

More Self Management
Courses - Hassocks 2nd
Oct and Worthing 7 Nov

EFT Course 11th and
12th October

Lifting Your Spirits
Workshop 15th Oct

Service Provision - a
Domiciliary Service for
the Severely Affected at
Last

Chichester Research
Presentation by Willy
Weