversionary and peripheral. I also wanted to protect my girls, elderly parents, aunts on their own cancer journey, and siblings scattered across the world. Dick, hitherto undemonstrative and sometimes appearing frustrated by my idiosyncrasies, was transformed, and has been wonderfully supportive ever since. He instinctively knew how to handle me, providing physical and practical help and helping me to prepare mentally for the onslaught to come.

The things I would have liked help with when first diagnosed

1. The initial diagnosis felt like a death sentence. I was numbed by the shock, guilty that I had somehow failed myself, and I wondered how to get out of the nightmare. People were very kind, but no-one was able to talk to me. Looking back I was helped by the fact that it took four weeks for the full extent of my cancer to be known – a week for the first clinic appointment, another week for the results of the biopsy from my left breast, another week for the MRI scan and then a further 5 days for the biopsy on my right breast and another two days to surgery. It gave me time to clear my desk, get my will updated, tell all the people I wanted or needed to inform, and gather information to help me make the life-changing decisions about my treatment.
2. Preparing for cancer treatment – surgery, chemotherapy or radiotherapy - *is* a big deal. There are a lot of things to think about – not just about your health treatment. It is easy to get overwhelmed by things and cluttered up in detail: having a ‘to do’ list of personal and household tasks was helpful. My partner was wonderful: when he could see I was disintegrating into a gibbering wreck he took control – making me talk about my fears and reassuring me that whatever happened he would be there for me. I’ve always thought that ‘how to’ toolkits – things to look out for when buying a house, for instance – are very helpful and it shouldn’t be too difficult for the hospital to provide a similar checklist for patients at the time of the diagnosis. It would make people realise that practitioners were interested in the whole person, not just in repairing their health.
3. Breaking the bad news to those close to me was very difficult. My partner, Dick, was marvellous and was with me at every stage, but the hardest people to tell were my children (Vicky and Kate, then in their early 20s) and my parents (in their mid-80s and living abroad). I would have liked some help in sharing my bad news with them. They felt excluded in that I had waited until the cancer was confirmed before telling them and they felt that they should have been informed sooner. I felt that I had to support them, rather than their supporting me. I also did not have the energy or time to sustain the filtering of information from the practitioners, and it was only when I wrote everything down that they were able to fully make sense of what I was trying to say to them or understand what I was feeling. I would have liked some guidance about what to say to the people around me, as well as to the ‘outside world’ although this may be difficult because everyone’s circumstances are so different.

Chapter 4: First line treatment

Surgery

When I woke up from the surgery, I was quite surprised by the level of pain in my arms and the fact that I couldn't use my arms or hands. Tasks like washing were difficult as I could not wring out my flannel or lift my towel. I could not lie on my side or get out of bed. Eating was also difficult, but I did not have much appetite, and soon resorted to having food cut up and brought in from home. I was in hospital for 12 days.

I realised that such a large tumour must have been present for a long time - some people referred to the HRT I had taken for 2 years from 1999-2001; but it could well have been there long beforehand. I felt guilty about not having discovered the cancer earlier – and then angry that the regular screening hadn't found it either. The Breast Care nurse told me not to beat myself up over this and to get on with the rest of my life – sound advice, but difficult to put into practice!

I was discharged with an information pack including leaflets about Tamoxifen, Arimidex, details of a bra fitting service in Pontypridd, and details of the helpline and peer support from Breast Cancer Care. The Breast Cancer care information was useful, but as I wasn't to start the hormone treatment for 10 months and haven't needed a bra since my surgery, the rest of the pack was not.

After I returned home Dick got me back on my feet – in the early days this included helping me to get in and out of bed, to wash and to dress - he prepared all my meals, managed the household, took on the shopping and allowed me to recover in peace. The girls also helped, but it was his patience, encouragement and reassurance that made the difference. My friend Pam was also a great support; she telephoned me regularly and was always there when I needed her.

At the end of November I felt able to sit at my computer again. I found a photograph for my annual Christmas card and wrote an upbeat message to all my friends and relatives to reassure them that I was all right. So many people had written to me, sent me cards and flowers, and messages of good will; a few people had come to see me. This was so important, as one of my fears was to be isolated by my illness.

The District Nurses came in for about two weeks after I got home and at the end of this I went back to the Royal Glamorgan Hospital to be signed off by the surgeon.

Breast implants

During my initial surgery temporary breast implants were inserted under my pectoral muscles and in December 2006 I started weekly visits to augment their size. A small amount of saline was injected into a port in each breast at regular intervals, designed to stretch the skin and make it ready for the permanent implant. This was a very easy procedure and it was nearly complete by the time the chemotherapy started, and although it then slowed down, I was quite ready for the permanent implants by the time they were inserted in May 2007. This was a very smooth operation and I was out of hospital the next day, with a check-up two weeks later. I was and remain pleased with the result.

Chemotherapy

In December 2006 Dick and I met my Oncologist, Dr Abraham, and Specialist Oncology Nurse, Gail Williams. They discussed with me the next stages in the cancer treatment. I was to have 6 courses of chemotherapy (the recently introduced FEC-T treatment involved 3 sessions of Fluorouracil, Epirubicin, Cyclophosphamide (FEC) and 3 of Docetaxel (Taxotere), followed by the breast implants, and then four weeks of radiotherapy, before starting 5 years' hormone treatment. They told me to enjoy my Christmas and that I would start the chemotherapy afterwards. I was given a prescription for a free wig and a referral to a physiotherapist at my local hospital.

Before the first chemotherapy treatment I had a Hickman line put into a vein in my neck, so as to enable the chemotherapy to be infused without using either arm, for fear of lymphoedema. This was a very delicate procedure, performed under local anaesthetic. The Hickman line was also used for blood tests, which saved me a huge amount of trouble for the next five months, and I was grateful to have had it. There is apparently a high risk of serious infection with a Hickman line and everyone who came into contact with it was very cautious. Also, not everyone had been trained to use it, which occasionally caused delays.

About 10 days after my first treatment I had an infection and was kept in isolation in Velindre for a few days. After that the dosage of the chemotherapy was reduced by 15% and I had additional medication to prevent further infections. After the second treatment I was very sick and became dehydrated, and was back in Velindre for another couple of days. The FEC irritated my bladder and this still causes me problems unless I continue to drink regularly.

I had opted for a 'cold cap' (a very heavy frozen rubber cap, like a swimming cap, which is taken out of the freezer and put straight onto your scalp and is designed to prevent hair loss during chemotherapy), but a lot of my hair fell out anyway. I wore my wig from the end of February until November, always avoiding going out on windy days without a headscarf or hood.

A particular issue for me was the use of steroids, which are dispensed with the chemotherapy. I had previously had bad experiences with them – flickering lights, restlessness, cold sweat and a feeling that my head would burst. This re-occurred with the treatment and I took the minimum dose required during the chemo and probably suffered for it.

Some of the sessions at the hospital were extremely long. I used to go home after my Oncologist appointment, returning after lunch for chemotherapy. On the day of the third session, there was a snow-storm and ensuing traffic chaos: Dick and I were at the hospital for 9 hours and I arrived home exhausted. For people who cannot go home, who travel long distances, or rely on hospital transport, these long sessions must be an added burden.

The fourth session was the first session of Taxotere: four days later I told the widower of my friend Rhiannon that I was planning to give up the chemo as I felt so awful – he told Rhiannon's former consultant, who told my consultant, and later that week I was called in to discuss how the plan was going! We agreed that I would return to the FEC. The final chemo session was on Friday 13th April – a day on which everything went wrong: the ward was short staffed, the chemo prescription was wrong, the cold cap had to be done twice, and I was again at the hospital for 10 hours.

I was very glad to have the chemotherapy behind me. My Oncologist told me recently that she didn't know how I managed to get through it. I still haven't decided whether I would go through it again if my cancer reoccurred. It was very traumatic and took a long time to recover from. I worked very hard on all fronts to sleep, eat and live well, and just wanted to get back to normality. The chemo has left a number of legacies, some of which still remain: painful, brittle and lost nails, restlessness, cramps in my legs, a vulnerability to the elements, intolerance to the sun, an irritated bladder, a dry mouth and altered taste – I can no longer stand salty, sugary or powdery food and drink cold water throughout the day. I lost over 50 lb in weight, which I have not managed to regain. The chemo changed me from being robust, with a strong constitution, to being more vulnerable and sensitive and needing to assess more carefully whether I can embark on a particular activity and how I will manage it.

Radiotherapy

Dick came with me for a check-up for my breast implants in May 2007 and I asked the Surgeon about the impact of the forthcoming radiotherapy on my implants, which I did not want to damage. The Senior Registrar in the Oncology unit had been unconvincing about the benefits of radiotherapy, and I was already in pain from the mastectomy. On reflection, asking the Surgeon about the radiotherapy was not a good idea – but no one else seemed to have any idea about its effects on my implants and suggested that he would know. He asked me why I needed radiotherapy: a small tumour with a clear margin would not need it. I did not know at the time, but the secretary typing up the dictated notes of my surgery had recorded the size of the tumour wrongly (my 60-70mm tumour had been recorded as 16-17mm). During the discussion the error

came to light; the Surgeon went to talk to my Oncologist, but on return did not change his advice, and by this point I (who already had fears about the radiotherapy) had made up my mind to stick with this.

A few weeks later, the Senior Registrar on the surgeon's team wrote the following poster, designed to lead to changes in practice of recording numbers, which he hoped to publish in the BMJ, and needed my permission to quote my case. It was only then that I realised the error and the possible consequences for my further treatment. About a year later I found out that the article had not been published, but reassuringly, it had led to changed practice in the hospital.

Size matters - or: What doctors can learn from Bingo ...

Ludger Barthelmes, Katherine E Liddington, Eifion Vaughan-Williams

The confusion was considerable. The patient was not keen on the idea of radiotherapy. She was told she may not require it considering the small size of her tumour. Why was she treated with a mastectomy and reconstruction for such an apparently small tumour? It turned out that the original measurement of the large tumour was wrongly transferred from the tape on to the typed letter. The mistake went unnoticed and perpetuated itself in subsequent letters. Fortunately, it was identified and the patient came to no harm, although it caused her distress and uncertainty and led to several hours of additional counselling before she agreed to proceed with treatment.

This example is by no means unique and results from a peculiarity of the English language where numbers between 13 and 19 phonetically resemble decimals between 30 and 90. It can lead to inappropriate treatment decisions in radiology, pathology and medicine, which are based on size.

At the Royal Glamorgan Hospital the surgical team has started a campaign using stickers and labels on Dictaphones and posters in outpatients, to encourage doctors to dictate individual digits, rather than full numbers. It's early days yet, but we hope it will take on, like Bingo!

Excerpt from poster submitted to the BMJ, July 2007 (unpublished)

Before I knew about the error (in June 2007) I told my Oncologist, that I was going on holiday and wasn't going on with the treatment. She asked me to come to see her and spent a long time trying to persuade me about the long term risks of the cancer coming back and how the radiotherapy would mitigate these. Eventually and reluctantly I went along with it, despite my fears of being burned (as a child I was frightened of fire and fireworks) and my hatred of tattoos (I associate involuntary tattooing with the barbarism of Auschwitz). With so much going on I failed to ask if I could avoid being tattooed; and although the tattoos are miniscule I remain angry with myself for not having stood up against this, with the Oncologist for not having apparently given me a choice, and with the system for not thinking about using brown ink. I spent two years wanting to get the tattoo removed – an albeit trivial, but daily, reminder of the hated radiotherapy.

When I discussed this recently with my Specialist Oncology Nurse, she suggested that I might wish to write to Velindre to ask whether henna could be used instead of permanent tattoo ink. She also said that she could refer me to a clinic to get the tattoo removed as I would not need it again. I decided to write to the Macmillan Information and Support Radiographer to express how I felt. Her

response to this was that I had given my permission and that the permanent dots were needed to establish exactly where the previous beams had been in case further radiotherapy was ever needed; but I could have them removed by laser surgery if I wanted....! It's clearly time to move on.

I was fortunate not to have any skin problems with the radiotherapy, but I still blame it for some of the chronic pain and fatigue. A year later the Oncology team were still at pains to provide me with epidemiological evidence of the long term benefits. However, for me this episode was the worst stage of my treatment and it is still in my rucksack – the experiences of my life that still burden me.

Things I would have liked more help with during my primary treatment

1. Through my friend I knew something about how the cancer develops and how the disease had affected her physically and emotionally. But it wasn't enough, as she wasn't there any more and my journey started differently and took a different course. I was able to ask the usual things about the treatment programme and prognosis, which is useful in providing a framework for the 'free fall' you experience as you're going through the treatment. I was grateful for the detail but confused by conflicting information provided by my surgeon and oncologist, resulting from the error in my records. Fortunately for me because of the error, I did not discover the correct prognosis for about a year, when I was better able to cope with it. This makes me wonder whether it is worth knowing the depth of the hole you are in.
2. I would have liked to have better warning before my mastectomies about how much pain I would experience after my surgery, how long this would last, and even the possibility of it being permanent. I worked really hard to exercise my arms and restore the mobility in my shoulders, arms and hands but felt all the time that I wasn't doing enough to address the pain. I'm sure that practitioners are aware of the risk of patients with mastectomies experiencing chronic pain, but every time I asked about it, I was told that it was 'early days' and would get better, which added to my sense of failure when it did not.
3. A physiotherapist came around the day after my surgery and told me and showed me the exercises to do. The little booklet I received included mention of lymphoedema (swelling), but little was made of it – almost as if it was an incidental inconvenience to be put up with, rather than something that could be prevented, avoided and if necessary treated. More information at the point of the post surgery visit from the physiotherapist would have been helpful. This, together with the importance of mobilisation exercises could also be reinforced by the Community Nurses who visit in the first days and weeks following surgery.
4. I felt guilty for months that I had sufficiently neglected my good health to have got cancer, and even worse on being told that it could have been there for years. I was angry with myself for not having discovered it earlier. It took a presentation at a course 18 months later to realise that lobular cancer is rarely found by a mammogram. Only then was I able to assuage my guilt and anger. Many practitioners said that patients with lobular cancer present late – but it would have been helpful for someone to explain right at the start *why* this happens, that even practitioners fail to spot it, and that it is not their fault. Instead, I was asked by several people about my lifestyle and risk factors – but that only made me feel much worse. It's more helpful to think of cancer as something that just happens.

5. I told friends and associates that my treatment would last around 8 to 9 months and that then I expected to be back to 'normal' as this was the impression that most practitioners gave me. 'Normal' to me meant being an active contributor to my family, friends and community, working full time, living well, and enjoying my hobbies. I still enjoy everything I do – and many things I appreciate even more than I used to – but no-one even hinted that I would not return to the same 'normality'. So for many months I felt I was not trying hard enough and should have been recovering more quickly. It would be helpful to everyone facing the trauma of a cancer diagnosis and treatment to be told not to plan too far into the future until the treatment is over.
6. Before I went to meet the Oncologist I went onto the Internet to find information about chemotherapy, radiotherapy, and hormone treatment. I wanted to know what the treatment would do and its side effects, both short and long term. I'm glad I did this, as I felt prepared, able to understand what was being proposed and why, and was able to ask what I thought were relevant questions. I received an information pack on discharge from the hospital, but it contained very little of this, and there may be a case for considering what information could be provided in advance of this initial Planning Consultation with the Oncologist. People's information needs vary considerably; some people rely on the Internet, whilst others want the printed word. So more thought needs to be given to how, when and by whom this information might be delivered. Check lists, such as those in Breast Cancer Care's recent leaflets, would have helped.
7. I thought that the treatment plan I was given by the Oncologist at my initial meeting was very clear, but throughout the process I wasn't sure whether I had signed up to the whole of it or just to different parts. I was still involved in the breast implants process and wasn't sure of the logistics of this in relation to the chemotherapy. There is a lot of intervention from practitioners in the period between diagnosis, surgery, and chemotherapy / radiotherapy and many opportunities for dialogue and communication. A clear Information Plan could be developed alongside the Treatment Plan to address the above needs and support patients in moving forward through the treatment towards recovery. This information will vary according to the needs and circumstances of the patient and family / support network and their desire and capacity to manage information. However, patients are often traumatised, and their capacity to anticipate and identify their needs may be impaired because of this. So it is important that information is offered, accessible, and timely, rather than waiting for patients to articulate their needs.
8. I would like to have felt sufficiently empowered to say 'no' to anything at any stage or ask for more time to commit to my treatment, without feeling that I was under pressure to get through it.
9. My treatment left me with fatigue, chronic pain, peripheral neuropathy, lost nails, changed taste, weakness in my limbs, unexplained weight loss and menopausal symptoms. I found out only later that these were all side effects of the treatment. Being told this at the start would have simplified things, stopped me worrying and enabled me to get on with my life. I would also have liked a better sense of the milestones and how my treatment would help me long term. I did get this information, but not for many months.
10. Having a life-threatening illness like cancer has a huge emotional impact. By the end of the treatment I felt that all I had achieved was to replace a death sentence with a life sentence. I had taken all the risks; I would have to live with the consequences; and I had fallen from the top of my world into a state of limbo where I was unwell and in pain. I did not know how to pick myself up. I needed information about where to go for help and guidance about how to help myself.

The most valuable things I have learned are:

1. Cancer just happens and it's no-one's fault. Looking for causes and risk factors is something that practitioners do – but very little is seemingly known about what triggers cancer and discussing it certainly did not help me. It was very unfortunate that no-one discovered it earlier, but I cannot turn the clock back and I must move on.
2. Whilst the people treating me have more knowledge than I of the big cancer picture, I have unique knowledge about how I feel. Conceiving my cancer treatment in terms of two 'battles'- with my Oncologist treating my cancer and me championing my well-being - has helped me to better channel my energy on recovery and quality of life and to realise that the best decisions are usually a compromise of different objectives.
3. Information can be useful and can help to provide a perspective, but it is no substitute for good advice, knowledge or experience. I have spent much time in trying to find what I needed, and getting frustrated when that information did not seem to be available, when sometimes I would have been better off simply trusting those people who were trying to care for me.
4. Practitioners can repair your health, but it's your resources – your mind, body, emotions and spirit – that enable you to recover. The process of healing depends to a great extent on you, and you need to approach it in a systematic way, looking at the best way to help yourself.
5. Although I felt at the end of the treatment that I had simply commuted a death sentence into a life sentence, as time has passed I've got to grips with my life, I now just see it as my life again. I have been given the opportunity to enjoy the rest of my life. Recognising this has helped me to appreciate the things I used to like doing even more and brought back my sense of purpose.
6. Engaging with family and close friends and making them fully understand what I had gone through was very important in reducing my isolation and helping them to accommodate my needs and respect my integrity.

chapter 5: Ongoing surveillance

Prognosis

At the first meeting with the surgeon after my surgery, we discussed the staging and my prognosis. The staging of my cancer was IIIA, T3, N1, M0, with a 'Nottingham Prognostic Index' (NPI) of 5.4. This is an indicator based on tumour size, nodal involvement and cancer type. Developed at Nottingham's City Hospital and first published in 1992, the NPI seeks to use some objective parameters to determine the odds that a newly diagnosed patient would benefit from adjuvant chemotherapy, based on 'overall survival' rates at 15 years post diagnosis.

The calculation is as follows:

- 0.2 x maximum tumour size (mine was 7 cm) plus
- 1, 2, or 3 points for tumour grade (mine was grade 2) plus
- 1, 2, or 3 points for number of nodes affected (mine was 2 as I had 1-3 nodes affected)

It was found that 80% of those with a NPI of less than 3.4 were alive at 15 years; 42% of those with a score of 3.4-5.4 were alive; and 13% of those with a score of greater than 5.4 were alive. The lower the likelihood of survival is, the greater the benefits of chemotherapy. I was told that my score was 5.4, that my stage of cancer was 'moderately difficult' to address and I would need chemotherapy.

Initially I was told that without further treatment my 10 year survival expectancy was 70% and with chemotherapy and 5 years hormone treatment it would rise to 84% [this prognosis gave me much encouragement in the early months, but it was based on an erroneous record of the tumour size, the error only being discovered 6 months later).

The Adjuvant! Online Prognosis¹, indicated a 43% survival rate at 10 years without treatment rising to 67% with chemotherapy and hormone treatment, with a 50% chance of disease free survival over this period. Of course, probabilities are only useful for large populations: you don't know which side of the probability you as an individual will end up on, but it was good to know the odds. It was important to me to have some idea of what I (or rather my Oncologist) was up against, and it has helped me to value and use each day to the full.

Within the last year two close acquaintances died from cancer and I was prompted to write this short piece in May 2009.

¹ There is now a Adjuvant! Online version for patients

Their long battle against cancer

When I heard that Elwyn and Avis had lost their long battle against cancer it made me think about my own experience. When I was told I would need surgery, chemotherapy, radiotherapy and hormone treatment, and I was scanned, weighed, and tattooed, I felt I was being launched onto a battle-field without equipment or training. You just focus on survival!

Afterwards, I went on a mission to put my life back together again. I re-connected with friends, developed a routine of exercise, and walking, found new healthy foods and recipes, rested, pursued my singing, photography and houseplants, carried on with voluntary and paid work, and was very glad to be left in peace.

But things did not turn out as I thought they would. Two years on I still feel wounded by the onslaught, subject to widespread chronic pain, and feeling much older. Was it worth the effort?

My Oncologist is a very dedicated and caring person with a reassuring manner and an extraordinary memory. Little things mentioned two years ago are retained. I feel confident that she is doing her best for me - as well as for the scores of her other patients. I like to think she treats me as a whole person, but I know she is entirely single-minded. It is she who is fighting the battle with my cancer. While I'm battling for the best quality of life I can achieve, without a thought that the cancer might return, she ensures that if it does come back she will be the first to know about it.

I have always felt that there are two battles going on. Hers is fighting my cancer. Mine is fighting to keep as much as I can of my old life - my "quality of life". So far, she is on the winning side: I've made the 2 year milestone and am onto the 5 year milestone. The prognosis indicated odds of 2:1 that she would win this first battle and it seemed a worthwhile cause, although at the time I heretically challenged her treatment plan, its speed of implementation, whether all elements of it were necessary, and I worried about lymphoedema, neuropathy, the long term effects of radiotherapy etc. I am glad that the treatment has worked and I can get on with the rest of my life. I seldom think of her battle with my cancer any more, whilst I have a daily struggle to retain the comfortable life I once enjoyed.

Sometimes, she reminds me of the ongoing campaign she is fighting on my behalf - an invitation to see her or undergo another test. I treat these as an interruption to my own battle, but realise that there is a chance, however slim, that one day she will discover that she hasn't been wholly successful. If this happens, I am sure she will want me to join forces with her again and do battle on her territory. I can't say that I will.

And so, when I heard that Elwyn and Avis lost their long battle against cancer, I sensed that this wasn't one battle, but the last of many unrecognised, and perhaps unremarkable, battles in a long war of attrition from cancer. On the one hand there was the war against the cancer; on the other their fight to keep their dignity and integrity, and the normality of the life they once knew. Some of these battles they undoubtedly won.

Follow-up appointments

The protocol for follow up with the Surgeon's clinic is initially 6 monthly and then annually and with the Oncologist is 6-monthly, with additional appointments if need be. Scans and follow-ups also occur from time to time, although there does not seem to be a pattern.

The coherent route-map created for me by the Surgeon and Oncologist became less clear once the treatment ended. It seems to me that there is a state of limbo in the six months to a year after treatment, when things have changed for you, you are slowly recovering, and you need a lot more guidance than you get. I note that the recently published NICE Guideline recommends that a written treatment plan be drawn up and a copy sent to the GP and patient: I think that this is an excellent idea².

Three years on I return to the Surgeon's clinic annually and to the Oncologist every 6 months. I remain unsure why I return to the surgeon's clinic – he has already told me that if I have a problem with either of the implants he would sort it out. In February 2008 I wrote to the Surgeon to ask whether I needed to attend the appointment made for me the following November; I received a brief reply in September 2008 saying that he did want his nurse to see me, and would I report to Radiology first for my annual mammogram?

Another pointless invitation came in March 2008 to attend Breast Test Wales' screening in Caerphilly. I wrote a hard-hitting letter of complaint, and received a charming and fulsome letter of apology from the Director, which made me realise the huge size of the NHS and the extraordinary difficulties of tying up its different components into something that makes sense (and is seamless) for the user.

I went to my first follow-up appointment with the Oncologist in October 2007. I had no idea what to expect or what the purpose of this follow-up visit was. I was in a lot of pain, which I had been told would go / should have gone, I was still suffering the after-effects of the chemo, still angry about being bounced into the radiotherapy, and had not yet settled to the Arimidex. I had by this stage lost 14 kilos (30lbs) in weight, for which I could not get an explanation. My Oncologist was away on compassionate leave and I was met by a locum who had arrived in South Wales a week before. He asked me about my concerns and I told him about my weight loss. I explained that my taste for sugar and salt had been affected by the chemo, but he immediately suggested that I ate ice cream! This still gives me moments of bemusement: I cannot quite reconcile the years of training and professional development with the inept performance that greeted me that morning.

He also told me I was depressed. I overheard other people being told they were depressed. Whilst I understand that it figures quite largely in people who have been diagnosed with cancer, I wonder

² NICE, February 2009, *Early and locally advanced breast cancer: diagnosis and treatment*, page vii.

whether this is just a way of dismissing patients who have reached the end of their treatment. I was traumatised, anxious, frustrated, and angry – but I wasn't depressed. I found it an affront to be told this by someone who had clearly not bothered to open my file, who could not explain why I was there, who had no answers for any of my questions, and whose competence I questioned. My wonderful Specialist Oncology Nurse came to the rescue, suggesting appointments with the Dietician and the Pain Management Clinic in Velindre. My letter of complaint to the Oncologist was met with a helpful and charming reply on her return to work and follow-up appointments since then have all been worthwhile. I have moved on from this very low ebb and would only say that this and the following 6 months was the time that I really needed help. My nurse was a lifeline for me. By contrast, my Aunt Erika, being treated privately for ovarian cancer in London, was largely left to her own devices.

A cause of my frustration was that the reality of my experience differed from what I had been told to expect. For example, a Senior Registrar in the Oncology Unit told me that it was worthwhile investing six months of my life in undergoing treatment in order to enjoy a further 30 years of life. Certainly the chemotherapy and radiotherapy were completed in eight months, but that wasn't the end of the matter as it took much longer to recover from the treatment and some of the side effects may be permanent.

There is a need for better ongoing information and advice long after the main thrust of the treatment has taken place. This information need is not the same as that required at the point of diagnosis and planning. After the initial treatment there is more time, informed consent has taken place, and it is more about ways of achieving well-being and less about the intricacies of treatment. There is a need for bespoke information, tailored to individual needs. Although in practice many of the information sources say similar things, people need help in being signposted to information and in interpreting the material being offered. This is also a good time to learn about new research and treatments – to provide encouragement and hope.

Under the spotlight

In December 2007 I reacted to a novocaine / adrenalin injection at the dentist and collapsed in the street. I was taken into Caerphilly Miners Hospital in a different Trust where, when it was found that I had previously had cancer, I was subjected to every possible test and scan for the next 5 days, eventually passing this 'MOT' with flying colours. I spent most of my time in an observation ward trying to persuade the medical and nursing staff to let me out, so that I could write my Christmas cards and go to my Christmas parties.

There were some amusing incidents too. Since my surgery I have always insisted that my blood pressure is taken on my leg, to avoid the risk of lymphoedema, and I always measure my own lying down so that the pressure band is around the level of my heart. The nursing staff decided otherwise and took my blood pressure when I was sitting, standing or lying – only to discover that the readings were 50 points higher when I was standing up. I became an object of great interest

and, although I suggested that this might be the effect of gravity, this was outside normal experience, and some weeks later my GP called me into the surgery to follow this up.

I have since had many more scans and tests at regular intervals. In February 2009 I mentioned ongoing back pain. My Oncologist arranged for a CT scan as a precaution, but I had forgotten about it when the appointment came up in April. The radiology team put 'the wind up' me by inviting me back for a bone scan and MRI scan almost immediately without explaining what they were looking for. Here is a short report I wrote following the MRI scan:

Coping with claustrophobia in a MRI Scanner

I got an invitation for a CT scan in April 2009, followed by bone and MRI scans in short order. Why do invitations for scans always arrive on Friday or Saturday when it's too late to contact anyone to ask why? I spent the next 10 days trying to divert my attention from the prospect of the MRI scan - but I also worked out a survival strategy. I was going to practice what I had learned in my Mindfulness course inside the scanner.

I arrived on time for my appointment, but the schedule was running half an hour late: I passed the time in deep breathing. When my questionnaire was checked, I was told that I couldn't have the scan until the radiographers were sure that my breast implants didn't contain any metal. My hospital records were called up; the implants were fine; and an hour later I was given the go ahead.

The last MRI scan in 2006 had completely 'wiped me out': I'd come out of the scan three times and by the end of it was a gibbering wreck. This time I had worked out some tools to get me through: deep breathing, eyes closed, and meditation. I knew that my feet and lower body would be outside the tube and I focused a body scan on these areas for the whole of the 20 minutes, whilst keeping my eyes closed, maintaining my deep breathing and staying completely still. I also used my visualisation practice - taking my 'little self' into situations that might potentially be frightening or stressful. Mindfulness Meditation³ practice helped me to be kind to my vulnerable self. I came out of the scan as if I'd just had a quiet lie down and I was quite proud of myself.

I have become accustomed to having ongoing surveillance. It seems that everyone keeps an eye out for you when you have had a cancer diagnosis. In my less charitable moments I feel that this overprotection is locking the stable door after the horse has bolted – if only the screening had found my cancer earlier.... Otherwise I find it both reassuring and worrying. It is reassuring to think that my Oncologist is maintaining her vigilance; it is worrying that she feels she needs to. I have the feeling that if my cancer does come back, she won't be altogether surprised - but this only crosses my mind when something new arises.

I find that different departments and trusts have no idea about what else might be happening to me – and there is a risk that someone else will start screening me all over again. But overall, my Oncology team effectively ensure that the service is as seamless as it can be.

³ This is a meditation process I learned on a course in Cardiff in 2008 – further details are found on pages 46-48

Chapter 6: Hormone therapy

I have devoted a whole chapter to hormone therapy because of its significant impact on our physical and psychological health and well-being over the 5 years or more that we take it. Hormone therapy is designed to inhibit the production of oestrogen or to deactivate oestrogen receptors, thus preventing 'oestrogen positive' cancer cells from reproducing. They should therefore improve the survival rates of people with breast cancer.

Arimidex

I was offered Arimidex, designed to inhibit the production of aromatase, a key to oestrogen development. Once the chemotherapy and radiotherapy were over I started taking it in August 2007. There were no immediate serious side effects, although initially I found that I had hot flushes in the evening and had to limit my meal sizes as eating made me hot. It also made me tired. After a couple of months I started to ache.

As time went on, however, I began to develop pain in my joints, my hands and feet, hips, knees, ankles, the length of my back, neck, shoulders, elbows, wrists, hands, and in the veins and leg muscles. I wake at night feeling stressed and needing to move about. Other side effects that I wasn't told about included e.g. a cough, dry / irritable throat, breathlessness, fatigue, and muscle weakness. Most of these side effects have worried me sufficiently to take them to my GP and in some cases he has decided to refer me to a specialist. Knowing more about the possible side effects could have prevented my anxiety and wasteful use of my GP's time.

Whilst it seems reasonable not to worry patients with too much information, just giving us a fairly basic leaflet produced by the manufacturer for a drug that we are going to take for a minimum of 5 years seems inadequate. The Arimidex leaflet was expanded in March 2009, but even now hasn't given me enough information to assess whether I am just making a fuss or have sufficient grounds to ask to make a change.

I thought it would be helpful to evaluate the information obtained from some websites I used, if only to show that a lot of time can be saved by getting a full picture at the beginning. More details of websites I have used to find out more about Arimidex are shown in the Appendix.

Web sites and what they do and do not tell you about side effects of Arimidex

	Arimidex website & leaflet	Cancer Research UK	Emedtv (US website)	Affects me now
Allergic reactions / skin rash	✓	✓	✓	
Hot flushes	36%	>10%	36%	✓
Nausea	✓	10%	13%	✓
Vomiting	✓		13%	
Weakness / fatigue	✓	10%	19%	✓
Mood disturbances		✓	19%	
Anxiety / depression			13%	
Headaches	✓	✓	18%	
Carpel tunnel syndrome	✓	✓		
Arthritis			17%	✓
Joint pain / stiffness	✓	10%	15%	✓
Bone pain / back pain			12%	✓
Thinning of hair	✓	✓		✓
Sore / dry throat			14%	✓
Cough			8-11%	✓
Difficulty breathing			8-11%	✓
Osteoporosis / fractures	10%	✓	8-11%	
Insomnia			10%	✓
Dizziness			8-11%	✓
Swelling / water retention			8-11%	
Abdominal pain			8-11%	✓
Constipation			8-11%	✓
Diarrhoea	✓	✓	8-11%	✓
High cholesterol / raised lipids	✓		8-11%	
Vaginal dryness / bleeding/ discharge	4-5%	✓	3-7%	
Infections			8-11%	
Weight gain			9%	
Loss of appetite / weight loss	✓	✓	8-11%	✓
Breast pain			8-11%	
Urinary tract / bladder problems			8-11%	✓
Blood clots / stroke / heart attack	2-3%		✓	
Jaundice	✓			
Muscle pain			3-7%	✓
Cataracts			3-7%	
Dry mouth			3-7%	✓

As time has gone on my teeth have chipped, my bones have thinned and my hair has lost its vitality, but the most obvious problems for me are pain, bladder problems, and fatigue. I will need to consider how long to put up with this drug once I have reached the 5 year milestone.

Changing to Exemestane

The side effects of Arimidex (aches and pains) gradually got worse until at the end of the first year I asked to stop the Arimidex. It was only then (some 2 years after my diagnosis) that my Oncologist made me fully realise the importance of continuing with hormone treatment for as long as it works. I was prescribed Exemestane instead. This was a mistake as within an hour I was feeling ill. I went to the GP's emergency clinic the next day and wrote the following report.

Exemestane

Took 1st tablet on Saturday 19th July at 8.30 pm with some food. Report 22nd July 2008.

Within 1 hour my skin was tingling, I had pins and needles in my lower lip and started a cold sweat. I remained very cold for 36 hours, with shaking limbs; this cold sweat was intolerable and only started to diminish the following evening. My dizziness started again at around 10 o'clock, I felt sick and agitated. It wasn't a cold night, but I covered myself with blankets and hot water bottle etc but it took a couple hours to get to sleep. I was awakened by a tummy ache at 3 am, and could not go back to sleep until 6 am. When I woke in the morning I felt exhausted, had a headache and problems with my eyes (peculiar flashing light and distorted vision). I also had difficulty in passing water and drinking the next day and abdominal pain, which has lingered together with pain after eating, indigestion and constipation. I was also concerned to have some spontaneous bruising - on my hand and leg - which meant that I could not have my acupuncture treatment yesterday. All these effects are diminishing now, but my body feels that it has gone through an awful experience and I will not take this drug again under any circumstances.

Back to Arimidex

At a recent follow-up visit I mentioned to one of the nurses that I was back on Arimidex; she mentioned that so many people change from one treatment to another because of unforeseen side-effects. It makes me think that side-effects of these drugs are underreported because the ostensible benefits are thought to outweigh the side effects – and so we are just expected to put up with them.

I agreed to go back to Arimidex because at least I could function with it. My Oncologist suggested that I turned to Tamoxifen, but no-one in my (albeit limited) experience has had a good word for it. I've therefore decided to stay with Arimidex, because it seems to work for me, I've got used to it, and, while on some days I feel less good, so much has already been invested in my survival and well-being, which I don't want to throw away.

Chapter 7: Support, help and advice

Voluntary sector support

When I was discharged from hospital after my initial surgery I was given a little folder with some information about Breast Cancer Care. This charity provides local support, information, and e-forums (in which people can get involved in Internet-based discussions). When I returned from my initial surgery in 2007, I registered my interest in getting information and also in getting peer support. This is offered by women who are at least 2 years post diagnosis, have had some training, and are able to provide information about their own experiences to people who ask for support. Various women gave me support on a variety of questions and they also gave me what encouragement they could.

I also used the Breast Cancer Care web site www.breastcancercare.org.uk. This is both well laid out and informative. The charity also provides effective information on diagnosis, primary, secondary cancer, living with side effects of treatment etc. which can be obtained at their face to face services or downloaded from the web-site. Being registered on Breast Cancer Care's database also meant that I was given information about the Look Good Feel Better outreach programme, supporting patients – see website: www.lookgoodfeelbetter.co.uk. I went to one of the Look Good Feel Good days and greatly enjoyed the variety of activities, although at the time (early in 2007) the day was too long for me.

One of the peer supporters told me about a local Breastfriends group, which meets twice monthly at the Whittaker Lounge in Rhiwbina, Cardiff on the second Friday 1-3 pm and the last Monday 7-9 pm. [website: www.breastfriendscandv.org.uk]. I have been to some interesting talks there, e.g. information about the Bristol Cancer Centre to make-up and wigs, new research findings, lymphoedema, exercises, tai chi - and I still go if something appeals. They also have a library and up to date news about cancer developments.

Specialist support from breast cancer nurses

One of the things that my friend, Rhiannon Bevan told me was that her Specialist Oncology Nurse was 'worth her weight in gold'. I had the same experience with mine - part of the service provided by the former Cancer Care Cymru. Nothing was ever too much trouble for her – whether it was finding information, arranging for other help, making sure that I was all right, listening to my worries, and smoothing gaps between different parts of the service. She ensured that there was 'seamless' support from a fragmented service across different trusts. Her being there made the difference between a service which had shortcomings and one which overall was very good. She made me feel that I mattered – she would rather take the time to sort out my problem than have me worrying about anything. Looking back at my treatment, I find it astonishing that anyone would

contemplate losing this post on the team, as for me it was one of the most important⁴. The funding for the post was recently threatened; I am glad that alternative funding has been found for the time being, although this needs to be sustained.

Breast Cancer Support Programme

The Breast Cancer nurses at the Royal Glamorgan Hospital organised a 6 week course of three hour sessions per week to help people who had been diagnosed and treated for their breast cancer in the previous year. I was invited to the course in April-June 2008, some 18 months after my surgery and at a low time for me.

I had already been to the pain clinic and been given a variety of medication none of which I could get used to and which made me feel quite poorly. The medication was unable to address my problem of not knowing what to do with my arms at rest: this meant that a three hour session, even if broken up into 45 minute slots, was too long for me. I also needed to move my feet, legs, back and neck and have regular drinks of water. I met someone with whom I had been in hospital, who seemed to be in a very poor way; this upset me. I also met others who had had their diagnosis and surgery a year after me, but seemed to be in better shape than I; this upset me too.

The Support Programme was well thought-out with well presented sessions and time for questions. They filled in many gaps and augmented my knowledge and essentially it was a really worthwhile programme. In one of the sessions the Consultant Radiologist gave a very clear presentation about the screening process and I asked her how it was that lobular cancer was not detectable on a mammogram, she said it did not show up as a lump, but instead looked like a crumpled piece of paper – as if there was a fault on the x-ray. This was exactly what I had been told when recalled for further tests at Breast Test Wales in 2005, 18 months before my large tumour had reached the surface of my breast. I was completely distraught at the realisation that my cancer could have been found before it had progressed so far. At that time I had had further mammograms, an ultra-sound scan and close examination by a doctor – and all this was repeated at the time of diagnosis: if they couldn't find it, how on earth should I have been expected to? I left the course in tears, and didn't go back.

Painful as this incident was, it was pivotal in my recovery as it helped me to gain absolution from the deadly weight of guilt for failing to discover my cancer sooner. I began to accept that the cancer was nobody's fault; and it certainly wasn't *my* fault. It was just something that had happened; and I needed to move on. I had a lot to move on from. I was still getting over the chemo and at the time didn't think the treatment had been worth all the problems it had caused. I was very tired. It was beginning to dawn on me that my pain was 'chronic'. I was worried about how I was going to manage the rest of my life – not being able to get around easily, carry luggage, open tins, cut bread, peel vegetables, or open doors. This was the start of getting a grip on myself.

⁴ Note that Clinical nurse specialists are included as a standard part of the Multi-Disciplinary Team in the NHS Wales National Standards for Breast Cancer Services (2005)

Things I would like to have known when getting on with my life after treatment:

1. My information needs at the time of diagnosis and treatment were almost exclusively about my health. Once I had finished treatment and was trying to recover, the information I needed focused on my well-being and how my physical and mental condition impinged on this. After the treatment I felt as if I was left on my own to get on with my life. In my view this needs to change to give people like me the tools to put them in the driving seat of their lives. I eventually sought out, gathered, and selected the information I needed for myself – but it took several months, when having a Counselling, Advice or Information Session within a month of the Radiotherapy ending would have made all the difference.
2. Information about where to go for help might include:
 - a. activities held locally – e.g. Breastfriends, Breast Cancer Care events
 - b. what you can expect from the local library
 - c. useful web sites
 - d. help with finances and employment, benefits and disability
 - e. courses, talks and group support – e.g. walking for health groups, yoga and pilates, advice about osteoporosis or lymphoedema
 - f. details of equipment, aids and adaptations – as needed
 - g. when to ask for help and from whom
 - h. different sorts of treatment and support available
3. Guidance about how to help myself might include:
 - a. the importance of healthy eating, appropriate information and web sites
 - b. the need for regular exercise / activity to address fatigue
 - c. addressing fatigue and sleep problems, feeling low
 - d. learning to 'pace' and plan each day, meditation, visioning, and self-hypnosis skills
 - e. ways of enhancing my capacity to take control of my life
 - f. focus on quality of life and enjoyment of hobbies, friends and relationships
 - g. managing day to day, focusing on the here and now, and learning how to say 'no'

Chapter 8: Primary care – the role of my GP

Before my cancer diagnosis, I rarely went to see my GP and throughout my treatment went there only once. I wasn't really sure what the role of my GP was in terms of the post-cancer treatment support. In particular, I was unsure how to deal with the neuropathic pain that had emerged from the surgery and chemotherapy, as this was initially treated at the Oncology Clinic and then at the Chronic Pain Management Service at Velindre Hospital.

Unfortunately, in recent years I have developed a sensitivity to many drugs, which appears to have been aggravated by the powerful toxins in the chemotherapy. *Amitriptyline* that I was offered to address the neuropathic pain completely wiped me out, leaving me drowsy and with a sense of having been drugged. I slept for 16 hours, had a dry mouth, could not put a sentence together, and felt quite lethargic. I was unable to keep my balance or go for my highly valued daily walk. I gave up on this treatment because of its side effects long before the 4-6 weeks needed to give it a chance to work.

I was offered *Gabapentin*. I was anxious about trying out this new medication, and although I did try it, I quickly abandoned it when I experienced bad side effects - drowsiness, flashing vision and balance problems, including losing my balance on the stairs at home.

In December 2007 I had a fall in the street and was taken by ambulance to my local hospital. This prompted a referral back to my GP, Dr Rob Jones. Over the next few months, I visited the surgery regularly, with a range of complaints, mainly focussing on pain. At first my GP continued experimenting with the various range of medication available to relieve chronic pain, with a clear strategy of building up from those with the least side effects to increasingly stronger doses.

These drugs made me feel dreadful, as well as very frustrated. All the medication set off my vertigo and made me feel quite sick. Some also made me feel distressed. Others made me drowsy. Steroid based drugs made my head feel as if it was exploding, whilst morphine (opiate) based drugs gave me a raging thirst, and made me hot and itchy. Over the next two months we exhausted the armoury of drugs, as well as my patience.

This was a low point for me. I was in pain and I didn't know what to do about it. I wasn't able to talk about my pain without feeling distressed. The medication on offer did not suit me. I did not understand what was happening to me or what I particularly had done to deserve this outcome. I was 'drowning' but needed to get a grip on myself and do things my way. In the light of hindsight, none of the people advising me had the time to sort me out in a coherent way. I felt that I was being pushed down a cul de sac, with increasingly strong medication that dulled my senses, undermined my well-being, and prevented my day to day functioning. I was rather afraid that I would stultify there, remaining a permanent burden on others – particularly my family – as well as the NHS.

In my experience, the type of medication I was most comfortable left me most in control. It was also the least effective in tackling my sensitivity to chronic pain. As it is, I would rather have the pain than the side effects. If I thought that taking medication for a few months would permanently reduce my chronic pain without my losing my other senses (especially my balance, which is quite vulnerable), I would take it; but no one can provide this guarantee. Its inability to achieve a good outcome without side effects makes medication a generally unsatisfactory option for me.⁵

I'm sure that I could have remained in this state of limbo, continuing to visit the GP even though I had exhausted all the obvious options. My GP ever resourceful, once he realised that medication was not the answer for me, suggested that I go on a pain management course, training myself to think differently about myself, my situation, values and lifestyle in a way where I was more in control – and therefore less of a victim of what had happened to me. I was so relieved to be given an alternative, which had the potential of suiting my needs. I booked into a Breathworks course at the Buddhist Centre in Cardiff, starting in September 2008 (more about this later). This was the start of a new beginning in addressing my pain. Who you consult is a bit of a lottery. I have been very fortunate in my GP, but it could have been so different.

Eighteen months after my low point, I responded to an advertisement in the local paper from a group of chronic pain sufferers who wanted to expand their network and meet others. They had a monthly exercise class followed by refreshments and an opportunity to exchange information and ideas. This small, welcoming, group showed great enterprise in setting up a regular get-together – a very good way to get out, get moving, address isolation, share information etc. The conversation turned towards help from the doctor. All of them visited their GP regularly, and all felt that the way in which their GP responded to their needs was deficient in some way – either because they had to wait for an appointment or because their GP was unable to adequately address their pain, the side effects or other related problems. I realised how far I had moved from this position of dependency and how glad I was that my GP had pointed me in another direction.

I have often thought that we as patients need a better understanding of the role of the GP, because there is a danger of wasting this valuable resource. When I first went to my GP it was to look for a solution to my pain. Then it was to look for reassurance that I was doing all I could to address it. But now that I am living with my pain, and I have the skills to manage it, I feel we don't need to discuss this anymore. At the same time, I'm glad of the assurance that there is an open door if I need help. I also know that my relationship with my GP is good enough for him to be the person to whom I will turn for advice if my cancer were to return. Whilst both are objective, professional and dispassionate, my Oncologist knows about my cancer, but my GP knows about me. Having a GP you can trust is so important. In the days of Group Practices, this is seldom available – and I know I am very fortunate.

⁵ I occasionally use *Capsaicin* (hot chilli) cream, which echoes some of my pains without the side effects, although because it burns my skin I can use it only infrequently in short bursts.

Chapter 9: The effect on my family

Both my parents and my partner Dick lost one of their parents before they were 30 years old, and somehow I sense that they all suffered a loss from not having their role models still alive until their middle age. By contrast, my brothers and sisters have had the comfort of our parents living healthy lives well into their eighties.

One of my constant regrets about being ill is the effect on the rest of my family. I'm sorry that my daughters, in their early twenties, should have been exposed to a possibility - however remote - of losing me while they are still young. Although I will do all I can to avoid this, I know that it has been painful for them, and it is an added burden on their lives. It has also brought us closer together and helped us all to recognise that you cannot take anything for granted and need to make the most of every day of your life.

I don't really know how my partner Dick manages it - but he has been able to continue his life without burdening or making demands on me, he allows me to say 'no' without judgement, and he supports me when I need it. I had hoped that he would make a contribution to my story, but he says that he doesn't want to - and I respect this.

However, here is a contribution from my daughter, Vicky.

The Effects of Mum's Cancer on her Family

My parents both knew of mum's cancer before my sister or I. When we were told, we were both naturally shocked and upset; however, it wasn't until much later - following mum's surgery and months of suffering - that the realisation of what she was going through really hit us as a family. Initially, everything happened so suddenly and subsequent events unfolded so rapidly, that it was as though none of us had been allowed the time to properly absorb the news and come to terms with mum's diagnosis.

Although it has changed her physically, mum's diagnosis has not altered her spirit or her strength. We are all so proud of how brave she has been and I am constantly in awe of the fact that, though she suffers so frequently and so intensely, she complains so little. Mum manages her pain with a quiet dignity and determination and I will always admire her courage and the way in which she has accepted cancer not as an end, but as a new chapter to which she must adapt and carry on.

Besides the obvious factors of mum's suffering and the fear of the unknown, one of the hardest things for me has been not being able to give my mum a hug. Early on, the physical contact of an embrace would hurt her and this would leave me feeling particularly upset. It seems the most natural way to show someone that you care, yet a hug would cause her discomfort. Another difficult aspect has been not knowing what to do to help and feeling that all efforts to make her life more comfortable have been futile. Mum has always been fiercely independent and we have not wanted to take that away from her.

Chapter 10: Conclusions about my journey through the health care system

Mine is an ongoing story and whilst I don't want to draw any conclusions about my experiences, there are things – good and bad – that happened to me that perhaps deserve further thought.

- I still cannot quite reconcile the fact that invasive lobular breast cancer behaves differently from invasive ductal breast cancer and yet it is treated just the same. I was pleased to learn recently about the discovery of a gene for lobular cancer; and I would personally like to see further research into tailor-made treatment and better methods of screening for breast cancer. As it is, I wasted many years going along to screening, when I already had a cancer which could not be detected by it, and the cost to both me and the NHS of not diagnosing my cancer earlier has been high.
- One of the promises of the NHS in Wales in the 21st Century is seamless care for patients. In my experience practitioners worked very hard to achieve a smooth transition between different parts of the service. Despite this, the reality was somewhat different, in my case resulting in concurrent follow-up appointments, and the risk of duplication of or gaps in scanning etc. There were also gaps between the trust and my GP (I was insufficiently aware of my GP's role post treatment) and between different trusts, which seem unable to share my records and results. I stress that no harm was done to me and the care I experienced was very good - but this added a burden of indecision, when my focus needed to be on the treatment. My Specialist Oncology Nurse was a lifeline throughout my treatment and recovery, making the huge and fragmented NHS appear as seamless as it could be. This role needs greater recognition.
- I was bewildered and frightened when I eventually discovered that my pathology records contained a significant error that led to conflicting advice being given to me by my Oncologist and Surgeon about the need for radiotherapy. It undermined what was already fragile trust. I was very reassured by the protocol subsequently developed at the Royal Glamorgan Hospital – an indication of quality care and good safety practice by the Trust.
- The treatment plan I had was clear, coherent, timely and robust; the follow-up was unclear, fragmented, flimsy and uncoordinated, with no timescale or planning. This may seem heretical to many practitioners, but to my mind, achieving a good recovery and quality of life after treatment are just as important as undergoing the treatment itself. Otherwise, what's the point? I thought that the immediate follow-up to my treatment was poor in every respect, of which being told to eat ice cream and stop being depressed by someone

who couldn't explain why he or I were in a room together is just one trivial example. Post treatment support needs to be coherent, patient centred, timely, accessible, and planned.

- I know that as much as realistically possible has been done to get rid of my cancer and stop it from returning, and that my chances of survival have been significantly improved because of the treatment. However, I had no idea that it would take me so long to recover from the treatment itself – and I remain haunted by the advice I was given in the early days of treatment – that it was surely worth my while spending 6 months of my life undergoing treatment so as to enjoy a further 30 years of life. I'm sure that it was well-meant, but it was unrealistic. In hindsight it took me much longer than 6 months to get back on my feet, and the prospect of living another 30 years (until I'm nearly 90) with chronic pain may not be as attractive an idea as it used to be. I found this advice unhelpful then, and now it irritates me. The truth (that we just don't know how people will be affected by treatment) would have been more acceptable. Unfortunately, the level of trust we place in advice we are given is determined by its 'weakest link' – and some of these links were very fragile.
- I would not like to have to estimate the cost of all my cancer treatment or the subsequent investment in getting me back on my feet. I count myself very fortunate and I fully appreciate the immense value of the help and the benefits that have resulted. Others may question the affordability of this, and its accessibility and appropriateness for all, but I would simply point out that I too have invested time, money and effort into making this approach work for me. Showing me the way, and enabling me to work things out for myself, has been invaluable for me. It has also prevented me from becoming a burden on the community.

Section C: Pain Management

Chapter 11: Introduction

All the advice I was given and the information I read on the Internet suggested that the main focus of my attention throughout my first line treatment should be on getting through it. I followed this, but as time went by I became aware that the after-effects were lingering. At my first annual review after surgery, the Senior Nurse Practitioner told me that the pains in my upper body – ribs, breast area, neck, shoulders and arms – were just ‘early days’ and they would get better, but six months later (18 months after my surgery) my Oncologist and my GP had both concluded that I was suffering from chronic pain.

I have only recently discovered just how prevalent post breast cancer surgery pain is, affecting around half of all patients⁶. Initially, I thought that I was on my own and then I thought it was my fault – something that I had done or not done had contributed to the problem. Why did it have to happen to me? Would anything have been different if I hadn’t allowed myself to be rushed into the chemotherapy / radiotherapy so soon after major surgery, if I hadn’t continued to work and remain active throughout the treatment even though I was below par? Was it my sensitivity to drugs or the fact that I hadn’t managed to take a lot of steroids? Was it the breast implants? I have repeatedly asked myself and others these questions over the past three years. It is a waste of time; there is no going back and there are no answers; I have to move on.

I have to acknowledge, though, that I had a significant amount of treatment within a very short space of time – a bilateral mastectomy, chemotherapy, breast implants and radiotherapy within nine months, with hormone therapy starting straight afterwards. The miscellany of pain - nerve pain in the mastectomy area and my arms, peripheral neuropathy in my hand, and joint pain across most of my skeleton – shows little sign of abating. Whilst I manage it better, it has altered my life and I carry it along in my rucksack on a daily basis.

I have been lucky. My chronic pain was recognised relatively early and I’ve had a great deal of help in learning how to manage it.

This section describes the steps that have been taken to help me. Some of this help has been available within the NHS, other parts were available from the voluntary sector or provided commercially. The main people signposting help for me were my Specialist Oncology Nurse and my GP. I also got a lot of tips from my local Breastfriends group. Some of it is also based on interpretation of information that I found for myself and my willingness to explore new ways of applying advice I gained from others to address my needs.

⁶ Journal of the American Medical Association, vol 302, No 18. November 11, 2009 Gartner et al, Prevalence of and Factors Associated with Persistent Pain Following Breast Cancer Surgery - other references are included in the information section.

I start this section by describing my pain sensations, as this helped me to understand what I was up against, has helped me to communicate with the people caring for me, and has helped them to find an effective way of dealing with me. Tackling my pain has involved tackling the physical, emotional, spiritual and mental overload and searching for the things that make me feel less burdened and more at ease in my body. There are four critical aspects to this: physiotherapy, mindfulness meditation, pain management planning and creative writing. I end the section with a short chapter on what happens to me when I exceed my limits.



Walking at Cwm Cadlan, Brecon Beacons, October 2009

Chapter 12: Describing my pain

The first thing that breaks my consciousness as I awake and the last thing before I go to sleep at night is discomfort. I find two aspects of this particularly difficult: the first is that it never goes away and the second that the nature of the pain and discomfort varies in different parts of my body. I didn't expect any of this, wasn't warned that it might happen, don't understand how it came about, and can't quite accept that it may never go away. It has changed my life because my body used to be a comfortable place to be; but now it's not. The stress of living with this constant pain and discomfort saps my energy and constrains my well-being.

I only really began to manage my pain when I could coherently describe the experience. It's over a year since I first did this. The pain itself has not changed at all, but my ability to tolerate it and my emotional attitude towards it have both changed. The process of writing about it for the first time was difficult as initially, it exacerbated some of the sensations. However, getting to know it intimately has helped to detach me from the 'secondary suffering' that I experienced a year ago as it has somehow helped me to divorce myself from it. It has also helped me to become more indifferent to others' perceptions about my ability to cope. This has been a slow process and I've had a huge amount of help.

Before they happened to me I would not have believed that the sensations I experience existed. Let me attempt to describe them. In my hands, arms and upper body I have a constant deep hum, like a droning bee buzzing around, prickling my skin, absorbing my energy and pulling me down. This part of my body is sensitive to the external environment, particularly to hot or cold weather, to windy conditions and to water and the sun. This is a sensation rather than a pain like a head-ache; it is a restless tingle and it is unpleasant. I feel the need to wrap myself up, not from the cold, but from the outside – and also to give my outer layers some support and protection from the elements, especially around my shoulders and arms. I have this same feeling as I get tired, or if I've been sitting for a bit. The sensation most near to it is like very low frequency, but loud chanting in a very small space, like monks in a temple; it never stops and eventually you have had enough of it and need to get out of the room. The buzz of a strip light, the wind, or the sound volume from the television being too high will all aggravate it in the same way as this low frequency hum. Things that help most are the peace and tranquillity of the countryside, beautiful music, lovely scenery – in fact anything that supports the senses without overloading them. Chronic pain is draining, and there is a need to support those good things in me that otherwise could be lost.

Whilst I have other pain that 'hurts' more, this 'neuropathic' pain is the most debilitating element. This sensation never goes away – I take it out with my family, on holiday, to work or choir practice, on walks and to bed. Sometimes I manage it better: when I'm diverted, enjoying what I'm doing,

less tired, or in a positive mood. If I'm stressed, tired, away from home, or not wholly able to control things, the sensations start to attack me, making me feel vulnerable, struggling to eat, having hot flushes and cold sweats, thirsty, needing to escape, and irritating my bladder. If I let things go too far, I get the feeling of being trapped inside the shell of my body looking on at the world outside of which I'm not really a part; when this happens to me it takes hours, or even days, to restore myself. It's better not to get to this point!

As well as the droning, tingling sensation, I have cramp like pain in my arms and hands, making the conventional handshake something to avoid. Again, it's always there. I particularly notice it when I'm trying to cut bread, peel vegetables, peg out washing, open doors, open tins and jars, put a coin in a shopping trolley, lift the kettle or saucepans, take the handbrake off the car or drive around a corner, or even switch on a light. I need to rest my hands on a cushion, arm of a chair, or against my body when I'm walking or sitting down; I take regular breaks when I'm sitting at the computer. During each day, I frequently stretch my arms, rotate my shoulder blades, massage my arm pits and keep my upper body moving. I've managed to keep the mobility in my arms, and although I've lost some flexibility, dexterity and strength in them I can still do most of the things I used to do.

Another sort of pain that was caused by the mastectomies is that some areas in my breast area, under my arms and into my ribs at the back are numb. There are spots on my breast bone, and across the ribs under and over my left breast that feel like they've been pierced by a steel wire, which is either very hot or very cold and very sharp and which burned or froze my flesh. Some places are painful to the touch, and some points, when touched, create a sensation somewhere else (e.g. if I massage my breast bone, it affects my funny bone). These pains affect me more when I'm relaxed – which makes it difficult to relax.

Another element of this particular area of pain is the continuing tightness across my chest. Initially I thought that this was because the implants were inserted under my (stretched) pectoral muscles, and that it would go away as the muscles and tendons got more used to their new position, but two years on it's clear that this isn't going to happen. This tightness makes it painful for me to take a deep breath and I consciously push myself to do this. I find it hard to maintain the good breath control needed for meditating, singing and walking, when I'm tired and so it's important to me to keep practicing. Singing in concerts, concentrating on the music and staying within the limits of my pain remains a challenge which I haven't always mastered – but I will!

Most of the specific pain that came directly from the chemotherapy disappeared once the treatment finished, but pains in my toes and my ring finger – especially around the nails - have lingered. I find it frustrating when practitioners who have no knowledge of chemotherapy and its long term effects tell me that, for example, losing toe nails or having pains in my nails are 'nothing to do with the chemo' - because I did not have these problems before the chemotherapy and I am sure that they are chemo induced.

The chemo also made me restless – possibly ‘the fight or flight’ reaction to discomfort or a feeling of being poisoned – and I also think that the buzzing skin assault has as much to do with the chemo as the surgery. For some reason the assault on my body which took place over the 9 months after my diagnosis was too much for me to cope with – and I’m still in the process of recovering from it.

Before all this started I lived with a bad back, which meant that I’ve had to support my back, sit upright for short periods, and keep my lower back warm. Arimidex has exacerbated my back pain and has also caused joints, hands, wrists, ankles and feet to ache. When it is hot and humid or cold and damp I ache more. The aches wake me at night. Trying to get comfortable means keeping warm, but not too hot, keeping my hands and feet moving, but not too tired, pacing my day, including limiting the driving, shopping, hanging up washing, standing, sitting at the computer, singing etc.

So living with chronic pain means that day and night I am on the move. This takes a huge amount of energy and over the months, I have also battled with fatigue, trying to maintain my weight and a feeling of being constantly overloaded, physically, emotionally, psychologically and spiritually. If I exceed what I can manage, I ‘pay’ for it – through not sleeping, having bad dreams of not being able to live independently, feeling tired or unwell for a few hours or days. It is therefore vital to my well-being to manage my chronic pain effectively and stay within tolerable limits.

Chapter 13: Physiotherapy

I was very fortunate to be referred to the Physiotherapy Department of the Caerphilly and District Miners Hospital, where Sue Jones, a senior physiotherapist took me on as her patient in January 2007. I had been referred because of post-mastectomy pain, presumably because it was thought at the time that something could be done about it, and the need to maximise my mobility following the surgery. After a couple of sessions my chemotherapy kicked in and we agreed that I wasn't up to pushing myself too hard. I had a break until October 2007, by which stage I was through the chemo and radiotherapy.

Sue gave me confidence that I was doing the best for myself and the courage to keep trying. She employed several strategies: showing me exercises to strengthen and mobilise and yoga movements to achieve a good practice and balance, which I practiced between sessions. She invited me to hydrotherapy sessions, strapped my back, and gave me acupuncture. I continued to see her every two to three weeks for about 18 months. I was aware (although she at no stage let me worry about it) of her targets, and the constraints on her keeping patients with chronic pain, who were making negligible progress.

I fear that it must be frustrating for practitioners, when their patients make imperceptible progress. My physiotherapist made a big difference to me because she encouraged me to aspire to the limits of what I could do, without expecting great results. She told me that I was doing well, explained how to treat my allodynia (the skin pain that comes with neuropathic pain). She explored different acupuncture points and tried to make me feel better in myself, as this ultimately made the pain more manageable. The fact that she thought I was worth helping has made all the difference to me. She never gave up on me and did not allow me to lose hope at a critical time in my recovery. Her kindness, patience care, and practical support has made her one of the special people in my journey.

Before I was discharged in March 2009 we discussed a series of exercises – see table overleaf. I also had a stress ball to exercise my hands, an acu-pen to stimulate key points on my arms and shoulders and a TENS machine – all of which have a place in my toolkit. I also make regular use of a hot water bottle and microwavable scarf, sit with cushions around me, and have a footstool to support my back and legs.

After I finished physiotherapy treatment I carried on with the exercises, going for walks, and doing my best to manage the pain. However, as time went on I became increasingly uncomfortable and realised that I needed additional help. It was soon apparent to me that although I was trying to manage myself, my fatigue, sleeplessness, pain, lack of energy, etc., there were still some gaps that I did not have the skill or the knowledge to fill myself. Over the next three months I found it increasingly hard to manage all these elements.

My exercise routine – March 2009

Type of activity	Description
Yoga – 5-10 minutes	Achieving balance and calm Recognise the value of stretching
Strengthening – 5-10 minutes	Slow movements with resistance using water (e.g. moving arms and legs in pool or swimming), stretching an elastic band, or lifting a stone or weights
Balance – 5-10 minutes	Stand on one leg and then the other Rock from side to side / front to back Bend knee with feet behind
Allodynia (skin sensitivity) – 3-5 minutes	Stroke affected parts of the skin with a soft cloth, scarf or towel each morning Stroke affected parts with a silk scarf at night Accept that improvement will be slow
Abduction (hips) – 5 minutes	Move hips and feet from side to side Elastic band around knees and splay knees while sitting Stretch using elastic band to strengthen arms
Walking – 30-45 minutes	Enjoy a little every day...

At my next 6-monthly appointment with the Oncologist I discussed these concerns and we agreed that I should go back for more physiotherapy. I was taken on again straight away and given acupuncture and foot massage at regular appointments since then. The purpose of the physiotherapy is to get me to feel better, and thus enhance my energy and tackle fatigue. This should reduce pain and interrupted sleep and stop the pain getting me down. It is noticeable that for the few days after the treatment, I feel better and am able to do more.

I also have advice on an *ad hoc* basis – e.g. where to apply my acu-pen in addressing pain, or lying on hard balls at pressure points to stimulate aching muscles. I have been helped to develop exercises which focus on Mindful Movements, Yoga and Pilates, the aim of which is to improve balance, stability, flexibility and posture. I used to do exercises just to improve my mobility and address back pain. Now I particularly focus on moving my arms and shoulders as gracefully as I can to make beautiful shapes and exercise in front of a mirror to assess the effect. I was advised to take my time, to be aware of my breathing, to enjoy the exercise and to feel the stretches and the pauses. Over the last few months I have made progress and, although my pain is not improved, my balance and strength are.

I have also tried to develop a more strategic approach to addressing my pain, conserving my physical well-being and maintaining my mobility, strength, flexibility, and posture. I don't do everything on the list every day, but I do each of them at least once a week.

My exercise routine – July 2009

What	Likely cause	How
Joint pains - feet, ankles, shins, thighs, hips	Arimidex	<input type="checkbox"/> Abduction hips - elastic band around knees and ankles, <input type="checkbox"/> Stretching in morning, <input type="checkbox"/> Rocking knees side to side with arms above head , <input type="checkbox"/> stretching and moving from side to side, arching back, <input type="checkbox"/> Yoga exercises - small movements delicate balance, stand upright <input type="checkbox"/> Kneel down with feet behind and touch toes behind
Pains in arms and hands	Surgery / chemo	<input type="checkbox"/> Rest arm in pocket / on table <input type="checkbox"/> Wear gloves <input type="checkbox"/> Keep hands moving - but limit time on cutting, peeling, weeding <input type="checkbox"/> Massage hands <input type="checkbox"/> Stress ball
Pains in back, shoulders, neck	Surgery	<input type="checkbox"/> Keep moving <input type="checkbox"/> Go for walk (45 min each day - more when I feel good) <input type="checkbox"/> Don't get too hot or too cold <input type="checkbox"/> Stretching <input type="checkbox"/> Lie down or sit quietly and try to get comfortable for a short time
Pain around mastectomy area and in ribs	Surgery Chemo Radiotherapy	<input type="checkbox"/> Breathing exercises / meditation <input type="checkbox"/> Massage the area with aqueous cream to keep skin moist <input type="checkbox"/> Hot pepper cream - helps but burns skin <input type="checkbox"/> Walking - avoiding stress - music and calm
Fingernails and toe nails - pain	Chemo	<input type="checkbox"/> Wish this would go away - nothing helps <input type="checkbox"/> Soak feet in warm water and massage feet
Fatigue	everything	<input type="checkbox"/> Walking and keeping active physically <input type="checkbox"/> Focus on mobility / agility / strength and stamina <input type="checkbox"/> Mind exercises / creative writing <input type="checkbox"/> Balancing physical, mental and emotional energy
Lack of strength in arms	Surgery	<input type="checkbox"/> 5 mins each day - stone - elastic band - use tins as weights <input type="checkbox"/> Slow movements
Balance	Pre-existing	<input type="checkbox"/> Stand on one leg and then the other <input type="checkbox"/> Rock side to side and back to front <input type="checkbox"/> Bend knee - feet behind
Allodynia	Chronic pain	<input type="checkbox"/> Soft cloth in the morning / wrapping myself up in a light wrap <input type="checkbox"/> Wear warm light weight clothes that protect the shoulders
Tight chest / breathing	Arimidex	<input type="checkbox"/> Breathing exercises & Mindfulness of breathing <input type="checkbox"/> Walking fast up the mountain and trying to expand chest <input type="checkbox"/> Singing - focusing on long breaths and exhaling slowly

Obviously the physiotherapy service is a scarce resource, which will not be available to me indefinitely, but for the time being, I'm so grateful to have it.

Chapter 14: Mindfulness

Breathworks course

Mindfulness is a type of meditation that involves focussing your mind on the present. To be mindful is to be aware of your thoughts and actions in the present, without judging yourself. Research suggests that it may improve mood, decrease stress and boost immune function.

The Mindfulness course I went on is run by 'Breathworks' at the Buddhist Centre in Cardiff in 8 weekly 2½ hour sessions. It was recommended to me by my GP, Dr Rob Jones, largely because I responded so poorly to the pain management medication he prescribed.⁷ This course was a bit of a risk for me – I hadn't done anything like this before, had to travel to Cardiff in the evening to take it, and to commit for an 8-week course and daily practice. My mother kindly paid the course fees for me and I didn't have anything to lose by taking it. Before the course started in September 2008, Atapini, the course leader contacted me to tell me of the course requirements and suggested a 500 page book *Full Catastrophe Living* by Jon Kabat-Zinn, an American psychologist who had developed the course concept in the 1990s.

The course seeks to focus on two key principles: (1) the need to focus on the present moment and (2) to respond, rather than react, to our circumstances. It included the following elements:⁸

1. **Breath awareness:** learning how to use the breath to soften resistance to pain or let go of tension
2. **The body scan:** developing awareness of the body
3. **Mindful movement:** based on yoga and pilates
4. **Mindfulness of daily life:** pacing, keeping diaries, developing realistic awareness of our limitations and boundaries
5. **Three minute breathing space:** bringing a sense of calm, peace, and presence into your daily life
6. **Mindfulness of breathing:** learning to listen to ourselves and our needs
7. **Kindly awareness:** becoming aware of the pleasant and unpleasant aspects of our own experience and broadening our awareness to include other people; developing empathy with our pain
8. **The human condition:** broadening our own experience and developing acceptance.

⁷ Further details of this course and a similar course in Caerphilly are shown in Part E

⁸ Many parts of the course are covered by the Expert Patient Programme, run in the community over 6 weeks to help people with chronic health problems to manage their long term health. Further details: www.eppwales.org. Course handbook: *Self Management of Long Term Health Conditions: A handbook* ISBN 978-1-933503-12-7

Course diary

I was talking with my partner Dick about my expectations from the course, and how I would assess its value. He suggested that I keep a diary of my experiences. The diary I kept outlines what we did on the course, how I responded to it, and how I felt from day to day. Some of the benefits of keeping the diary were to identify the limits of my energy, showing me how to pace, identifying the things that I could not do easily, facing the unpleasant whilst focusing on the pleasant.

Reflections on mindfulness

What I learned

- Managing pain is about knowing and managing yourself; it requires you to achieve a balance and take yourself towards the rather vague concept of where you want to be - this means:
 - being honest about your limitations and what you can do about them
 - deciding what's most important to you (e.g. I might have made more progress if I hadn't needed to continue to work, or attend meetings, or not give in when tired - but I might have felt depressed or felt that I wasn't doing my little bit)
- No-one can cope with the whole gamut of life - dealing with bite sized chunks makes it possible to focus on the detail and take decisions
- Rational thoughts are much faster than emotional thoughts; decisions about living should be based on both
- That sometimes I need to show my 'private face' as well as my 'public face' (kindly awareness)

What mindfulness can do

- It can help us to take time out without feeling guilty
- It can be achieved through practice - repetition trains us to work in a particular mode
- It can help us to question our daily routine and habits in a systematic, but kindly, way - and thus address barriers to achieving what you really want
- It draws together the physical, the rational, emotional and spiritual being (e.g. with a focus on breathing, the here and now, and on 'being') and thus helps to use what causes pleasure and joy as a counterbalance to pain
- It helps to understand pain, why it feels heavy and drags us down ⁹
- It helps us to recognise pain and acknowledge it and thus face it
- It gives us another set of tools - I find I need very many tools sometimes at the same time

Additional points

- The benefit for me was to be more in control of my life - I felt much better with 'user-led' rather than system-led solutions
- Mindfulness led me to get equipment to help me - heated gloves, potato peeler and better knives - also taught me to ask for help with cutting things
- I probably would get even more from mindfulness if I worked from time to time with an activity diary (but this takes time to do properly and for long enough for this to be useful).

⁹ For this reason I would always do a body scan from my feet up, in an 'uplifting' direction finishing with the head

This course came just at the right time for me and even though I was not very well throughout it, I started to become grounded at a more stable level of well-being.

One excellent, but unpredicted, outcome of the course was that my daughters on reading my diary identified some gadgets to improve my comfort. The following Christmas I received a microwavable scarf and a battery operated vegetable peeler – both of which remain in daily use.

Practising mindfulness

After the Mindfulness course I continued daily practice supplemented with ‘drop in’ sessions and daily courses at the Buddhist Centre in Cardiff in addition to daily practice. As time has gone on the formality of ‘practising mindfulness’ has gone. In its place is daily practice at intervals throughout the day. This usually starts with a body scan of 20 minutes on waking, followed by exercises and stretching while I’m still in bed. By the time I get myself up and dressed, I have already worked out how I feel and how I need to plan my day accordingly.

The course has taught me that I cannot sit at the computer for more than 15-20 minutes at a time, so the day is interspersed by getting up and stretching, fetching a glass of water, filling my hot water bottle or my microwavable scarf, or walking upstairs or to the back of the house. When I’m out at a meeting or a seminar, I make sure that I get regular breaks and take time out with deep breathing (3 minute breathing space) or standing up and walking around for a few minutes and stretching.

Part of my plan is to get out every day for a good walk. When I’m walking I practice Kindly Awareness, or the Body Scan, Walking Meditation - or simply contemplating myself in the wider environment around me. I tell myself how well I’m doing and how important it is for me to keep going and not give up. When I feel particularly uncomfortable or under par I practice smiling at myself and thinking about how my ‘public face’ hides my ‘private being’ at that moment.

I no longer take eating for granted and mindfulness helps me to relax enough to eat well. I have fortunately got equipment to help with food preparation (e.g. food processor, battery operated peeler, light-weight pans). I plan meals that don’t need a lot of cooking or that can be easily prepared in advance. I ensure that I prepare my meals before my appetite wears off or I’m too tired. I also think about the food I am eating and the benefits I am getting from the food.

Daily chores are also planned in bite sized chunks. My day is completely organised in this way. Mindfulness may seem like a bit of a straight-jacket, but without it, I’m not sure that I would make it through a whole day. For me the discipline of mindfulness saves a lot of energy in balancing the pain and activity with pleasures and rest. I only wish it would do the same for me overnight as it does throughout the day.

Chapter 15: The Chronic Pain Management Service

Introduction

Once again, I was very fortunate to be taken on by the Chronic Pain Management Service. Initially, in December 2007 I went to get medication there, but it soon became apparent that this approach wasn't going to be suitable for me. Later on in 2008 I was approached by Dr Jo Hampson a Consultant Psychologist, and she has tried to see me at 2, 3 or 4 weekly intervals ever since. She has employed a variety of approaches e.g. Cognitive Behaviour Therapy and building on the Mindfulness course, thus helping me to manage my pain.

Some of the more important messages have been as follows:

Messages taught at the Pain Management Clinic

Message	Comment
Being kind to myself	I should always assess my needs and capabilities before committing myself (whether for myself or for others)
Being aware of self and pain	I should not exceed my energy levels – if I do I feel ill, cannot eat, and cannot manage my pain
Don't waste time on things you cannot change	I've spent months agonising about how I got to this point, what to say to others, what others think of me, whether they understand my pain – much better to put this all behind me and get on with my life
Do spend time on things you can improve	Managing my time and my feelings, spending time on things I enjoy, on planning and pacing, actively deciding to cut back on things that are overburdening me are very worthwhile
Be realistic about what you can and cannot do	This means detailed planning when facing new challenges so that you are not suddenly faced with a stressful situation where you are not in control – as this will worsen your pain
Recognise that some days won't be so good	I can give myself permission to take a day off or go to bed for a rest if I don't feel well
Invest in yourself	This means eating well, getting up and moving around when I need to, ensuring that I'm comfortable, get enough sleep, pacing, and enjoy myself, while living life within my capabilities
Celebrate successes and milestones	And don't beat myself up if I don't achieve them.
Don't expect the pain to go away	I'm still hoping one day that it will. Whilst I'm prepared to live with pain – I cannot contemplate fighting further battles (e.g. if the cancer comes back) if I'm still in pain

I'm particularly conscious of the need to be kind to myself, which is mentioned to me at every session. I would have 'beaten myself up' psychologically long ago, if I hadn't been to the Chronic Pain Management Service.

I have also learned the importance of planning for future events and activities as a way of managing pain and keeping it in proportion. The essence of what I have learned about pain management is that the pain is a 'given' – you cannot do anything about the pain. What you can do is to adjust everything else in your life so that the pain doesn't become a burden. This is a very hard lesson to learn – one I'm still trying to grapple with every day.

Pain Management Tools

Keeping a diary

I started this process by keeping a pain diary for a week. This showed all activities, such as breaks, change of scene, when I went for my walk, how I felt at different times of the day etc. As can be seen from this I experienced quite a high level of pain – in March 2009 it was never below 7 out of 10, but it got worse as I became more tired or didn't give myself a break when I needed one.

Extract from Day 2 Diary

Time	Activity	Pain score at start	Pain score at end
8.15 - 8.45	Got up, dressed and breakfast, exercises	7 – nice relaxed breakfast – food for today prepared	7 lovely morning and despite disrupted sleep felt good
8.45 – 9.45	Responded to e-mails and wrote up notes of last meeting	7 -	7 – had to work quickly but everything was organised
10.00-12.30	Meeting with CC (libraries) in conservatory	7 I moved around as much as I could – went to get a drink	8 the sun on my arms is very uncomfortable – took off layers
12.30 1:15	Lunch	8 I tried to keep very relaxed and quiet	7
1.30-2.30	Walk	7 Still very uncomfortable - too hot / cold pain around shoulders / back /arms	7 pleasant walk – I don't feel 100% - can't put my finger on anything
2.30 – 3.15	Computer work with journal	7	7 I'm starting to get very tired
3.30 – 4.45	Manuscript Central course	7 on the telephone for an hour's computer training from US	8 this was much too long and its late
4.45– 5.10	Snack and drink of water	8	7
5.10-6.30	Archiving with Vicky	7	9 – this was meant to be for 2 hours but I'm too tired
6.30 – 8:00	Cooked and ate evening meal and rested	9 lay very quietly on sofa for a good hour	7
8:00 – 9:00	Telephoned Mother, responded to e-mails	7	7
9:00-10:00	Journal	7	8
11.15	In bed	8	Did not sleep well – woke at 2am, 5am and 7am & I ache

Extract from Day 6 diary

Time	Activity	Pain score at start	Pain score at end
8:05 – 8.45	Got up, dressed, breakfast, exercises	8	8 – very uncomfortable night – did not feel well
8.45-10.45	Report writing	8	8 – hands ached and arms tired
10.45 11.15	Respond to e-mails	8	8 – this isn't a good day – cold and damp and I must keep moving
11.30 -12.00	Meeting	8	8 - my neck is bad today and I have a head ache
12.00 12.30	e-mails	8	8 – I'm hanging in there – aching all over but managing
12:30 – 1:15	Made a snack for lunch	8	7 – still aching but its not stressing me out too much
1.15-2.00	Went for a walk up mountain	7	7 it was nice to get out and get fresh air, but very windy and cold - my feet, knees, back and neck are aching – but I feel better
2:00 – 4:00	Computer work	7	7 This was a creative writing exercise which I enjoyed very much. My hands ache
4:15 – 7:00	Meeting with an associate	7	7 I had a very nice time, but I'm tired
7:15- 8.30	Evening meal and made a couple of calls to family	7	7 enjoyed this meal, but I'm in pain - under pressure to complete agreed actions re voluntary work
8.30 - 10.30-	Report writing	7	8. enjoyed writing this – but should really have stopped before now.
10.30- 11.45	Complete activity diary Went to bed	8	9 - this was the last day – my body is really stressed – back ache, shoulders and arms especially, painful feet and my skin is prickling from the stress and I feel very sweaty. Go directly to bed. [Slept badly]

Although I kept this diary for a week, I have reproduced scores for only two days as each day looks much the same.

The diary enabled me to start working on a plan. The points I drew from the diary were:

- Working at the computer needs to be controlled, somehow: this is difficult because it is a large part of my job, but I need to ensure that I have breaks (even when I'm absorbed by or enjoying what I'm doing)
- I must limit the duration of meetings – and give myself permission to get up after 20-30 minutes
- There seems to be very little I can do to address the pain in my arms and hands – therefore ensuring that I don't overuse them is essential
- My pain is increased if I am stressed or fatigued and it takes time to reduce it
- I need completely different activities for my breaks – eating and drinking, meditation / breathing spaces/ a good walk / physical movement and yoga – most important is the need to keep moving
- I am frequently fatigued – so good breaks at lunchtime and late afternoon are important part of my routine
- If I go to bed too tired or too uncomfortable, I sleep badly.

- I'm much affected by my environment – although I need to be outside in the fresh air, the wind and cold affect my pain and I need to make allowances for them; also being in direct sunlight makes me very uncomfortable
- I may have to 'pay' for doing something that I want / need to do – I need to think about this before starting.

Six months on, one of my ongoing tasks will be to take another diary for a week to see whether I've moved on at all. I've kept a pain diary for one day recently and experienced similar pain scores, which suggests to me that I have reached a plateau, a point where I can only maintain my position and prevent it from getting any worse.

Keeping a diary for a longer period than a week might also be useful in exploring how well my planning and pacing is working for me – or whether some other intervention or tool is needed as well.

Developing a Pain Management Plan

Activities are important to me because they improve the quality of my life, are an element of my job, or are part of my 'social contract' with others. However, I cannot do everything I want to and need to prioritise and plan to ensure that I contain my pain and stay within the limits of my energy. If the pain becomes aggressive, I get a cold sweat, my clothes become uncomfortable around my skin, my mouth becomes dry, and I feel thirsty, I need to pass water, and I may feel sick. Getting into this state is horrible. If I get too tired, I feel ill, I lose my appetite and I cannot sleep.

General measures to take are:

- breaking up the activity into manageable parts
- breaks throughout the day, including having breaks from speaking to people
- a regular walk where I can contemplate things / free my mind,
- limiting the time spent in any one day being active,
- time out including exercises, 3-minute breathing space, quiet relaxed music or no sound, getting a breath of fresh air,
- wearing light clothes which don't put pressure on my chest, arms, back and neck and wearing gloves and heavy socks to support hands and feet,
- avoiding heavy meals and drinking plenty of water.

Managing meetings and events

This was the first activity I decided to plan for. I was finding it difficult to Chair a meeting as I had to concentrate on the 12 board members who were keen and lively and I wanted to get the best out of them over the 4 hours they were in the meeting. I find sitting in meetings stressful, largely because of the need to concentrate for long periods, when my survival plan gives me permission to break things up into manageable parts.

Event 1: Plan for Chairing a Board meeting

Potential hurdles / my feelings	How to address them
Meeting starts at 11 and finishes around 3 p.m. There are 25 items on the agenda, 12 board members to keep in order, and some complex issues. I want to retain the sharpness of the meeting and trustees' confidence in me. There is a buffet lunch and trustees are encouraged to speak to the staff. I don't want to get too tired.	<ul style="list-style-type: none"> ▪ Thorough preparation and good briefing ▪ Early night the night before ▪ Not too many things to do before I leave ▪ Get there early enough and ensure a comfortable chair ▪ Bottles of water to hand ▪ Take my food with me ▪ Taking deep breaths whilst papers are being presented ▪ Concentrate on appearing enthusiastic ▪ Check out how I feel every half hour ▪ Finding a way of resting my arm so that it doesn't get too tired ▪ Taking jacket off if I start to get warm; shawl on if I get too cold ▪ Concentrate on relaxation as much as I can ▪ Disappear to the ladies at the break ▪ Don't hang about at the end – get home quickly and relax for at least half an hour ▪ Go for a walk ▪ Don't do too much for the rest of the day ▪ Early night

Result: I was very tired after this and even though I did everything above to try and feel better I still felt fairly wretched when I left the meeting. It was a lovely day and I went for a walk once I got home, but I was too tired to eat well. I had a little rest early evening, but had an interrupted night's sleep and woke the next day feeling tired, although I did make choir practice that evening.

A few weeks later I had to give a presentation at a public event in Cardiff. I would have taken the bus, but had a dental appointment beforehand and was pushed for time. I had the added challenges of driving into the city, finding parking and getting there on time and being sociable in a broader arena, but otherwise the planning and result were similar.

I was so tired after this event that I decided to review my voluntary activities with a view to cutting back. In March 2009 I tendered my resignation to another Board I had been on for 10 years. Six months later I have no regrets about my decision, but I still believe that most of my fellow board members have no real understanding of the factors that led to my decision and I do regret this.

Managing visitors and social events

People say that managing visitors and social events should be less strenuous and more enjoyable than work related activities, but to my mind they bring their own challenges. It is much easier for me if people come to visit me because I have control over my environment, my food, and the timetable. Originally this involved Dick and the girls in a lot of work, such as cooking and cleaning, but I've recently engaged a cleaner, which has made a world of difference for me.

Example 1: Dinner invitation.

This started at 8 pm on a Friday, when everyone had been at work all week. Dick wasn't able to come. The hostess was meticulous in her preparations, consulting on menus etc. I was given a lift there and back. But I was very tired and cold; we did not eat until 9.30 and did not leave until 12.30 am. It took a few days to recover and I felt that I let everyone else down because I was unable to enjoy this to the full.

Managing bigger social events: a trip to London

My very dear Aunt Erika celebrated her 80th birthday in April 2009 and the whole family was invited to the party – a dinner in a restaurant not far from my aunts' and parents' homes in North London. Vicky, Kate and I wanted to go. I got Vicky insured to drive my car so that we could share the driving. We left early and had a relaxed day and lovely family meal.

The good parts were the pleasure we gave, the support the girls gave me when travelling, the lovely afternoon walk, and the lovely evening. Aunt Erika, back on chemo, really enjoyed her party even though she found it exhausting. The event has brought a lasting good feeling for me and my Aunt, who are uplifted by these pleasant events that connect us; it is very important to make them happen.

The bad part of the trip was we had to get up at 5.30 a.m. the next morning so that we could get back to Caerphilly for Kate's work. I spent the next five days recovering from lack of sleep, the burden of travelling and being in pain. It served as a lesson to me to avoid travelling too early in the morning or too late at night.

Managing working trips

Part of my job involves travelling to other parts of the UK or Europe. Whenever I feel daunted by this I remind myself that I do not want to accept that cancer and its treatment has stopped me from doing anything.

In the spring and summer of 2009 I committed myself to undertaking some fieldwork in Coleraine, Northern Ireland, to addressing a conference in Oslo and to attending a conference in Edinburgh.

When the Oslo conference was cancelled, I was very relieved. It made me realise how much I had been dreading the trip – this is not like the ‘me’ I used to be. This has made planning vital for me.

Example 2: Plan of action for the trip to Coleraine.

This is based on an outline that Dr Jo Hampson gave me. It seemed sensible to separate all the elements of the trip as part of an overall plan. I had not been to the hotel before and knew that we were reliant on a hire-car to carry out the fieldwork. This was a three day trip and I needed a plan for 72 hours. I went with my colleague Alain and here is the plan.

1: Planning the activity in advance

Potential hurdles / my feelings	How to address them
Find that last minute extras are stressful. Hotel - will it cater for my needs/ be comfortable?	<ul style="list-style-type: none"> ▪ Plan all the fieldwork well in advance and agree who is doing what ▪ Negotiate a timetable to include breaks ▪ Order some extra pillows in advance; take hot water bottle ▪ Take some dry stores with me - nuts, fruit, chocolate ▪ Tell Alain about my needs - e.g. for breaks, rest, recovery and fill gaps in food provision from local shops ▪ Plan for all the times outside the fieldwork - time to be alone and relax / meditate / yoga / physical movement

2: The journey

Potential hurdles / my feelings	How to address them
Travelling difficult and stressful - worry about traffic, parking, checking in and carrying bags	<ul style="list-style-type: none"> ▪ Purchase a new easy to manage suitcase ▪ Take clothes that I can wash / dry overnight if necessary ▪ Travel light ▪ Include shawl, warm jacket, walking shoes and walking gear ▪ Not travelling until afternoon - don't rush the morning ▪ Lunchtime walk ▪ Pack in plenty of time ▪ Leave in plenty of time ▪ Take food and water (see below for travel pack of food) ▪ Plenty of deep breathing ▪ Relaxation on the flight ▪ Don't decline any offers of help

3: Managing the fieldwork

Potential hurdles / my feelings	How to address them
Keeping warm and comfortable	<ul style="list-style-type: none"> ▪ Take shawl / wear layers to cope with the environment each day ▪ Wear comfortable clothes - short walking breaks during day ▪ Take time out - 3 minute breathing space between interviews ▪ Eat a small meal at night and go to bed early if possible ▪ Prepare each night for next day ▪ Concentrate on relaxation as much as I can ▪ Short walk before each day's activity
Breaks during the day	
Finding vegetarian food - small frequent meals	

4: Recovering

Potential hurdles / my feelings	How to address them
Every time I have done something with travelling, I have come back very tired - I've a dinner party the next evening	<ul style="list-style-type: none">▪ Go for a good walk▪ Early night▪ Eat what I can - don't push it if too tired▪ Don't expect to have a full night sleep - get up if need be and sleep in the next day▪ Have a rest in the afternoon

Result: I planned this well. I sufficiently acknowledged how tiring fieldwork is - concentrating on what people are saying, recording accurately etc. I did everything I set out to do: I walked along the Giants Causeway, took some lovely photographs, got fresh air in the morning and evening, ate all my snacks, picked up extra fruit and yoghurt, exercised and looked after myself as well as I could. I was very tired and in considerable pain when I reached the airport for the journey back, but I was in remarkably good shape considering what I had put myself through! I was pleased with myself – pleased that I'd generally anticipated the areas where I was vulnerable and had a way of addressing these before they became a problem. Unfortunately, on our way back we flew in a propeller plane and the hum from the engines set off my neuropathic pain and allodynia, which took about 10 days to settle down.

This should have made me more confident about planning my holiday and my trip to the conference in Edinburgh, but when I got to these I realised that I had the same fears, the situation would not be quite the same, and I would need to plan the event as meticulously as I did for Coleraine – with an ongoing risk that something unforeseen might arise. I did make a comprehensive plan, considering all the risks and options and in practice the trip went largely according to plan. In July I had to go back with my colleague Alain to Coleraine for the day – also on the propeller aircraft. I had told him about the allodynia, and he kindly booked seats for us at the very front of the plane in front of the propellers, and I suffered much less.

Tips on travelling:

- Travelling is very stressful - need to plan every step of the way and try to anticipate every difficulty, so that you limit the stress and consequent pain, discomfort and fatigue
- Hourly stops when driving - 10 minute break - 3 minute breathing space, deep breathing, moving and yoga stretches, walk around the car, drink of water
- Limit the amount of travelling you attempt in one day and over a few days - it's fatiguing - it's very tiring
- When driving make sure you are comfortable - e.g. put a pillow in front of you so that the seat belt doesn't press on your chest; put a pillow on your lap to support your arm
- Managing luggage - a big problem when using public transport - get help, travel light and avoid situations where you have to lift or drag heavy luggage - I now limit my main luggage to 5 kg and hand luggage to 2 kg
- Avoid carrying papers for meetings - arrive early and get them printed up on arrival.
- Try to avoid being jostled around on buses and travelling in crowds
- Include in your plan a recovery programme- it's then that fatigue sets in!

Planning my birthday celebrations

I report on this as it provides a measure of the extent to which I have had to adapt commonplace activities to suit my life as it is now.

My twin sister, Jane and I reached our 60th birthday in July 2009 and we wanted to celebrate together. Jane lives in New Zealand and had planned a trip to Europe around a conference in Cork, Eire. We agreed that we would celebrate our birthday together in August in London at the end of her trip and before the beginning of my summer holiday.

My family wanted to give me a party, but the thought of a large celebration was a worry. Instead I decided to celebrate with a series of birthday events – lunches, going for walks, dinner, and tea parties. I got to know two new restaurants, went to Bristol to see a college friend, and enjoyed most of the other activities at home or close to home. There were 3 lunches, 2 tea parties, 2 dinners and 2 walks, plus a lunch and buffet on my actual birthday. My friends are wonderful. The celebrations were really lovely. Dick and the girls had done everything possible to give me a birthday that was exactly right for me. I'm so fortunate to have them.

The activities started in mid July and were over by 31st July. I was really tired by then. The weather in July was quite changeable and I had done a lot in the three months before – with a full programme of singing in concerts with my choir, travel, work, my voluntary activities, and excitement. I spent time doing almost nothing for a few days, trying to recharge my batteries and feel that I could manage again. I also cancelled a few activities.

Family weekend in London

I phoned my twin sister Jane to wish her a belated happy birthday and to finalise our plans for our joint weekend in London. We had arranged a Primary School reunion, a birthday lunch for all the family at our sister Judith's house, a visit from our brother David on his way back to Washington DC, and a trip to see an old family friend in Cambridgeshire. Jane told me that her daughter Lizzie had arranged a surprise on the evening before my holiday - would I be at Piccadilly Circus at 6.30 pm? Alarm bells rang for me and I told Dick. In fact, my girls were part of the surprise; they had arranged to go up to London for the day, meet for a light snack and see a show. Dick made them tell me the plans and give me time to plan it.

Whilst I'm sad that they were no longer able to give me a surprise, I think we all recognised that I would not have been able to cope with any of it had I not been able to plan it. As it was, I managed to enjoy each element of the week-end as fully as my energy levels allowed. I took regular breaks and did not allow myself to 'engage' all the time. The spontaneous evening imposed the greatest load on me – travelling into London on the tube at rush hour, a quick meal, getting to the theatre through the crowds, the loud music in the show (*Mama Mia!*), the emotions of saying goodbye to

Jane for another year and my girls for three weeks, getting home, getting to bed and having to be out by 9 o'clock the next morning. It did take me several days to recover, but again, it was worth it and has provided me with a warm and very happy memory.

I prepared a plan similar to the ones already outlined above. One element that I haven't mentioned is accommodating the need to eat regularly and frequently - since the chemotherapy and hormone therapy I manage only small meals, but also seek a variety of food to ensure that eating less doesn't mean eating less well. My diet of choice is vegetarian, with no salt, sugar, or wheat and is substantially based on raw vegetables and fruit. I don't feel able to expect others to accommodate my needs entirely. Therefore as far as possible I take my own food and negotiate meals with others. Here is an extract of my week-end food plan.

Example 3: Extract of the weekend plan: food preparation

Event	Plan
Saturday journey	<ul style="list-style-type: none"> ▪ Water (2 small and 1 large bottle) ▪ Apples / nuts / carrot cake for snacks (take 8 apples for 4 days)
Saturday lunch	<ul style="list-style-type: none"> ▪ Eating out: salad - add seed mixture ▪ Buy some fruit, milk and yoghurt on way to flat
Saturday evening	<ul style="list-style-type: none"> ▪ lentil / tomatoes/ courgettes / beans / soya/ butter beans and chickpea dish - prepare in advance and freeze until Saturday - take with me ▪ fruit and yoghurt ▪ take oats for porridge ▪ take rye bread (freeze anything that is left for journey back ▪ herbal tea
Sunday morning	<ul style="list-style-type: none"> ▪ take rice, nuts, dried fruit and seeds enough for 1 week - cook Saturday night for Sunday, Monday and Tuesday ▪ anything left can be frozen
Sunday lunchtime	<ul style="list-style-type: none"> ▪ birthday lunch with Judith - poached salmon and vegetables plus fresh fruit
Sunday evening	<ul style="list-style-type: none"> ▪ vegetarian dish (can be frozen) and vegetables ▪ fruit and dessert (fruit fool); nuts ▪ chocolate - take bars with me
Monday breakfast	<ul style="list-style-type: none"> ▪ breakfast (rice, nuts, seeds, apple and plain yoghurt) ▪ herbal tea
Monday lunch	<ul style="list-style-type: none"> ▪ take a salad with seeds, nuts and beans with me to Mary
Monday tea time	<ul style="list-style-type: none"> ▪ fruit nuts / bread and cottage cheese ▪ fruit
Monday evening	<ul style="list-style-type: none"> ▪ out at surprise - snack when we get in?
Tuesday morning	<ul style="list-style-type: none"> ▪ rice breakfast for me ▪ milk for the girls' breakfast

Three week holiday in Austria

My plan for the holiday was for three weeks and covered everything from the suitcase, food/menus and clothes I was taking, to cleaning the car, times I needed to leave, what I needed to do to ensure that when I got back I could gradually ease myself back into my usual routine without too much pressure. I knew I needed to plan things well in advance, and I negotiated with everyone so that they weren't surprised by my need to manage my day.

I took my pain on holiday with me and I brought it back; I did not sleep or eat better or worse than at home; I wasn't less tired and my body did not feel less stressed. But I enjoyed myself, I renewed my acquaintance with friends there, and I gave my parents a lot of pleasure.

Example 4: Extract from my holiday plan:

1 The journey

Potential hurdles / my feelings	How to address them
Travelling difficult and stressful - worry about traffic, parking, checking in and carrying bags	<ul style="list-style-type: none"> ▪ Packing early in new easy to manage suitcase ▪ Travel light - aim for 5 kg max & layers of washable clothes ▪ Leave in plenty of time ▪ Take food and water ▪ Plenty of deep breathing ▪ Relaxation on the flight ▪ Take warm shawl and cushion ▪ Travel in walking gear ▪ Take mobile phone / camera/ passport / ticket / money/ address book / mp3 player/ crosswords/ book
Eating when I'm stressed and tired	<ul style="list-style-type: none"> ▪ Negotiate with mother what I'm eating and when ▪ When I arrive it will be warm and I need to acclimatise ▪ A walk in the evening

2. Managing the accommodation, food, clothing, and timetable

Potential hurdles / my feelings	How to address them
Food choices - I need to be able to manage this	<ul style="list-style-type: none"> ▪ Take spices with me - everything else is there / can be bought ▪ Take a few recipes and plastic containers ▪ Select places and menus that I can manage ▪ Balance eating in with eating out ▪ Snacks between meals if I need them
Things to do	<ul style="list-style-type: none"> ▪ Material for writing ▪ Notebook and plug ▪ Entertainment - book, music, etc
Doing too much - getting too tired	<ul style="list-style-type: none"> ▪ Plan as much as possible in advance ▪ Get to bed early ▪ Pam there 15th - 20th

Ongoing planning

Dick mentioned recently that I haven't spent enough time with him recently and he needs a change of scene. The girls and he would like to go away with me for a few days, and find it difficult to understand that I can go to London for the weekend, but find a few days in a hotel with them is more daunting. The difference is that when I'm on familiar territory, I simply replicate my coping behaviour. If I went on a family holiday or to stay with friends, the barriers would be: 1) planning for the unknown – the food, accommodation, the timetable etc; 2) not being in control of my environment; and 3) constraining the enjoyment of the others because I can't sit comfortably for very long. I was recently discussing with Jo Hampson about the burdens of having to manage my life, when she asked me why I didn't just do without the plan. I soon realised that without it, I could easily fall off my ledge into the abyss below.

A further development of the planning process was to plan for a longer period and not just for an event. The idea was to get me to think about the balance of my activities and to consider whether I still needed to cut further the extent to which I expended energy. I set it out in order of priority – starting with my health, well-being, voluntary activities and paid work. Two months into the plan I was still broadly on target, although little extras had crept in and I haven't always been able to predict when I'm going to overdo it.

Example 5: A quarterly plan

Date/ Activity	Health	Social / family - pleasure	Voluntary	Editor of IJCS	Paid Work
Sept	Exercises / walk / rests Physiotherapy Pain clinic	Garden project Choir walks Writing Try new recipes School reunion	CDMH meeting Choir practices (4) Keep Wales Tidy	Update - write and circulate Action points from board Set up virtual board mtg IFHE regional meeting New Special issues	Projects
Oct	Exercises / walk / rests Physiotherapy Pain clinic	Photography project New Recipes Toolkit Choir walks (2)	CDMH meeting Choir practices (4) Concert 9/10	Finalise reviewers' list Update Board Copy for January issue Update on manuscripts	Projects
Nov	Exercises / walk / rests RGH clinic Dentist	Visit M & D London (2w/e) Cathy N's 60 th - Bristol (1) Finish toolkit?	KWT Concerts (2) Choir practices (4) CDMH Feasibility study etc 4 days	Journal update Support for guest editors Invite authors to review International Consumer Research Conference 2011	Projects

I have continued with making quarterly plans to ensure that I maintain a balance between the various aspects of my life and do not overdo my commitments. It's all too easy to fill every day and then wonder what you've left for investing in yourself. My focus has to be on the first two columns of the plan (which involve investing in my health, pleasure and well-being), rather than the last two (which involve expending my energy and reserves).

Chapter 16: Creative writing as a way of addressing pain

At critical points in my life – the happiest and most difficult – I have turned to writing as a way of absorbing the emotion exploding within me. Perhaps it's not surprising that creative writing has figured so importantly for me as a tool for coping with my cancer experience. I recently came across a piece I wrote on the day my cancer was diagnosed. It isn't particularly long or noteworthy, covering the key points in my life, what is important to me, the people who meant the most and made the most difference to me, and what I wanted for my family. At that time I was seriously questioning my survival – although I was too frightened to mention this.

After I finished my Breathworks course in November 2008 I met with Christine Wilson, whose interests are in the therapeutic potential of creative writing; I hoped to use it as a tool to lift my emotions. Instead, it has become a way of getting to grips with my discomfort and frustrations. I have given myself permission to write creatively when I need to. One day, when I was walking on the mountain in a biting wind, wondering why I had gone out and feeling quite worn down by the weather, these thoughts came to me:

March winds

I have happy memories of winter and home in my childhood - the warmth of the coal fire, listening to stories or our mother's '78's by candlelight on Saturday evenings, and the happy chatter of childhood games. Our mother believed that fresh air was good for us, so many daylight hours were spent outdoors – walking or playing and helping our father with outdoor household chores or in the garden. The thrill of the wind at the top of the hill, the sheer beauty of dusky pink skies, the crackle of crisp leaves in the local woods are all cherished visions. Times were good: the warmth of the family long since obliterating the legacy of the cold's hostility – shivering myself to sleep under inadequate blankets, scraping marbled ice from inside the bedroom windows, taking turns to replenish the coal scuttle from the outside store.

Nearly sixty years on, the biting wind of an early March day of the coldest winter that I can remember, made me reflect on how far I have travelled since those early days and how much – and how little – has changed in my life. I have inherited my mother's belief in fresh air and seek it out despite the sting in the wind: I try to walk with a spring in my step and music in my head. I have also inherited my father's need for comfort – I look forward to the warm welcome at home, the candlelight on winter evenings, good conversation and music. Times are still good – but the unadulterated pleasure of woodland walks on crisp winter days is muted by pain. Each day I hope that my next outing will recapture the magic of winter in my youth, without the penalties that the years have brought with them.

Christine gave me an exercise to write a letter to my pain: I found this quite a challenge until I decided to give my pain a name. I thought that was the end of the matter – but the next time I saw her, she gave me the task of writing a response. This exercise was really helpful as it made me realise that my pain was part of me. The letters are shown in the following pages.

Home, April 2009

Dear Pain,

When you first came to visit me late in 2006 I was expecting you to stay only for a few months. I wasn't feeling that well, recovering from surgery, and I thought that as I got stronger, you would leave me. But then came the assault course on my body in 2007 - first the chemo, then the radiotherapy, and finally the Arimidex, all of which have left their footprint on me. I devoted all my energy to surviving this onslaught - and so did everyone around me. So I find it quite understandable that your arrival was not acknowledged until you were quite well established.

As the months passed I began to realise that you had come to stay with me, and all the people helping me began to suggest that it wasn't going to be so easy for me to get rid of you - if I ever could. My first instinct was to control you - as if you were a bad headache: take a pain killer, have a good sleep, and next day forget about it and move on. But then I realised that you weren't so much an assailant as a parasite. I went through months of frustration experimenting with a range of drugs designed to limit your impact, but which impaired my well-being even more.

When in 2008 I realised that you would be staying with me for a long time and that you would be with me for my waking moments - the first thing that greets me when I wake in the morning and the last thing that leaves me when I fall asleep - I was angry and frustrated. I had done everything I was told to do - exercises, healthy eating, resting and social activity. Why wasn't I getting a result? This wasn't expected; it doesn't happen to most people who don't do what they are told - so why did it happen to me? Was I depressed? Was it psychosomatic? Why did the medication not 'agree' with me? I didn't want sympathy and I was certainly getting no-where fast.

I tried to dismiss you as an irritant - an unwelcome guest. I wanted to be in control. I was told I had to "manage you", but I had no idea what that meant. The mere thought of spending time on you did not inspire me. Nonetheless because of the Mindfulness Course I took last year, I was persuaded to pay attention to you, to negotiate with you, to exercise, relax, and pace myself better. I was taught to focus on the things I like doing - and fit in everything else around this. So I have focused on being with my friends, taking photographs, going on walks, enjoying nice days, fresh air, good food, and appreciating my family. I have given up a few things along the way, but not as many as I feared I would have to, and I've made the decisions quite calmly and without regret.

So where are we, in Spring 2009? You remain for me an uninvited and unwelcome intruder, who has had a big impact on my well-being. But I accept that you have come to stay and the best thing I can do is accept you and try to keep you in proportion. I'm not going to let you invade my space. And I'm going to keep you in your place. I hope that one day you will be sorry that you have visited me; I'd like you to have a sense of remorse - because you do nothing to justify your existence, while I work quite hard to justify mine.

I'm going to call you 'Mistletoe', because I regard you as a parasite that draws on the host without giving anything back. You're also quite deceptive - other people only know that you're there when my guard is down - like a tree without its leaves. No-one knows quite how to get rid of you and you're too nebulous to become an object of hatred.

Are there any good things about you? Since we're going to have to 'shake along' together, I think you could try to be a bit more helpful to me. If you're not going to let me rest calmly in my own being, I'm not going to let you rest either. You're going to watch over me, let me know when I'm tired, under stress, or need to get out of a situation. You will prompt me to go out for a walk, move around, breathe deeply, and take exercise. You're going to stop me from overdoing things, like sitting for hours trying to finish a paper or travelling for miles to snatch a few hours' of a friend's company. And most particularly, you are going to let me go from time to time to do the things I like and remain positive about my life. Just think, the longer I go on, the longer you can survive too.

Your Host

c/o Host, April 26th 2009

Dear Host,

I am glad that you have sought to communicate with me directly and have given me the opportunity to respond to you. I realise that there's much more to you than meets the eye - at least my eye. You're really quite complex and operate at many levels. You like to keep a lot of yourself!

I appreciate your treating me seriously and I will do my best to be your alter ego and critical friend. But I need to know you better - not just the calm exterior but the whole you. I suppose you think that hiding your inner thoughts gives you more power over me. I would like you to learn to trust and respect me more - but I can understand why you don't because I have got a nasty side to me and I have to admit that I did creep in uninvited and I have overstayed whatever welcome you might have given me.

I normally visit my hosts for quite a short time. It's usually, like you, after they've had surgery or an accident or some sort of trauma. In most cases they manage to let me go after a few months. I've spent my whole existence as a free mercurial spirit, darting around without responsibility or commitment. It's a new experience for me to reside with a host for a long time and I'm beginning to realise that I'm going to have to learn to behave differently and more maturely and to be more responsible and supportive to you. As you say, wherever you go, I have to go too.

It must be very trying for you to have to put up with me as an interference in your otherwise tranquil existence. I'm sure that you would like to have some time to yourself and I desperately desire to be free of you too. But we both need to accept that I cannot escape from you, so I'd like to explain the challenges for me - so that we can help each other in making our co-existence more tolerable.

You very rightly called me a parasite, and I do like the name Mistletoe that you have given me. What you must realise is that I'm incapable of doing anything for myself. Everything rests on your shoulders! I cannot take the initiative - so whatever you do has to be for both of us. That must be very hard for you to bear; but while I may depend on you, I need not be a burden. You still have plenty of resources you can use to keep me in my place. It's your choice - not mine!

I think you are mentally very tough and disciplined; you like to be in control of the mechanics of your life; and to be self-reliant. You also want to test yourself all the time and stretch yourself to the limits! You don't accept boundaries easily and you have high aspirations for yourself. You are far more attuned to 'doing' than you are to 'being'. This doesn't make you easy to live with: a benign host would be more tolerant and flexible, and would make me feel more comfortable. But I've been with you long enough now to know that whilst I may be able to shave off a few rough edges, I'm not going to change "the nature of the beast."

I find it very tedious staying with you, day after day, trapped in your body, and reflecting your every mood. I'm happy when you feel well, content when you're calm, and pleased to see you enjoy yourself. I know how much you love to be outside on a nice day, with the mountains, fresh air, fields, and trees. I realise that you like calmness, the stillness of the countryside and your own company. I am concerned when you don't feel well, and I get very irritated when you don't let go of things that cause you stress. I appreciate that this is a new ball game for you too - but please, for my sake as well as yours, please try to stay out of the things that stress you! I admire your search for perfection - but what does it matter if you let someone else have a go at doing their best too?

I think you are doing very well at controlling the environment in which you're trying to survive, but please bear in mind you've got me to think about now as well as yourself. The way you are now suggests to me that you have always been able to identify and take on new challenges - learning new things, travelling to new places, exploring the unknown - and as you've succeeded you have become inherently more confident. But times have changed: there are going to be things that you can't do and the challenge for you is to merge the things that you could do with the more limited resources you now have.

I thought you planned your recent trip to Ulster superbly. You resisted the temptation to take your laptop and write up notes in the evening, instead focusing on going for a good walk along the coast and taking in the magnificent scenery of the Giants' Causeway. You spent a lot of time making sure that you ate regularly, and went to bed early enough to militate against your nightly wakefulness. I know that when you finished the job you were tired, but you were pleased with yourself that you'd kept me in my place. It was very unfortunate, when you had done so much to help both of us, that you flew back on a propeller driven plane that irritated me so much - who would have known that would happen? We won't do it again if we can help it, will we? I'm sorry that I haven't been able to settle down since and that you remain so tired, but you've got over things before - I'm sure that you will manage again!

I notice that you are pretty good at learning from your last experience. You seem to be pretty good at identifying those things that went well and why, remembering what went less well, and working out the risks and the new arrangements needed for the next venture. Perhaps you should keep a diary, as there are so many things to be taken into account and managing everything in your head is a lot for even the most organised brain to contemplate.

I also have noticed that you're pretty enthusiastic about learning new things. As long as you don't push me too hard, I'm game to do these things too. I like the yoga exercises we're doing together. But I know that you're quite hard on yourself - you're determined that they're doing you good and they're not harming you - but I know that I'm hurting you when you do them. I hope you will stop if this continues for more than a few weeks. For the same reason, I'm glad that you haven't taken on the idea of swimming - just wait a bit until your skin gets a bit less sensitive to me! It's good to follow your own instincts, but you also need to listen to those trying to help you.

I know that when you are tired or out of sorts you don't seem to be able to cope with me very well. Neither of us seems to know how I'm going to behave and I'm sure this causes you some anxiety. It's easy for others to provide advice, such as, "don't get too tired!", "don't take this on!" or "don't try this out!". It's a bit like the 'medicine dispensing saga' that we endured last year. That's not going to satisfy you! You have to keep going - keep on top of things.

But what about me? While you're looking for diversion, I'm struggling. You can't just ignore me because I'll turn nasty! If you remember that we're likely to continue to co-exist, and that you need to consider me too, I'm willing to go along with you. If you ignore me or push me too hard, we'll end up working against each other. You may even be forced to think that I'm in control - which I know you did last year. The point is, if you're not in control, I'm not in control either. Who knows what I might do to you when my nasty side is let loose? I appreciate that we've already moved a long way from this point in the past few months, even though we did not understand each other very well at the beginning.

Writing to you has made me feel better about you. Thank you for hearing me out.

Your Mistletoe

Thinking about my pain as a character has been very helpful, although I have since wondered whether the rather benign and pretty name of Mistletoe was appropriate, when the adjective 'mercurial' is more apposite, given my pain's erratic, volatile and unstable behaviour. Having a name for my pain has helped to give it an identity and personality - and this has helped me to communicate with it.

Chapter 17: Over-reaching my Limits

It's very easy for me to overstretch myself because my pain makes me tired. Managing the existing layer of stress from the pain limits my ability to function. When I get overtired, it's difficult for me to put a sentence together, let alone cook and eat a meal, or keep my pain under control. Reaching my limits does not happen to me very often, but it does happen and I find it disconcerting and embarrassing; it's awful both for me and the people I'm with. One of my writing exercises was to explain how over-reaching my limits affected me. Here it is.

Over-reaching the limits

I have mentioned several times that managing pain takes up a lot of energy. I particularly notice my energy is being sapped when I'm engaged in a discussion, at a meeting or event, out on a windy day, or shopping – normal activities for most people. I used always to keep a little spare energy in reserve, but now this is more difficult. All that planning, pacing and diverting can do is to make the available energy go as far as it can; but I also need to limit the demands on my energy as my pain has its own ideas about how much it also needs.

However well I plan my day, on most days at some point I reach the limit of my energy and I find my body 'shutting down' quite quickly. This means for me: losing temperature control – hot flushes, cold sweat; my frame aches and the skin around my shoulders, upper arms and chest starts stabbing; I get a dry mouth, feel nauseous, lose my balance and my bladder feels irritated; I need to escape from a buzzing, droning noise as if I'm in a small temple where the music is too loud and getting louder.

My response is to wrap up my shoulders and get out – if possible straight away and into the fresh air for a walk followed by a drink of water and a snack. If I can't escape, it takes the rest of the day and sometimes a couple of days to recover. This doesn't stop me from enjoying my life, but it does limit its spontaneity – I need to assess my limits all the time. My fear is that eventually I will run out of energy and I won't find a way of getting it back.

An example

I love going out with the girls and Kate and I decided on the spur of the moment to have a look in the shops at the new retail park. It was very nice to be with her – but the shop environment was awful. I was standing around a bit while Kate tried on some clothes and soon began to feel poorly – the lights, the air conditioning, the piped music, lack of space, and a hostile atmosphere – I felt as if my body was under 'assault' – my vertigo set in, the skin in my upper body – front and back, arms and around my collar and shoulders – started to prickle, I was in a cold sweat, felt nauseous, with a dry mouth and irritated bladder (as if all the fluid in me needed to escape). I eventually got home and went for a quiet walk, but I felt overloaded for the next few days.

Chapter 18: Conclusions on Managing Pain

Accepting my pain

Acknowledging the existence of pain is an important element in managing it. Trying to ignore it doesn't work and it becomes as bad as ever once diversionary activities have been exhausted. The processes of describing my pain, characterising it, recognising its parasitic nature, and writing to it to set the terms in which I would accept it were all very important steps for me. It is important for me to remain in regular contact with my pain, through conversations with it when I am walking. I allow myself to be drawn to it during my breaks and breathing spaces during the day. I also try to follow the strategy of the late Christopher Reeves, focusing on it a short time before I get up in the morning but then keeping it in a 'box' away from my attention during the rest of my day.

Understanding my pain

The Chronic Pain Management Service and my Physiotherapist have helped me enormously in understanding the nature of chronic pain. Because it is persistent, parasitic, inflexible and burdensome has required me to adjust most of the rest of my life to accommodate it. The pain diary I have kept from time to time showed me that I've reached a plateau – or ledge - from which I am not able to climb, but from which I could fall. I have been engaged in meticulous and detailed planning to avoid over-reaching my limits. I have had to settle for pacing, doing less, a focus on 'being' and 'being kind to myself'. This has taken time, effort, determination and energy on my part as well as recognising that pain has changed my life. However, without the patience, understanding and support of people who made me feel I was worth helping, I doubt that I would ever have got to this point. I still over-reach myself from time to time – all too frequently from my perspective – but I still manage to keep going.

Understanding myself

In learning to understand my pain I have had to learn to understand myself. I am not one who says 'no' easily. I have often taken on too much and enjoyed the challenge of juggling. Instead of this, I've had to learn to let go, and think of myself and my energy levels. I've had to understand how much energy pain absorbs and to recognise when my reserves get low. Understanding how I've been affected physically, emotionally and psychologically by pain has been difficult. It has meant that I've had to better understand myself and to acknowledge that I alone can judge what's best for me. I've had to learn how to manage those close to me and make them appreciate my needs. I've learned that my life is more constrained; I describe it as living on a ledge.

Poem: My being in its new home on a ledge

Discarded from a former life, I landed here
My restored home, an insubstantial shelter
Protected by the warmth of those around me
Assaulted by indifference and ignorance of strangers
Two choices - exist, regret and wither - or embrace life and hope for more
The latter, a daily search for peace, serenity and purpose
Still clinging on, by the grace of God.

Managing my pain

This section of my story has been about the tools I have been kindly given to manage my pain. Before I got to this situation I would never have believed that so many tools existed – but then I would never have understood the complexities of chronic pain or recognised the need for so much help. The tools have helped me physically, mentally, psychologically and emotionally, and have offered me a range of opportunities within each strand to address all my needs. Whilst walking recently on a dull and windy day, I took the time to reflect on how far I had come in managing my situation. My mercurial pain, whipped up by the wind, started to throw a tantrum as I climbed the mountain, but I told it not to stop my enjoyment of the day, and as if I had taken an erratic child by the hand to control it, together we went on our way.

Part D: Achieving well-being

Chapter 19: Introduction

Having been ill has made it even more important for me to do the best for myself, and particularly to look after my health and well-being. While I was ill the focus of my attention was on what was happening to me physically, leaving the important mental, emotional, and practical or functional aspects of my well-being somewhat neglected. Getting my life together again has involved my revisiting these aspects of my life. This section of my story is about my attempts to bring the elements back into some kind of balance. I have sought to rationalise my situation and describe where I want to be. I describe my daily routine for achieving quality of life, supporting my physical well-being, keeping my spirits up, addressing ongoing side effects of treatment, preventing potential problems, and trying to keep the future in perspective.

Key principles – where and how I want to be

As individuals we often have a limited experience of being patients and therefore do not always behave in a way that most helps ourselves, our carers or the interaction between us. However, I want to be an active contributor to decisions about my treatment because I'm the one who has to live with the consequences. Hitherto my only experience as a patient was receiving one off treatment and moving on. My experience of cancer has been quite different because firstly the treatment has taken much longer and is still going on and secondly, there is always a risk that it will return. This makes it less easy to move on.

Over the past 18 months I had a greater focus on my well-being and finding a quality of life that suits me. Finding my own solutions has been an important element in my recovery process and in seeking a positive future. I have been able to explore the whole range of treatments on offer, and although some have had a negative impact on me, I'm now glad I tried them, as I know better what works for me. Some of the key things I have thought about and done are summarised below. I constantly remind myself of them – acknowledging that in some cases I'm still far from having reached where I want to be.

The principles of where I want to be

Key principle	My comments
Quality of life is my number one priority	My treatment and aftercare is a series of judgements about what is best for me - I can go through anything as long as I think that on balance the outcome is worth the investment
Focus on the positives & good things in life	Think of what I still have and not what I have lost – e.g. my hands may hurt, but I still have them!
Develop priorities about what I want out of life	This has been a challenge for me and took months of planning my time, and throwing out the things that I no longer had the energy to do, rearranging the way I took holidays and how I lived my life
Be realistic about what I can achieve	This has been very difficult for me - always a willing volunteer, but I don't have enough energy to do everything I want; I need to anticipate how I will feel; I need to say 'no' without worrying what others might think.
Don't beat myself up if I don't achieve everything	At best, people achieve only 85% of what they want to. I need to do as much as I want as long as it is satisfying. Each day, keep a list in 'bite sized' chunks of what I hope to achieve that day - it's nice to tick things off
Don't turn away well meant help	Losing independence often means having to do things when other people want to do it; I try to negotiate my own terms – e.g. when / how I want help
Don't expect anyone else to understand what I'm going through	I still get disappointed when others have no idea of or seem indifferent to my suffering. I find it irritating when people ask me how I feel or comment on how I look – good or bad. When I feel down, I practice putting on a smile – and hope that others will talk about something else
Don't waste time in speculating about why I'm in this situation	Maybe there isn't an answer and I can't turn the clock back. Why waste energy on something that isn't helpful? This is one of the hardest things - it took me a long time to move on
Achieve a balance between 'doing' and 'being'	I'm not very good at this, but meditation practice helps me to set aside time each day when I'm actively 'being'; it gives me a sense of calm and appreciation of my surroundings and recognition of the barrenness of busyness
Achieve a balance between mental and physical activity	Mental effort absorbs energy in a different way to physical activity; it needs to be balanced with physical activity, calmness and rest; I try to intersperse mental effort with walks, exercise, three minute breathing spaces and pacing to reduce the 'cognitive load' from the constant pain.
When pain is getting to me, don't ignore it	I spend about 20 minutes before I get up assessing my pain and conceptualising what it is doing to me; I then put it aside, get up and face the day; during the day if I'm in pain I will face it, but quickly try to turn my attention elsewhere
Be kind to myself	Celebrate successes and milestones however small they seem
Maintaining a good outcome	Monitor progress – even if I don't seem to be making discernable progress, I've still improved from where I was, and am working to maintain it
A whole range of strategies are needed to manage pain	Managing pain means marshalling my emotions, senses, energy, mind and physical strength; it's about managing myself – being relaxed, confident and in control – knowing myself and my needs
See myself and my needs as central, with others fitting around me	Having to cope with chronic pain is like having another dependent to look after; my own survival and well-being depends on my own needs being met so that I can keep my 'dependent' pain under control.
Chronic pain is life changing	To keep in control I need to plan everything in 'bite sized' chunks – the totality is too big!
Get to know my pain intimately	In order to understand what I'm up against in order to control and address it

Chapter 20: Addressing and preventing unwanted chronic conditions and side effects

Cancer treatment can have some nasty side effects. The ones I was most worried about were lymphoedema and osteoporosis, which fortunately I have avoided so far. However, as well as chronic pain, which for me was the most obvious legacy of the treatment, I've also experienced a number of menopausal side effects from the loss of oestrogen, and my sleep is interrupted between 3 and 6 times each night.

Addressing sleepless nights

I haven't slept really well since my surgery, chemotherapy or starting my hormone treatment. The surgery has made it difficult for me to lie on either side. The chemotherapy introduced me to stress and restlessness. The Arimidex has given me fatigue and joint pain, irritated my bladder, and disrupted my sleep pattern.

Keeping a diary

I discussed my disrupted sleep pattern with Dr Jo Hampson, my consultant at the Pain Management Clinic because I thought that my sleep pattern was largely interrupted because of pain. She gave me the following outline for a sleep diary.

Day / date	Lights out time	Wake-up time	Number of times awake	How well rested? (0-10)	Comment
Example Sun 6 th June	10.30 pm	6.00 am	4	4	Unable to get comfortable

I kept the diary for three weeks in September 2009; the last week is summarised below:

Day / date	Lights out time	Times awake					Get up time
		1	2	3	4	5	
Mon 21 st	23.30	23.30-0.30	2.50L	5.15L	6.15-7.30		8.00
Tues 22 nd	23.00	1.30L	2.55L	4.00	6.45L		7.45
Wed 23 rd	00.00		2.50L	4.16L	6.30 L		7.30
Thurs 24 th	23.00		2.15L	4.00L	5.55-7.00		7.00
Fri 25 th	23.00	2.50L	4.00L	5.07L	6.07L	7.00	7.45
Sat 26 th	23.30	1.05L	2.10L	4.25L	6.00	7.30	7.45
Sun 27 th	23.30	23.30-0.30	2.52L	5.30L	7.00		7.30

L= visits to the lavatory

The sleep pattern for the rest of the time is broadly the same. Things I have noticed about this pattern:

- I need to allow 30-50 minutes in bed getting comfortable and relaxing before I put the light out
- In my notes, I see that the reasons I wake up are i) discomfort (pain, skin hurting, stiffness) and ii) needing to go to the lavatory
- If I get out of bed immediately when I wake in the night I usually get back to sleep straight away
- Doing exercises, meditating, body scan etc are useful ways of getting back to sleep
- I need 20-30 minutes in bed doing mobilisation exercises in the morning before I get up
- I have got used to not feeling refreshed by sleep or being comfortable when I wake up in the morning – the best thing for me is to get up and get on with the day

Issues to address:

- Is this pattern of sleep doing me any harm?
- Am I doing the best for myself? Can I change my routine to reduce the number of interruptions to my sleep?
- Can anything else help me? I have thought of taking *Amitriptyline* on a Saturday night to get me a good night sleep – but the prospect of the side effects even for 1 day put me off.

Ways of supporting good sleep

These are the things I do to support good sleep¹⁰:

- Ensuring that my bedroom is a comfortable temperature and well ventilated
- Ensuring that my bed is comfortable (a memory mattress and pillow), other pillows to support my knees and feet, a light warm duvet, hot water bottle
- Wearing comfortable night clothes that don't hurt my skin and bed socks to support my aching feet
- Going to bed at roughly the same time each night, with time to get comfortable in bed and a short story / crossword / Sudoku to do or listen to radio before lights out
- Trying to get comfortable before I go to bed – this might be light movements and stretching exercises, hot water bottle or hot scarf
- Clearing my thoughts of the day that is gone – I write a list of the next day's activities, so that I don't need to worry about them
- Having a little snack at night (porridge, rice, ginger, tomatoes, and bananas are all supposed to be helpful as they contain melatonin) and regular meals throughout the day
- Limiting my drinking (water) in the evening¹¹

¹⁰ See www.patient.co.uk's website for Sleep Problems – A Self Help Guide

¹¹ I'm still working on this - e.g. replacing cold with hot water / herbal tea in the evening

- Getting up at the same time each day, keeping going with a routine throughout the day, and not napping in the afternoon
- Keeping physically active.

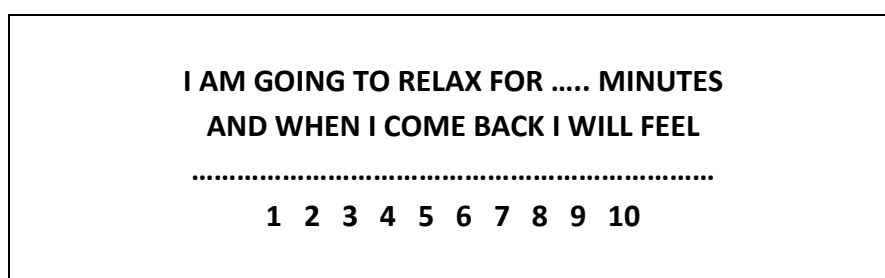
Other ways of addressing wakefulness

The following have been suggested and I have tried them

- ‘Acu-pen’¹² my natural steroid points (on each side of my knee cap) to reduce the likelihood of waking up between 1 am and 3 am
- Pay more attention to my bio-rhythms and the 12 hour cycles of the day, focussing on a relaxed afternoon to support less stress in the early hours
- Recognising this as a menopausal symptom and treat accordingly – I used a homeopathic remedy to help me sleep more deeply; this didn’t reduce the number of times I wake, but has helped me to go back to sleep straight away and removed the angst of wakefulness.

Self Hypnosis

I also went to the Sandville Self Help Centre in Kenfig Hill, near Bridgend, South Wales. This is a charity established nearly 20 years ago by Gwyneth Poacher. The centre offers therapies, such as Reiki, Reflexology, Hypnotherapy, Acupuncture and Pool Therapy to people with cancer. It is a wonderfully calm and relaxing haven in a quiet spot. While I was there I forgot about time or what was going on in the outside world. I learned how to self-hypnotise myself, using this card, and I have been doing it regularly when I wake at night. Its effects are similar to mindfulness, but they are more immediate.



These little improvements have made me feel that going to bed is something positive, rather than a means of passing the time between midnight and dawn.

¹² This puts an electric pulse on key acupuncture points and, like TENS machines, they provide pain relief and stimulate improvements

Coping with Fatigue

I spend most of my time feeling fatigued, needing to rest and conserve my energy. This may be because of chronic pain, the side effects of Arimidex or cancer treatment, because of the energy used in keeping my life on track, or simply because of my sleeping pattern. I would like to know more about fatigue and its causes as a way of helping myself address some of the symptoms. Here are some of the ways in which I cope with fatigue.

Coping with fatigue

- Keep going / keep moving
- Have a plan and purpose for each day
- Keep cheerful with pleasurable activities and pleasant surroundings
- Use techniques for pain management – pacing, planning, mindfulness and self hypnosis
- Take breaks throughout the day – if possible sit in a quiet place to relax for a few minutes
- Don't pack too much into the day
- Have a good break for meals, and if you're too tired don't eat too much
- Avoid long journeys – especially driving

Prevention of Lymphoedema

Around thirty years ago an acquaintance asked me if I would look after his girlfriend for the evening. She was dying of cancer and trying to move around with a hugely swollen leg. I gave her my dressing gown, wished her well, and never saw her again. This left a lasting impression on me, so when I heard that I was at risk of lymphoedema I was worried. I was at risk because all the lymph nodes on my left axilla (armpit) and four in the right armpit had been removed, thus impairing my lymphatic system. I was agitated about this, and asked a lot of questions at the time of my surgery and thereafter. However, the people treating me gave me the impression that it was an inconvenience rather than a priority. The lymphoedema physiotherapist at Velindre was a helpful and excellent source of useful information and advice.

The advice for people who have had treatment for breast cancer in both breasts is “to be an especially watchful advocate for yourself” as not all medical professionals know the precautions for avoiding lymphoedema. It is suggested that the leg or thigh can be used for blood pressure and blood can be drawn from the leg or foot.

I became a member of the Lymphoedema Support Network, a registered charity, provides a range of information and support, campaigns for better services for Lymphoedema sufferers. It produces a quarterly Magazine, *LymphLine*.

There is a South East Wales Lymphoedema Support Group, which meets at Velindre Hospital a few times a year. Further details are included in Section E.

Fortunately I did not get chronic lymphoedema, but I know people who have – many of whom did not look for specific information about how to avoid it. I think that my constant vigilance may have made a contribution to this. As well as observing the Do’s and Don’ts, I exercise to ensure good circulation, drink plenty of water, do not take salt, have a low fat diet, regularly massage/ brush my skin, wash in aqueous cream, avoid flying more than I need to, and avoid travelling to hot climates. Even so, for a couple of days after a short flight I’m aware of the heavy limbs.

The Autumn 2009 issue of *LymphLine* highlights the award of £1million funding for new research to test whether some women are especially prone to developing lymphoedema. It will track 200 patients diagnosed with cancer for 36 months, and is based on evidence that some 5% of women with only minimal surgery develop lymphoedema, whilst 66-75% of women with full axillary clearance surgery do not. So, it may be the case that you can do very little to help yourself – and that I’ve just been fortunate.

I also obtained information from the Internet. The table below is taken from a particularly helpful website provided by breastcare.org, an American self-help site.

Do’s and Don’ts in Preventing Lymphoedema

Do’s	Don’ts
<ul style="list-style-type: none"> • Moisturise your skin frequently 	<ul style="list-style-type: none"> • Use harsh soaps
<ul style="list-style-type: none"> • Use rubber gloves for washing dishes and cleaning 	<ul style="list-style-type: none"> • Have hot baths or showers, saunas or steam baths
<ul style="list-style-type: none"> • Wear protective gloves in the garden / for outside chores 	<ul style="list-style-type: none"> • Apply heated pads or hot compresses to the arm, neck, shoulder on the affected side
<ul style="list-style-type: none"> • Wear oven mitts when handling hot foods 	<ul style="list-style-type: none"> • Carry heavy objects, especially with the arm hanging down; or wear heavy shoulder bags
<ul style="list-style-type: none"> • Take frequent rests when cleaning or repetitive activities 	<ul style="list-style-type: none"> • Wear tight clothing
<ul style="list-style-type: none"> • Use insect repellents and apply anti-biotic ointment to insect bites, scratches or torn skin 	<ul style="list-style-type: none"> • Drink much alcohol or smoke (alcohol causes blood vessels to expand; smoking narrows the vessels, lessening the flow of fluids in the arm)
<ul style="list-style-type: none"> • Protect your arms from sunburn 	<ul style="list-style-type: none"> • Cut nails too low
<ul style="list-style-type: none"> • Use a thimble when sewing 	<ul style="list-style-type: none"> • Permit blood pressure testing on at risk arm
<ul style="list-style-type: none"> • Use an electric razor – not a safety razor 	<ul style="list-style-type: none"> • Permit skin to be pierced for injections, drawing blood or vaccination.

My concern about lymphoedema has affected my movements, for example, when I am practicing yoga I avoid positions which involve resting on my arms. I carefully assess how much I can carry and anything slightly heavy I carry next to my body or hold it with both hands and my arms bent. I also ask for help (e.g. getting people to carry hand luggage up or down steps).

Avoiding Osteoporosis

Someone said to me once that ‘everything about breast cancer treatment is a trade-off.’ I think of this when I take my Arimidex tablet, as osteoporosis is a known long term side effect. Osteoporosis is a loss of bone density caused by loss of oestrogen, lack of exercise or other lifestyle factors. It is measured by a DEXA scan of bones and comparing the bone density with that of ‘an average 30-year-old white woman’.

I had a DEXA scan in February 2008, which suggested osteopenia (that is a bone mineral density score of between -1.0 and -2.5 below the standard). I was told not to worry and to have my next DEXA scan in August 2009. At my local Breast Friends support group, a talk in May 2009 about the perils of osteoporosis for post menopausal women on hormone treatment prompted me to find out when this DEXA scan would take place. It took several weeks to find out that either my GP or Oncologist had to specifically request it, that it hadn’t been requested, and that there was a six month wait. I tell myself that I don’t mind the wait, that I’m doing all I can to help myself (walking, plenty of calcium and magnesium) and that I wouldn’t want to take the bisphosphonates anyway.

I had another DEXA scan in 2010 which suggested that osteopenia in my hip had increased. My GP was asked to discuss with me the desirability of taking bisphosphonates, but I have told him that I would not do so unless I had osteoporosis. In the meantime, I agreed to stick to my regime below.

Ways in which I think I am helping myself avoid osteoporosis

- Exercises - to enhance mobilisation and balance, to sustain flexibility and strengthen muscles
- Physical activity – a daily 45-60 minute walk up and down the mountain
- Getting enough sunshine / fresh air throughout the year, but especially in summer
- Getting enough vitamins and minerals from food – e.g. yogurt, cottage cheese, eggs, beans, pulses, nuts, fish and whole grains) and a focus on alkaline foods (e.g. green vegetables and dried fruits) that do not erode bone calcium
- Food supplements (e.g. omega oil, calcium & vitamin D, magnesium)

I have also signed up to get regular information from a US commercial campaign called Save our Bones – www.saveourbones.com, which provides some useful tips.

Physical activity

Physical activity (especially weight-bearing) is probably the most important way of protecting against osteoporosis and addressing arthritic pain. It is also important in maintaining my mental health, reducing stress, improving circulation and generally supporting good health. I started walking in my forties because I wanted to get fit and I always feel better when I'm physically active, so I resolved to maintain a level of fitness as soon as I recovered sufficiently from my surgery.

Being physically active became even more important for me since my diagnosis. This was something that I could do for myself, addressing negative thoughts, and helping my feeling of well-being. After my surgery I worked hard to mobilise my arms and shoulders and exercise regularly as well as taking a daily walk.

It is important for me to be able to invest in myself, to maintain my bones and joints, and enhance my fitness, muscle strength, flexibility, balance and posture. One of my aunts has severe osteoporosis, which prevents her from going out in wet or windy weather as she is afraid of falling and breaking a bone. All my family is afraid of my falling and breaking a bone, too – so I spend time each day working on my muscle strength, balance and posture and exercises to address my vertigo, a pre-existing condition, which for me is made worse by fatigue, immobility, and many medicines.

Those parts of me that ache are improved enormously by movement. The more uncomfortable I am the more I have to move. My whole body from the neck down aches when it isn't being used, so I spend a lot of the time I am in bed but not asleep doing exercises in bed, I keep moving my feet, I stretch every 15 – 20 minutes when sitting at the computer, and get up every half an hour. I feel the need to stretch my muscles and stroke my skin – and I constantly feel the need to keep moving.

Every day I take a walk, preferably up a hill or mountain if there is one, for 45 minutes or more. I have walked every day for the last 33 months, whatever the weather, and missing only those days I was in hospital or travelling. In the winter I try to walk in the late morning, lunchtime or early afternoon. In the summer I walk in the late afternoon or early evening. My daily 45 minute walk is a round trip of just over 2 miles up Caerphilly Mountain, with a climb of about 120 metres. My Sunday 60 minute walk is one of two circuits over the mountain. On Saturday afternoons I try to take a longer walk in pleasant surroundings, usually with a friend; I seldom go off the beaten track on my own or without a mobile phone. I always feel better when I've been for a walk. It forces me to focus on my breathing and movement, it helps my circulation, and it gives me a welcome diversion to sitting there feeling uncomfortable and sorry for myself. I think it also helps to address my fatigue.

My friend Rhiannon was very fit, and we regularly walked along the headland at Penarth until a few months before her death; it was a great morale booster. Walking gives me time to reflect on myself and the beautiful world in which we live. I dwell on my good fortune to live near the

mountain, to be able to climb it, to see the trees, butterflies, birds, bees, the leaves and blades of grass, to enjoy the wild flowers, breathe in the silky air, acknowledge the wind and rain on my face and feel that it is good to be alive.



Fforest Fawr, Caerphilly Mountain, November 2008

Walking is now an essential building block of my well-being. When I am walking I practice 'Mindful Movement', sympathising with all those parts of the body that are painful, but which I need to keep me going – my toes, feet, ankles, legs, knees, hips, back, neck, ribs, chest, shoulders and arms. I reflect on them and move on, telling each part that I'm glad I have them, that they are doing a good job and that I'm proud of their performance each day. I look for those parts of the body that are not hurting and are working well. If I'm particularly tired, I tell myself that if I can walk 10 paces I can walk 10 more – one foot goes after the other.... If I don't feel too well, I tell myself that I can make it, and that there will be a warm welcome when I get home. Walking is my daily gift to myself.

Eating well

As a Home Economist and a source of useful information about all aspects of food, my good friend Rhiannon was able to pass on a great deal of her knowledge of food and health to me in the 20 years I knew her. I also believe that eating well gave her the strength to outlive her prognosis by many months. By the time of my diagnosis, I already had a good basis for eating well. Post diagnosis, eating healthily has become even more important to me - partly because I am more aware of the importance of investing in my health and partly because, as one of the members of my Breastfriends group pointed out, eating is one of the things you have control over, unlike your illness or medication.

Diet and weight

In my early forties my weight started to creep up and by the time I had a hysterectomy in 1999 I weighed around 85 kilos (13 stone 9 pounds) with a Body Mass Index of 26. I waded through a lot of literature on diet, inspired by my friend Rhiannon, and after 2005, my Homeopath, Felicity Lee. I struggled to get my weight down and by the summer of 2006 I weighed 78 kilos (12 stone 4 pounds). I achieved this through a combination of exercise, eating less, and eating differently. I abandoned salt and sugar, red meat, and wheat flour, ate smaller meals more regularly, with a focus on low fat, low carbohydrate, high fibre, and plenty of vegetables.

Whilst this diet stood me in good stead in good times, it certainly wasn't the right sort of diet to withstand the rigours of chemotherapy or indeed chronic pain, and in the twelve months after my treatment began I lost 25 kilos (55 lbs). I was worried about this initially, because my family and health practitioners regarded unexplained weight loss as a 'problem' about which I needed to 'do' something. However, the Dietician at Velindre Hospital told me that there was nothing wrong with my diet; I just needed to enjoy my food, to eat as much as I could, and ensure that I ate all the minerals, vitamins and food groups, and ensure that I ate enough protein and calcium (as the chemo had turned me off useful foods, like cheese). I have used the US Department of Agriculture's website (www.ars.usda.gov) providing information on the content of 13,000 foodstuffs to introduce new foodstuffs, such as soya, and enhance my use of others.

Looking back I now see the irony of the situation – here was I having spent the last 15 years trying to lose weight and it was being handed to me on a plate! The problems have been largely cosmetic (i.e. looking thin, having to buy new clothes). Compensations are diminished high blood pressure, good mobility, and healthy heart. It was recently explained to me by a Dietician Lecturer at Queen Margaret University that not taking a significant amount of steroids during chemotherapy, the pain / chemo induced restlessness, the cancer itself which changes body metabolism, and hormone changes were just as likely to have contributed to this weight loss as my diet. She also said that I should concentrate on my health and well-being and not worry about body mass. Eating less does not mean eating less well.

Healthy Eating

Healthy eating is a huge and bewildering issue. The emphasis of healthy eating these days is about the impact of diet on weight, but it's really much more about making the most of opportunities to stay well. It's not just the purchasing or growing the ingredients of a balanced diet, but also knowing how to put them together, store them, and ensure that their food value is retained. There is a huge industry of people providing information that suits their product and not necessarily your body. Food fads often lack a scientific basis and you need to think about how food helps your changing needs – e.g. to maintain your bones, immune system, and vitality etc. – how much food you need, and how to get the best out of your food. It is also thought that a good diet can reduce

toxicity and therefore help to prevent cancer from returning. A large number of websites and published books reinforce this belief.

My experience with food

Around 3 years before my diagnosis I started to become intolerant to some basic foods – this happened to my twin sister too, although our food intolerances are different. Through my friendship with Rhiannon, my nutritionist associates in the International Journal of Consumer Studies, work with health promotion providers, and public information, I knew the basics of cutting out elements of a diet whilst still maintaining a balance. I cut out salt, refined sugar, onions and garlic, caffeine, all meat except chicken, and anything containing white flour. I doubled my intake of fruit and vegetables, added beans and lentils, seeds and unsalted nuts and also drank 6 glasses of tap water a day, and started to walk regularly (30 minutes, four times a week). Over the next two years problems of water retention, bloating, lethargy and high blood pressure diminished. It made me conscious of being able to improve my health through relatively small changes in my diet and behaviour.

After my surgery I lost my appetite and maintained a regime of eating four small meals a day, gradually getting back my strength, not overloading with food, yet never feeling hungry. To support my lymphatic system, I resolved to drink plenty of water and remove added salt and sugar from my diet¹³. I was sensitised to food that helped me and food that didn't. I still eat very regularly with snacks between small meals.

Although my interest in food was inspired by my admiration for my friend Rhiannon, it was also necessitated by the changes to my taste and body induced by my treatment. The chemotherapy and Arimidex repelled me from foods like cheese that no longer appealed and moved me towards foods that moisten the dry feeling in my mouth and body. I'm also challenged by the need to avoid food that I feel will harm me, as I still sometimes recall the feeling of being poisoned by the chemotherapy. I need to ensure that I eat enough food to maintain my weight, muscles, bones and good health. I need to eat very regularly, and to eat enough before I lose my appetite, even though I can't eat too much at one time because it makes me too hot. Although I lost a lot of weight in 2007, this has now stabilised and a better indication of my well-being has been that I have managed to avoid or fight off infections.

Homeopathy and Food

In May 2005, I broke a tooth, which wasn't properly treated, leading to a systemic infection and with lasting vertigo. Medication did not resolve the problem; the ENT consultant could find nothing wrong. Some 5 months later a colleague recommended her homeopath, Felicity Lee¹⁴, who found a

¹³ I have not been able to find any evidence to support this idea, but haven't experienced lymphoedema to date

¹⁴ More information can be found from her website www.felicitylee.co.uk

suitable remedy. Since then I have gone to her clinic regularly as the remedies she addresses not only seem to work well for me, but they also do not leave me with unwanted side effects.. She has helped me throughout my cancer journey, sorting out a miscellany of problems. As a pharmacist and vegetarian, she is a fund of useful information about the added value of foodstuffs compared with taking multi-vitamins and minerals – for example two Brazil nuts a day gives you all the selenium you need.

Typical menus

These are some examples of menus that I use regularly. I don't like spending a lot of time preparing food or washing up – so rely on preparing well in advance and freezing ingredients. My appetite declines as the day progresses, so I try to pack as much as I can into breakfast and eat smaller meals more frequently towards the end of the day. I drink 6 + glasses of water a day to keep my mouth moist – three in the morning, two in the afternoon, and one in the evening or overnight.

Typical breakfast

- Three or four heaped desert spoons cooked brown rice (rice can be stored in fridge for up to 3 days or can be frozen)
- Handfuls of pumpkin and sunflower seeds
- Tablespoon of mixed nuts – 2 Brazil, 2-3 walnuts, pecans, 5-6 cashews, almonds
- 1 apple or pear + dessertspoon of blueberries + grapes / any other seeds available
- 2 dried apricots (organic/unsulphured) and 1 dried fig chopped
- 2 tablespoons of natural, low fat, probiotic yoghurt (or an egg or cottage cheese)

Typical lunch (this might be at home or taken out to work)

- Cook red lentils (throw away water after cooking) and /or use cooked and frozen chickpeas, kidney, soya, cannellini or butter beans
- Add a selection of vegetables – leeks, carrots, courgettes, parsnips, sweet potatoes, sweet corn, green beans, broccoli, cauliflower, peppers, celery, peas, fennel etc (these could be frozen) – and enough water to steam
- Add to taste: root ginger (I use about a heaped teaspoon finely chopped), a few leaves of fresh basil, cumin seed, coriander seed, fennel seed, turmeric, curry, black pepper; add cashews and almonds if desired
- Bring to the boil, simmer for 5 minutes, keep lid on pan and let it rest for 5 minutes
- Can be eaten hot, warm or cold, supplement a buffet lunch or replace sandwiches
- Two portions of fresh fruit

Typical snack (mid-morning or mid-afternoon)

- Slice of homemade rye, caraway and sunflower seed bread with mashed avocado, lemon juice and pepper, or cottage cheese with dried or fresh fruit
- Home made carrot cake: my recipe is to mix the following ingredients in a food processor: 6 oz carrots, 6 oz cooked brown rice, 2 oz mixed nuts, 2 oz seeds (e.g. sunflower/pumpkin), 2 oz dried fruit (e.g. unsulphured apricots, figs), 2 eggs; put in a lined baking tray and cook for 30-35 minutes at 200°C gas mark 6; cut into slices; keep in fridge; if not to be eaten within three days, freeze
- Some fresh fruit or vegetables
- A piece of fruit with some nuts, seeds, dried fruit etc
- Small piece of dark chocolate (10-20 g) (morning) or a handful of almonds

Typical evening meal

I'm often struggling to eat by this time, and tempt myself with food that is easy to digest; this might be:

- A large bowl of vegetables (5 or 6 varieties either raw or lightly steamed with herbs and spices)
- Carbohydrate vegetables – e.g. sweet potatoes, carrots, parsnips etc
- Some form of protein – e.g. boiled egg, dhal, fish, beans, lentils chickpeas, nut loaf
- Fruit

Chapter 21: Uplifting my spirits

Having constant pain is a burden and this can weigh you down. I've realised that intellectually I have to accept it; physically I have to move one step ahead of it; and emotionally I need to ensure that I'm not overburdened. Part of this emotional investment is to find a way of uplifting my spirits. This is a constant challenge because it takes energy, determination and discipline – all of which are in short supply when I don't feel so well. Fortunately I was able to focus on enjoyable pastimes, and although some are more difficult now than they were before my cancer, I have continued to enjoy music and photography, which are briefly outlined below. I have relied on these in particular because they are familiar experiences that have been with me for most of my adult life, that I can draw on when I want to and which can't be taken away from me. They support my senses and give me pleasure.

Music

I am not a particularly knowledgeable musician, but when I was young my mother used to play classical symphonies from her much prized collection of '78s'. At times of crisis I have turned to music – maybe because it reminds me of my happy childhood, because of its soothing qualities, because it brings my emotions to the surface or because it provides me with a cushion protecting me from the world outside. Whatever the reason, I find that gentle music helps me to feel better, whilst troubled, discordant music does not.

Ten years ago I joined the Caerphilly Ladies Choir and have benefited greatly from regular practice and the fellowship of members. I have learned some lovely songs, with moving words and beautiful harmonies. It's very rewarding to sing and listen to music one knows well. Otherwise, I listen most often to choral music, pieces that remind me of happy events, celebrations, commemorations and even poignant moments in my life and I also like short pieces played on a clarinet or violin.

I don't miss not being able to go to concerts any more. I now cope less well with big stimuli to my senses, preferring instead light touches of music in small snatches in the calm of the conservatory or as a way of relaxing when I'm lying down. I find that when I'm alone with my thoughts, music touches me, supports my sub-conscious, and enhances my sense of well-being.

Photography

I've always wanted to be able to draw well, but never mastered it. Photography is the next best thing. I learned to take photographs of buildings, people and townscapes as part of a course in Urban Design and it served me well for the next thirty years; but in the last 10 years I have focused more on friends and family and on the natural environment. This is my way of being visually creative, enabling me to capture the moment and take it home. Photographs can absorb the silk-like air and sunshine I enjoyed on a walk last month, retain the blue cloudless skies, natural colours, and calmness of the place I visited, reflect the changing seasons and remind me of how I felt at the time. A photograph enables me to connect and live in harmony with my environment; it is *my* world – someone else's picture simply won't do!



Urbansee, Carinthia, Summer 2009

During 2007 when I was undergoing my treatment I took almost no photographs. It was as if my spirit was under attack and had too many other demands on it. I changed from film to digital photography in 2008. I get more instant satisfaction from the pictures without losing the enduring pleasure they give me. Taking pictures uplifts my spirits and also gives me material for visioning. My favourite photographs are of trees and of the Urbansee, the lake at St Urban in Carinthia, Austria, where my parents live and where I would like my ashes to be scattered when the time comes.

Living with myself

It is 3 years since my diagnosis. I spent the first six months consumed by guilt, fear and isolation: guilt about allowing the cancer to develop without my noticing it, guilt that I had inflicted pain on my family, fear of what could happen, and isolation from my not being able to adequately communicate my feelings with others. I spent the next year trying to cope with everything that had happened to me. It has only been in the last year that I have been able to bring together the emotional, physical and intellectual aspects of my well-being and write my story. The practical things I have done to make the most of each day are relatively straightforward, but they are underpinned by the mental side of living with myself.

Managing my vulnerable self

During the Mindfulness course, I began to realise that I have two faces – my public face is the one I display to others, whilst my private face is my vulnerable self, what is going on inside me, my fears and coping with chronic pain. I have gone through life being able to protect this vulnerable self from public scrutiny, but now that I feel less robust, I fear that it will be more exposed.

If I feel uncomfortable and low, I 'put on' my public face, focus on the good things in my life, try to smile at others, and remind myself that they can't be aware of how I'm feeling, and it's not their fault. I tell my private face that this is our little secret and give myself a pat on the back when people tell me how bright I look!

I also cajole myself into action: after a bad night's sleep I tell my vulnerable self that there's no point in lying there feeling sorry for myself and I have to get up and face the world. I tell myself that others have worked hard for me and made me think that it was worthwhile to invest in me – it's up to me to show how I value this, by doing the best for myself.

I tell myself that I can practically help myself by:

- Stretching myself to reasonable limits
- Getting fresh air every day, regular exercise, walking and keeping fit
- Eating and drinking well and regularly
- Resting, pacing, and managing my time and energy and monitoring how I feel
- Paying attention to how I look – wearing clothes that aren't too heavy /hot/thin
- Trying to feel good – focus on keeping a smile on my face
- Enjoying activities and telling myself frequently that it's all worth while
- Telling myself how well I'm coping against the odds
- Congratulating myself on achievements however small
- Reminding myself of the importance of my family to me – and me to them
- Remaining curious – learning to look at situations as if they were always new

Conquering my fears

Fear of isolation

One of my greatest fears when I became ill was a sense of isolation: many people I know who have been ill have given up work or social activities and somehow disappeared. I thought that would happen to me too. Although I work from home and much of the time I spend at work is solitary, I have been fortunate to have a large network of people with whom I work or socially interact. I was 57 when I had my diagnosis and was encouraged to think about retiring from work, but I really did not want to because of the ongoing interest, stimulation, and human contact it provides. I was fortunate that I had support for some of my work during my treatment, but otherwise I maintained my paid work commitments and most of my voluntary activity throughout.

I mention this because being alone has very little to do with the sense of isolation. At the time of my diagnosis, I had plenty of social contact, but felt lonely and isolated because I could not communicate with those around me about the things that were troubling me. I wasn't able to understand myself and what was happening to me. I was afraid that the next knock would damage me irreparably. I wasn't in control and I did not trust others to help me. Now that I am more in control of my inner self, I am more able to explore my feelings, my hopes, and regrets and more able to be alone without feeling isolated. I also need to be alone to lighten my cognitive load, reflect on the way life is treating me, and to give myself time to absorb the knocks, to realise that nothing can get to me, and to move on. Being at peace with myself is a very important tool in managing pain.



Reflection - mirroring or clarifying reality?

Fear of the unknown

One of the things I learned from Mindfulness is to focus on the here and now. I don't have the energy to contemplate the enormity of the big picture – sometimes it's hard enough just to manage getting through each day. I often resort to the advice of my Aunt Erika: you can't do anything about what happened yesterday and you can't do anything about tomorrow – so you only need to be concerned about what's in front of you today. If you really learn to focus on today, the unknown somehow gets absorbed into the background and you don't need to waste time on it. Fear is such a destructive emotion – I'm really sorry that I didn't work to tackle it earlier in life!



Urbansee in the early morning: June 2009

Fear of losing control

During my cancer journey, much of my life seemed out of control and an important element of my recovery has been a search to regain control. Ironically, before my diagnosis, I controlled very little of my life. A much larger part consisted in providing a network of support for my family and extended family, being part of my community and wider social fabric. But control mattered less to me then than it does now. Now, I can do less for myself and am more reliant on others. Now I have my chronic pain to manage and need others to understand my needs.

The process of becoming more in control of my smaller domain has not been painless. I have worried about asking for help, about what others will think of me when I say 'no', about not conforming to the pattern of behaviour that I once followed, and of setting my own standards. I have had to be honest with myself and acknowledge my weaknesses as well as my strengths. I have had to recognise that there are uncertainties that I cannot control. I have had to be realistic about my expectations, and not be disheartened by the lack of results compared with my

investment. There are also things that I still need to work on – for example, being ‘kinder’ to myself, focusing on the things I value about my existence, focusing on the things that help me to enjoy life (such as being creative with writing, enjoying times with friends and family, being part of volunteering with others, going on outings etc) and delegating more to others and giving them a chance to shine.

Overall, I have managed to plan my life in a systematic way and create an existence where I am able to do things my way. I’m much more cautious about making arrangements that are onerous, inconvenient or burdensome, but I still get caught out sometimes and have to pay the price. Achieving this has required a whole year of actively planning and organising myself and a lot of support from others. I regard myself as very fortunate to have had this opportunity to move forward with the rest of my life and also to live in an environment and at a time in my life when I have had the time and space to nurture my needs.

The future

Fortunately none of us can see around the corner, but most of us think about it. I see my future as an extension of this ongoing story, living on my ledge, exploring creativity and maintaining a sense of purpose.

I was asked recently whether I had developed emergency reserves, for tackling future crises. I have consistently said that if the cancer returned I would be undecided about further treatment. If this were to happen, I know that my story will help me to decide. Writing it, and reflecting on the experiences that underpin it, have helped me to lighten my rucksack, and have taken me to new realms of knowledge, self-awareness, and appreciation of my life and of the people who have helped me to get it back.

I would like to thank all the people who have realised the importance for me of finding my own solutions and have had sufficient faith in me to allow me to implement them. Mine is an ongoing journey of discovery, in which I have been helped to define the road ahead more clearly – and I’m glad to be back in the driving seat!

“By three methods we may learn wisdom: first, by reflection, which is noblest; second, by imitation, which is easiest; and third by experience, which is the bitterest.”

Confucius 551-479 BC

Part E: Addressing my Information Needs

Chapter 22: Introduction

The importance of information

I have spent most of my working life as a researcher - asking questions, collecting evidence, finding things out, managing, and analysing information – so information is a valuable tool for me.

I was recently involved in a study to assess the information and service needs of people with serious mental health problems, when a young woman told me:

“When I am ill, I want to be sure that I receive the best treatment available. When I am better, I just want to get on with my life.”

I completely agree with this perspective and would only add: *“How can we be sure that the treatment we receive is the best available?”* Without information we cannot.

Information is a fundamental building block of self awareness and empowerment. It provides reassurance, helps to make sense of the unfamiliar and to overcome fear of the unknown. It aids communication by providing a framework for discussion. It is a means of supporting engagement and a context for decision-making. It can also save money in reassuring patients that they are doing their best for themselves – much cheaper than tackling depression!

Decisions about treatment are never black and white and the ‘best’ for each of us will vary. This seems particularly true of cancer, which is complex and where the outcome and side-effects of treatment are unpredictable. Therefore information that helps to reassure us that a particular path is the ‘best’ for us is vital.

My experience

Having access to enough information has been essential for me in coping with my diagnosis, treatment, and in achieving a good quality of life afterwards.

When I was first diagnosed I was initially traumatised. I had to make informed decisions very quickly and trust that the people who were treating me would give me the best treatment available. I needed information to help me understand the treatment being proposed, why it was being offered, when it would take place, the choices available, potential side effects, etc. I needed information to be more confident in discharging my responsibility in getting the best for myself. It was also important in giving my *informed* consent for the treatment. I wanted information that was accurate, accessible, appropriate, and, importantly, independent of the people treating me.

At the time of my diagnosis, I also needed information to better understand my new situation and make sense of what was happening to me, to help me to conquer my fears, and also to assuage my guilt about getting cancer and not having discovered it earlier. In the early days not everyone felt comfortable with my approach of scrutinising the information being provided, and I was encouraged at times to turn to more 'important' things, like sorting out my emotions and making practical decisions. I felt I was being judged by the information I requested.

I felt that no-one recognised the importance of this information to me, and at the time was dissatisfied with the response, which I felt represented information that practitioners wanted me to have, rather than what I thought I needed. The hospital discharge information pack contained some information I was not going to need for 8 months and some information that was never going to be useful to me, whilst some of my questions were not answered for some 18 months.

After my treatment was over, I wanted to get on with my life and find the best way to recover. At this stage I had the opportunity to take my time, to assess my needs, search for information and decide the best course of action for me. I needed information about healthy eating, exercises, addressing insomnia, places to go for walks, comfortable clothing, kitchen equipment etc. Some of this was available from individual practitioners - Lymphoedema Physiotherapist, Dietician, my Homeopath and all the practitioners I have mentioned individually. My Oncology Nurse Specialist in particular went to a lot of trouble to fill in gaps, provide evidence of good practice and to respond to my many questions. However, there were many gaps and I actively had to seek ways of filling them, even though I felt unwell.

Some excellent information is available from the Cancer Charities. Fortunately, I had access to information from the Internet – e.g. Breast Cancer Care, Cancer Research and Macmillan Cancer Care. I supplemented this with searching in specific research journals and going to talks on the subject. Having information which I knew was researched independently of the clinical practitioners treating me was also very important.

Since my diagnosis I have never suffered from 'information overload'. Much of the information provided was very good, and I cannot claim to be dissatisfied with it. However, many of my (admittedly ill-defined) needs were unsatisfied, which led to many months of searching for solutions that were right for me. For my part, *I never want to be in a situation again where I fail myself because of ignorance* – because I did not know that lobular cancer doesn't form a lump or show up on a mammogram or because of my misplaced confidence that screening would pick up any cancer that exists.

With the benefit of hindsight, the following are critical pieces of information for me. Receiving this in an accessible format at the appropriate time would have made my experience less difficult.

Essential information for me

Information	Reasons
Explaining the difficulties of screening for lobular cancer - and explaining the 'risk factors'	Getting an adequate explanation of why the screening programme had not found my cancer was pivotal to my recovery - e.g. an explanation of the impracticality of using MRI for screening everyone unless they were 'at risk'
The diagnosis, prognosis and treatment options and treatment care plan, including the side effects of drugs	Important to know why a treatment is being planned, how valuable it is likely to be, what the limitations of treatment are, and the short term and long term side effects - the NICE Guideline- <i>Early and locally advanced breast cancer</i> - pages vi - ix is very helpful
A written information plan to accompany the care plan as recommended by NICE	Knowing where to go for advice, what to look for, what to ask and when to seek specialist advice saves time, energy, and anxiety
Practical strategies for dealing with quality of life issues	Tailored information especially about chronic pain, fatigue, treatment side effects, nutrition keeps me going - e.g. details of appropriate websites, published material and research, and access to a library
Information about what is going on / available locally	Much of the most useful support and information has been provided by peer support and voluntary groups

My assessment of information provision

I genuinely believe that everyone would feel better if their information needs were better satisfied. There is some excellent information around (e.g. published newsletters of Breast Cancer Care, the regularly updated web-sites of Macmillan Cancer Care and others, talks to my local Breastfriends Group). However, in general, information is fragmented and often does not provide the whole story. There is some duplication in information provision, with many information sources saying similar things, particularly about treatment – which is reassuring and may reach a wider audience. More significantly, there are information gaps, particularly about achieving wellbeing post treatment. When I looked for it, almost no information was available at my local library or GP surgery and there were few information outlets for people who are not computer literate or have no Internet access.

In general information works best when it is appropriately targeted, is available to people at the point they need it, is offered in places that they think of going to (e.g. GP surgery, library, clinics), is in an accessible format / medium (e.g. for those who do not have access to the Internet as well as those who do) and is meaningful (e.g. research results may need to be interpreted into a clear and accessible language for patients).

To my mind, much work is needed to better assess and address the information needs of people with or who have had cancer and the people caring for them. People's usual motives for seeking information, their information seeking skills and their information seeking behaviour (e.g. in 'shopping around', researching an issue or finding out about community activities) vary enormously. Why should cancer be different?

Whilst clinicians may find it easier to address the information needs of patients who ask for a lot of information or ask for information in a more coherent way than those who don't, this certainly does not mean that the former are 'coping' and the latter are 'in denial'.

There should also be a better understanding of the information needs of patients at various stages of their cancer journey and a more responsive information service to meet those needs. There is also a need to assess who is best placed to provide such information – an information specialist, nurse, clinician or allied professional.

Information seeking skills – computer literacy, health literacy and functional literacy – represent a significant barrier for many people in getting the help they need. Therefore there is a need for better mechanisms for practitioners to more accurately determine their patients' information seeking skills, their capacity to handle information, and the type of provision required. As the government has recognised the critical importance of patient information in the delivery of a world class cancer service in Wales ¹⁵ this is a plea for research to enlighten our understanding of patients' information needs and underpin its effective delivery.

¹⁵ The Welsh Assembly Government identifies information as critically important in its strategy, *Designed to Tackle Cancer (2008-2015)*

Appendix: Sources of information I have used

This Appendix lists the many sources of information I have collected over the past three years in addressing my information needs. They are set out by section.

Information leaflets provided by Cancer Care Organisations

Cancer care charities have recognised the importance of good quality, well targeted information for patients. Here is an example of the material provided by Breast Cancer Care. I was given leaflets about Breast Cancer Care on diagnosis and put in touch with its peer support service as part of my discharge pack from hospital. This was a lifeline. I went to an excellent Pamper Day, where I was given more information, and I've been to a consultation forum in Cardiff, all of which have been beneficial.

Breast Cancer Care

Breast Cancer Care provides an excellent range of well targeted, accessible, well illustrated and easy to read leaflets covering the following areas:

- Breast health
- Breast problems
- Diagnosis
- Men and breast cancer
- Younger women
- Treatments
- Secondary breast cancer
- Health and well-being
- Financial and practical advice

The leaflets are free of charge and are regularly updated. At the time I had my surgery I was given the booklet *Breast Cancer and You – coping with a diagnosis*, the leaflet *Invasive Lobular Breast Cancer* (Factsheet Number 30), a leaflet about *Tamoxifen* and a booklet about *Breast Implants*.

Breast Cancer Care also provides online support, peer support, forums and discussion groups.

Breast Cancer Care Wales, Central and South Wales is at:

1st Floor, 14 Cathedral Road, Cardiff CF11 9LJ

Telephone 0845 077 1894

Email: cym@breastcancercare.org.uk

Web: <http://www.breastcancercare.org.uk/>

Just as I was completing the final text of my toolkit Breast Cancer Care published a remarkable loose-leaf tool for people living with and beyond breast cancer. The tool, Moving Forward¹⁶, is based on widespread research and consultation with cancer survivors, and it addresses many of my basic needs – as well as being a good resource for my toolbox!

Tenovus

The aims of Tenovus are to help prevent, treat and find a cure for cancer, by offering support, advice and treatment for cancer patients, information on cancer prevention and funding for research to improve the outcomes for people with cancer. It works right at the heart of the community. The Tenovus Cancer support team includes: an Oncology Nurse Specialist, Counsellors, Welfare Rights Officers and Social Workers.

Tenovus, Gleider House, Ty Glas Road, Cardiff, CF14 5BD.

Freephone Cancer Support Line: 0808 8081010

Web: www.tenovus.org.uk

Macmillan Cancer Support

Macmillan Cancer Support provides free, high quality information for people affected by cancer through publications, a website and a phone service. Its vision is for all people affected by cancer to have the information they want, when they want it and in a format they are comfortable with.

- www.macmillan.org.uk - for access to a wide range of resources
- <http://be.macmillan.org.uk> – for ordering printed leaflets, audio and CD versions. There is also some information in other languages.
- Telephone helpline: 0808 808 00 00

There are more than 80 booklets and 300+ fact sheets. Specific questions and answers are published on the website as 'Cancer Q&As'. Information is available on cancer, cancer treatments, and all aspects of living with cancer. In 2008 Macmillan and Cancerbackup merged, creating the UK's largest online cancer community.

All the information has the highest level of quality assurance: it falls in line with accepted national and international guidelines and the results of systematic reviews. Where no such guidelines exist, the information is based on scientific evidence such as data from published clinical trials, or combined analyses of trials. Where such evidence is not available, the information is based on a consensus view of experts. The information is accredited by the NHS and follows the guidelines of the Plain English Campaign. Information booklets that describe treatments are produced to meet the criteria of the Discern Index, a nationally recognised measure of health information quality.

¹⁶Moving Forward (www.breastcancercare.org.uk) (2010)



Macmillan Cancer Support is also a certified member of the Information Standard. This is a quality assurance standard that has been established to improve the quality of health and social care information i.e. it is supported by the best evidence, is produced according to strict quality-control guidelines and people affected by cancer are at the heart of all the content.

Information collected from the Internet

Listed below is a selection of websites I used to inform myself. Many of the websites say the same things, but some of the websites are more accessible and user friendly and some of the information is better presented. The websites listed here aren't necessarily the best websites, but they are all ones I was satisfied with.

About the Internet

The Internet is a hugely important tool for patients, practitioners, citizens, and the wider community. However, the Internet remains largely unregulated and should be used with caution. Not all web sites are easily navigated; and not all are completely transparent. Some guidelines on using the Internet as a research tool:

- Use sites provided by organisations you know
- Look to see when the website was last updated to ensure you get the latest information
- Avoid sites using Internet to sell goods and services (including commercial sites where you have to pay for information)
- Avoid data from small studies, short term trials, research that is not evaluated or where results are inconclusive
- Don't use the results of one study, whilst ignoring others, just because they suit your purpose - you need to be completely objective!

Information about Diagnosis and Initial Treatment Options

Part B, Chapters 3 and 4

Information	Where found
Breast cancer - risk factors	www.tiscali.co.uk/lifestyle/ ; www.patient.co.uk
Lobular Cancer	www.breastcancer.org.uk (this included a photograph of lobular cancer - explained why it was not visible in a mammogram) www.icr.ac.uk (Institute of Cancer Research) www.breakthrough.org.uk
Staging	www.cancer.org - information about Nottingham Prognostic Index, Adjuvant! Online; & TNM (tumour, node, metastasis) staging www.besttreatments.co.uk www.cancerbackup.org.uk (site now www.macmillan.org.uk) ¹⁷ - Nottingham Prognostic Index, TNM Staging Adjuvant! Online Prognosis has now a patients' version
Protocols for treatment	NICE, February 2009, Early and locally advanced breast cancer: diagnosis and treatment www.nice.org.uk NHS Wales National Standards for Breast Cancer Services (2005) www.nhs.wales.uk
Treatment Options	www.cancer.nexcura.com [US site, detailed and informative] www.breakthrough.org.uk [US site] www.breastcancercare.org.uk.uk - see also Breast Cancer Clinical Outcome Measures Project (1 st year report, 2006)
Breast reconstruction	www.macmillan.org.uk : Possible Complications after Breast Reconstruction www.macmillan.org.uk : Recovery after Breast Reconstruction

¹⁷ www.cancerbackup.org.uk site now www.macmillan.org.uk

Information about Chemotherapy

Information	Where found
Adjuvant therapy	www.mayoclinic.com/print/breast-cancer-treatment Breast Cancer Care - information leaflets
Installing Hickman Line	www.macmillan.org.uk
Chemotherapy Treatment	Velindre Cancer Centre: General Information Leaflet www.cancerhelp.org.uk www.cancer.org [American Cancer Society site] Breast Cancer Care booklet: Chemotherapy for Breast Cancer www.macmillan.org.uk - Mouth care; Coping with menopausal symptoms www.canceragnosis.com/chemotherapy
Steroids	www.macmillan.org.uk
FEC and Taxotere	www.macmillan.org.uk www.medscape.com NICE: Final Appraisal Determination on Docetaxel www.nice.org.uk TA109
Peripheral neuropathy	www.breastcancercare.org.uk.uk www.macmillan.org.uk

Information about Radiotherapy

Information	Where found
Fatigue	www.breastcancercare.org.uk www.cancer.org - 7 ways to manage fatigue
Radiotherapy	www.cancer.org - how it works, side effects, what's new www.breastcancer.org - planning session www.macmillan.org.uk Breast Cancer Online [www.bco.org] Implication of planned radiotherapy on breast reconstruction: radiotherapy and plastic surgery with implants ISSN 1470-9031 vol 8 (2005) www.cancernet.co.uk/rad-breast.htm www.bmj.com/cgi (2005) Radiotherapy & the Reconstructed Breast, Roiles M. www.admin.ox.ac.uk Radiotherapy improves 15-year Survival after breast cancer surgery (mews: Dec2005) www.mrw.interscience.wiley.com Cochrane Review (2008) Radiotherapy for Early Breast Cancer www.uhl-tr.uk - University of Leicester's pioneering research

Information collected about Hormone Therapy

Chapter 6

Information	Where found
Hormone Therapy	<p>NICE: (2006) Hormonal therapies for the adjuvant treatment of early oestrogen-receptor positive breast cancer www.nice.org.uk</p> <p>Cancer Research UK: www.cancerhelp.org.uk - Exemestane, Arimidex, Letrozole</p> <p>AstraZeneca (manufacturer) Patients Leaflet, Understanding Breast Cancer and the Role of Hormone Receptors in Tackling it (2009) www.arimidex.com</p> <p>www.cancernet.co.uk/arimidex.htm</p> <p>www.breastcancer.org.uk - side effects of aromatase inhibitors</p> <p>www.macmillan.org.uk - Arimidex</p> <p>www.accessdata.fda.gov [US Food and Drug Administration site] - Arimidex</p> <p>www.breast-cancer.emedtv.com/arimidex/arimidex-side-effects</p>

As I experienced a wide range of side effects from Arimidex (most of which I did not link to the Arimidex) I decided to look at the manufacturer's website to establish further what I should be asking for help about and what I should expect to put up with.

The manufacturer AstraZeneca's website (www.arimidex.com) includes an excellent *Patients Leaflet, Understanding Breast Cancer and the Role of Hormone Receptors in Tackling it*.

I also looked at Cancer Research UK's website, which has well-laid out information for patients - www.cancerhelp.org.uk.

I have recently accessed some of the American sites as these tend to be more informative and based on more extensive patient feedback: I thought the site by emedtv was particularly useful; this can be found at: (www.breast-cancer.emedtv.com/arimidex/arimidex-side-effects).

I reproduce again (from page 29) the different information about side effects which each of these sources attribute to Arimidex. It is interesting to see the differences between them.

Web sites and what they do and do not tell you about side effects of Arimidex

	Arimidex website & leaflet	Cancer Research UK	Emedtv (US website)
Allergic reactions / skin rash	✓	✓	✓
Hot flushes	36%	>10%	36%
Nausea	✓	10%	13%
Vomiting	✓		13%
Weakness / fatigue	✓	10%	19%
Mood disturbances		✓	19%
Anxiety / depression			13%
Headaches	✓	✓	18%
Carpel tunnel syndrome	✓	✓	
Arthritis			17%
Joint pain / stiffness	✓	10%	15%
Bone pain / back pain			12%
Thinning of hair	✓	✓	
Sore / dry throat			14%
Cough			8-11%
Difficulty breathing			8-11%
Osteoporosis / fractures	10%	✓	8-11%
Insomnia			10%
Dizziness			8-11%
Swelling / water retention			8-11%
Abdominal pain			8-11%
Constipation			8-11%
Diarrhoea	✓	✓	8-11%
High cholesterol / raised lipids	✓		8-11%
Vaginal dryness / bleeding/ discharge	4-5%	✓	3-7%
Infections			8-11%
Weight gain			9%
Loss of appetite / weight loss	✓	✓	8-11%
Breast pain			8-11%
Urinary tract / bladder problems			8-11%
Blood clots / stroke / heart attack	2-3%		✓
jaundice	✓		
Muscle pain			3-7%
Cataracts			3-7%
Dry mouth			3-7%

Chronic pain

Part C, Chapter 12

Research is now beginning to show that persistent pain and sensory disturbances following surgical treatment for breast cancer is a significant clinical problem *affecting up to 50% of patients*. The following article is widely reported – but other studies come to similar conclusions. Much research is now being done to prevent the incidence of chronic pain amongst breast cancer survivors.

Gartner, Jensen, Nielsen, Ewertz, Kroman, Kehlet: *The Prevalence of and Factors Associated with Persistent Pain Following Breast Cancer Surgery*, reported in the Journal of American Medical Association, Vol 302, No 18, Nov 2009 : 1985-1992. Web extract: <http://jama.ama-assn.org/cgi/content/abstract/302/18/1985>

This survey of 87% of 3754 eligible women receiving surgery in 2005 and 2006 in Denmark found that 47% reported pain, of whom 13% had severe pain, 39% had moderate pain and 48% had light pain. Factors associated with chronic pain were young age, and radiotherapy, axillary lymph node dissection. Pain affected parts other than the surgical area.

Poleshuck, Katz, Andrus, Hogan, Jung, Kulick, Dworkin (University of Rochester School of Medicine and Dentistry, New York): *Risk factors for Chronic pain following breast cancer surgery: a prospective study*, reported in the Journal of Pain, 2006 Sept: 7(9): 626-634
<http://www.ncbi.nlm.nih.gov/pubmed/16942948>

This suggested that younger age was associated with a significantly increased risk of developing chronic pain 3 months after surgery. Other variables contributing to high intensity chronic pain included more invasive surgery, radiotherapy, and clinically meaningful acute post-operative pain. Pre-operative emotional functioning variables did not contribute to the presence or intensity of chronic pain – suggesting that aggressive management of acute postoperative pain may reduce chronic pain.

Loftus and Laronga: *Evaluating Patients with Chronic Pain After Breast Cancer Surgery: The Search for Relief*, reported in the Journal of American Medical Association, Vol 302, No 18, Nov 2009: 2034-2035 Web: <http://jama.ama-assn.org/cgi/content/extract/302/18/2034>

This study reported that chronic pain after breast cancer occurs in approximately 50% of patients with reasons including nerve damage associated with axillary lymph node dissection, and interactions with adjuvant chemotherapy and radiotherapy.

Dr John Williams, speaking at the British Psychological Society's 2007 conference talked of the common and debilitating problem of neuropathic pain syndrome with additional musculoskeletal, physical and emotional components experienced by up to 30% of patients after breast surgery. He suggests that specific risk factors are poorly controlled acute pain, chemotherapy and preoperative stress. Reported in BPS 2007 conference highlights – <http://www.library.nus.uk/palliative/>

Researchers in Aberdeen were funded in 2006 by Cancer Research UK for a three year study of the clinical and psychological factors that might influence Post mastectomy Pain Syndrome or PMPS.

Websites about chronic pain

Information	Where found
General web sites	www.patient.co.uk – see extract overleaf
Drugs and their side effects	www.netdoctor.co.uk – google relevant drug www.prnewswire.co.uk - findings from <i>Neurology</i> journal on Pregabalin
TENS Machines	www.patient.co.uk - TENS Machines for pain relief www.acticare.com – Types of Electrotherapy
Acu-pen	Google acu-pen and web sites will be shown – price around £21-£25
Microwavable warm pads	Many are available commercially – google on Internet – e.g. scarf
Battery operated vegetable peeler	Google on Internet – available for around £10.
Organisations offering services for people with chronic pain	Action on Pain Helpline: 0845 603 1593 www.action-on-pain.co.uk Pain Concern: PO Box 13256, Haddington, EH41 4YD Tel 01620 822572 www.painconcern.org.uk Chronic Pain Policy Coalition - www.paincoalition.org.uk British Pain Society - www.britishpainsociety.org Pain Relief Foundation - www.painrelieffoundation.org.uk

Extract from Patient UK's website on Neuropathic Pain

The information below is summarised from the leaflet produced by Patient UK on Neuropathic Pain, which I came across recently and found helpful.

What is neuropathic pain?

Neuropathic pain comes from nerve problems. It is different from the common pain due to an injury, burn etc. There is often no injury or tissue damage that triggers the pain, but the function of the nerve is affected and sends misleading pain messages to the brain. Traditional painkillers often do not help very much. However, neuropathic pain is often eased by anti-depressant and anti-epileptic medicines. It is estimated that 1% of the population in the UK have chronic neuropathic pain - but it is higher than this amongst the older population and those with illnesses such as diabetes, cancer and shingles.

Medicines used to treat neuropathic pain:

- Painkillers: (e.g. paracetamol, anti-inflammatories, codeine, and morphine)
- Tricyclic anti-depressants: (e.g. amitriptyline) - it may take 4-6 weeks before the pain is addressed; side effects are drowsiness, dry mouth etc ; many people give up because of the side effects before this medication works
- Anti-epileptic medicines (e.g. gabapentin) - again it may take a few weeks to address the pain; side effects include drowsiness
- Capsaicin cream - this 'hot chilli cream is applied 3-4 times a day is thought to 'block' the nerves from sending pain messages; it takes up to 10 days to work fully and can burn the skin if not applied appropriately.

Physical treatments

- Physiotherapy
- Acupuncture
- Nerve blocks
- TENS Machines (Transcutaneous Electrical Nerve Stimulation)

Psychological treatments

This acknowledges that pain is 'self-limiting' and can be made worse by stress, anxiety and depression. Treatments include:

- Stress management
- Counselling
- Cognitive behaviour therapy
- Pain management programmes

Source: www.patient.co.uk

Physiotherapy and physical activity

Chapter 13

My physiotherapist gave me an excellent little booklet full of useful tips called the *Pain Toolkit*, by Peter Moore (petermoore2@yahoo.co.uk). This emphasises the importance of movement in addressing chronic pain.

Web sites about the value of physical activity

www.mypyramid.gov/pyramid/physical_activity.html - US Dept. Of Agriculture - healthy living for all ages (web site for young people, parents and public about healthy living). Site last modified 6th April 2009.

This points to the benefits of physical activity in:

- Improving self-esteem and feelings of well-being
- Increasing fitness levels
- Helping build and maintain bones, muscles and joints
- Building endurance and muscle strength
- Enhancing flexibility and posture
- Managing weight
- Lowering the risk of heart disease, colon cancer and type 2 diabetes
- Helping to control blood pressure
- Reducing feelings of depression and anxiety

Types of physical activity that are especially beneficial :

- Aerobic activities
- Resistance, strength and weight bearing
- Balance and stretching activities.

Additional information on how much exercise is needed by which population groups, how to go about it etc available and there is also information on healthy eating.

www.mayoclinic.com/health/fitness-tips-for-menopause - Mayo Clinic points to the benefits of regular physical activity as a way of:

- Preventing weight gain /maintaining muscle mass
- Reducing the risk of breast cancer
- Strengthening bones and reducing risk of osteoporosis / fractures
- Reducing the risk of cardiovascular disease and type 2 diabetes
- Boosting your mood

Four particular types of activity are recommended:

- Aerobic activity - walking, jogging, biking, swimming (increasing heart rate)
- Strength training
- Stretching - to improve flexibility, range of movements, & circulation; relieve stress
- Stability and balance

The site also provides more detailed information about specific fitness programmes.

Yoga and pilates

There is a wide range of available information and guidance about yoga and pilates. I've used:

Bob Bury: *A Pocket Book on Yoga* (1982) pub Octopus

Herdman and Wood: *A busy person's guide to pilates* (2003), pub WH Smith

ISBN 1 85675 1597

Mindfulness

Chapter 14

Jon Kabat-Zinn, *Full Catastrophe Living* (2001) ISBN 13-978-0749915858 (Jon Kabat-Zinn is an American psychologist who had developed the course concept in the 1990s).

Vidyamala Burch, *Living Well with Pain and Illness: The mindful way to free yourself from suffering* (2008)

Breathworks Guided Meditation CD's / MP3 downloads available from:

<http://www.breathworks-mindfulness.org.uk>

Breathworks Living Well with Pain and Illness Courses – Cardiff - 8 week daytime and evening courses available throughout the year at the Buddhist Centre in Cardiff Mindfulness Course in Cardiff, 12 St Peters Street, Roath Cardiff CF24 3BA Tel 07527 110096 email:

info@breathworks.cardiff.co.uk

Mindfulness Courses in Caerphilly take place at the SAMYE Centre (Sharing Advice and Mindfulness in Your Environment), 2a-4a Cardiff Road, Caerphilly CF83 1JN bookings@sfwales.org

www.GudeToPsychology.com – an interesting page looking at the Psychology of Stress, one of many websites covering issues such as mindfulness and cognitive behaviour therapy.

Addressing and preventing unwanted conditions and side effects

Part D, Chapter 20

Information about menopausal symptoms

Information	Where found
Menopausal symptoms	<i>Menopausal Symptoms and Breast Cancer</i> - Breast Cancer Care factsheet <i>Menopause without Medicine</i> , Linda Ojeda (2002) Thorsons www.macmillan.org.uk - Coping with menopausal symptoms

Addressing problems with sleeping

Information	Where found
Sleeping	www.patient.co.uk 's website for Sleep Problems - A Self Help Guide - prepared by Lesley Maunder and Lorner Cameron, Northumberland Department of Psychological Services and Research, Newcastle, North Tyneside and Northumberland mental health NHS Trust, 2003, revised 2006 http://sleep.emedtv.com/sleep/good-sleep-habits.html http://www.cardiff.ac.uk/cllng - Insomnia problems with sleep

Self Hypnosis

Sandville Self Help Centre in Kenfig Hill, near Bridgend, South Wales offers social and psychological care for patients and families. A range of complementary therapies and activities include: reflexology, yoga, aromatherapy, self-hypnosis, head and hand massage, Reiki, hairdressing, hydrotherapy, etc. There is no web site but contact: 01656 743344.

Arthritic Pain

I'm much attracted by the idea of drug-free approaches to tackling arthritis, with a focus on acid free or low acid diet, anti-inflammatory herbs and spices (e.g. ginger, cinnamon, turmeric), glucosamine etc. I dip into books such as:

Marguerite Patten and Jeannette Ewin (2001) *Eat to Beat Arthritis*

Christopher Vasey (1999) *The Acid-Alkaline Diet for Optimal Health*

Margaret Hills (1985, updated 2004) *Treating Arthritis the drug-free way*

Avoiding osteoporosis

Information	Where found
Osteoporosis	www.nice.org.uk - Osteoporosis secondary prevention http://houseofstrauss.co.uk - Is dairy the best source of calcium? www.netdoctor.co.uk - Calcichew D3 Forte www.bupa.co.uk www.mayoclinic.com

Most information material points to the value of weight bearing exercise to maintain the integrity of the bones.

Vivienne Goldschmidt , www.saveourbones.com runs a campaign against the use of bisphosphonates in treating osteoporosis, recommending instead a variety of natural remedies.

Vertigo and balance

People with osteoporosis fear most falling and breaking their bones. I have therefore included some information about vertigo and balance. I also have Cawthorne Cooksey Vestibular Retraining Exercises, given to me when I first got vertigo, which are worth persevering with.

Information	Where found
Vertigo and balance	BBC Health web site - www.bbc.co.uk/health www.thebalancemanual.com/ecourse - Information from Mike Ross, exercise physiologist specialising in senior health and fitness (US) - more information from betterbalance@aweber.com and mikeross@thebalancemanual.com .

Homeopathy

The Society of Homeopaths can be found on <http://homeopathy-soh.org>

My homeopath, Felicity Lee practices at the Natural Health Clinic, 98 Cathedral Road, Cardiff South Wales, CF11 9LP Tel: 029 2022 2221. She can be contacted via website – www.felicitylee.co.uk

Avoiding Lymphoedema

Website Information

Information	Where found
Lymphoedema	www.breastcancer.org (Do's and Don'ts) www.patient.co.uk www.macmillan.org.uk : Skin Care and Lymphoedema; The Lymphatic system; Exercises; Limb positioning and movement

Even with the web site information I didn't feel that I had enough information about the condition, so I became a member of the Lymphoedema Support Network, a registered charity, (No. 1018749). This provides a range of information and support, campaigns for better services for Lymphoedema sufferers. Membership costs £15 per year and includes a quarterly magazine, LymphLine, and access to free and low cost leaflets, DVDs etc.

The LSN, St Luke's Crypt, Sydney Street, London SW3 6NH.
Tel 020 7351 4480 (information and support); 0207 351 0990 (administration);
Fax 0207 7349 9809; e-mail: adminlsn@lymphoedema.freeserve.co.uk .
web site: www.lymphoedema.org/lsn

The South East Wales Lymphoedema Support Group meets at Velindre Hospital, Cardiff at 7.30 p.m. on the last Wednesday of every other month from March to November.

Contact: barbara.burbridge@tiscali.co.uk; webapps.rhondda-cynon-taf.gov.uk

Breastcancer.org includes particularly helpful pages of Do's and Don'ts in preventing lymphoedema – this is an American site developed by Dr. Marisa Weiss a breast cancer Oncologist, practicing in Philadelphia. Webpage: www.breastcancer.org/tips/lymphedema/avoid.jsp

Eating Well

Website information

There is a huge amount of information available on the Internet about healthy eating and useful nutrition. I've listed the following because the websites are accessible and informative.

Information	Where found
Food and Nutrition	<p>Food Standards Agency: 8 Tips for making healthier choices; Food labels - more informed choices www.foodstandards.gov.uk; www.food.gov.uk; or www.eatwell.gov.uk</p> <p>www.brianmac.co.uk/nutrit.htm British Dietetic Association</p> <p>www.ars.usda.gov US Department of Agriculture's website providing information on the nutritional content of 13,000 foodstuffs. Also check on the following http://www.nal.usda.gov/fnic/foodcomp/search/ US Department of Agriculture which runs site: http://www.mypyramid.gov/pyramid - accessible information about food and healthy eating</p> <p>World Cancer Research Fund: www.wcrf-uk.org - <i>Healthy Food on a Shoestring</i></p> <p>www.hsph.harvard.edu/nutritionsource - Harvard School of Public Health site</p>

Books on healthy eating

I have particularly enjoyed the following books:

Gayle Reichler with Nancy Burke: *Active Wellness* (1998), Time Life Books. Written by an American nutritionist who survived thyroid cancer in her 20s, this book looks at optimal eating, exercise, meditation (stress reduction) and mental and emotional growth. A range of foodstuffs are set out under the key food types – grains/starches, vegetables, fruits, protein, dairy, fat, sweets, alcohol – and portion sizes. A system for calculating daily allowances is provided, with guidance on best practice for people with conditions from osteoporosis to cancer. It shows the value of a systematic approach to eating and achieving a healthy food balance.

Barbara Cousins: *Cooking Without* – recipes free from added gluten, sugar, dairy products, yeast, salt and saturated fat (1997) Thorsons (Harper Collins Publishers, London) reprinted 2000. This provides excellent recipes for stimulating the palate, has encouraged me to experiment with new combinations of whole grains, beans, and nuts, herbs and spice, and enhance my use of brown rice and soya products.

Janet Wright, *The Top 100 Health Tips* (2008) Duncan Baird Publishers, London. This classifies and describes 100 foodstuffs as:

- health improvers (e.g. kiwi, raspberry, carrot, sweet pepper, coriander, turmeric, chickpea);
- detoxifiers and digestion soothers (e.g. apple, beetroot, broccoli, cauliflower, black pepper, cumin seed, ginger, yoghurt);
- fitness enhancers (e.g. grape, celery, lentil, pumpkin seed, cashews, egg, green beans);
- weight shifters (e.g. pears, strawberry, courgette, pea, almond, tuna, cottage cheese, rye);
- brain boosters (e.g. avocado, sweet potato, brown rice, cinnamon, Brazil nut, sunflower seed); and
- life lengtheners (e.g. fig, oats, blueberry, salmon, walnut, leek).

It has taught me to spread my diet to achieve the maximum range of health attributes. It stresses the importance of key foods in each group and the value of fruit and vegetables.

Leslie and Susannah Kenton: *Raw Energy – Eat your way to radiant health* (1984), Century Publishing, London. This book suggests that raw foods and primitive diets stay longer in the system and are healthier – I now try to cook my food as little as possible, and if cooked, eat my food warm rather than hot.

Local groups and cancer charities

The South East Wales Cancer Network has produced a Directory of cancer support services in South East Wales. This lists self help and support groups, voluntary sector hospice and palliative care providers and cancer related web-sites. The Directory for 2009-2010 is produced by:

Eleri Girt, Macmillan Patient Involvement Facilitator, South East Wales Cancer Network,
3rd Floor, 14 Cathedral Road, Cardiff CF11 9LJ

Tel 029 2019 6166 e-mail: Eleri.girt@sewcancer.wales.nhs.uk

Toni Muller, Patient Information Manager, Velindre Cancer Centre
Velindre Road, Whitchurch, Cardiff CF14 2 TL

Tel 029 2019 6132 e-mail: Toni.Muller@velindre-tr.wales.nhs.uk

Organisations listed in the Directory:

Breakthrough Breast Cancer: carries out research into breast cancer; produces information leaflets, fact sheets, newsletters. Helpline: 08080 100 200 www.breakthrough.org.uk

Breast Cancer Care: www.breastcancercare.org.uk : provides support and practical assistance, information leaflets, DVDs, newsletters, magazine; specific support for younger women, people with secondary breast cancer; information sessions and a cancer rehabilitation programme.

Helpline: 0800 800 6000 Monday – Friday 9.am – 5pm and Saturday 9.am – 2 pm

www.breastcancercare.org.uk

Breast Cancer Care Cymru: staffed Monday – Friday 9.am – 5pm

Breastfriends Cardiff and Vale: www.breastfriendscandv.org.uk: meets in Margaret Whittaker Coffee Lounge, Beulah United Reform Church, Rhiwbina, Cardiff Contact: Breast Cancer Care Cymru Message service 0845 077 1894

In the Pink: c/o Diane Jehu, Macmillan Breast Cancer Specialist Nurse, Prince Charles hospital, Merthyr Tydfil CF47 9DT Tel 01685 728645 meets on first Monday in the month at Dowlais Rugby Club, Dowlais and St Mair's Aberdare. www.nglam-tr.wales.nhs.uk/inthepink

LIFT – Life is for Today (Cowbridge) Contact: Anne 01446 772843 or Jane 01446 772325

e-mail: LIFT@injhydon.plus.com

Pontyclun and District Breast Cancer Support Group Contact: Barbara: 01443 237997

e-mail: enquiries@barbarathebread.co.uk Meetings first Monday every month at Bethel Baptist Centre Pontyclun.

Rhondda Breast Friends: Contact Diane Raybould Tel 01443 683220

www.rhonddabreastfriends.org.uk monthly meetings

South Gwent Breast Cancer Support Group, 1st Floor, The Council House, Ventnor Road, Cwmbran NP44 3JY Tel 01633 872221 e-mail: sgbcsg@tiscali.cco.uk
www.sgbcsg.homestead.com/welcome.html meet 2nd Monday of each month at Parkway Hotel, Cwmbran

Tenovus: www.tenovus.org.uk/ Telephone helpline 0808 808 1010

Macmillan Cancer Care: www.macmillan.org.uk Telephone 0808 808 0000

Drop in Centres:

- **Cancercareline** Drop in Centre, 15 Woodbine Road, Blackwood 01495 221660
- **Cancer Aid Merthyr** Drop In, Upper Union Street Dowlais 01685 379633
- **Cancer Support** (Cynon Valley) 76-78 Oxford Street, Mountain Ash 01443 479369
- **Helping Hands – Rhymney** 92 High Street Rhymney 01685 844888
- **Sandville**, Sandville Court, Ton Kenfig, Bridgend 01685 743344
- **The Bracken Trust** Cefnlllys Lane, Llandrindod Wells 01597 823646
- **Usk House Day Hospice** Bridge Street, Usk 01874 611717
- **Rhondda Breast Friends**, 15 Bronheulwen, Porth, Rhondda CF39 OB5 01443 683220
www.rhonddabreastfriends.org.uk e-mail: info@rhonddabreastfriends.org.uk - has a good contacts list.

This from the Internet was last updated in July 2010. The other data and information was checked in January 2011.

Katherine Hughes
February 2011
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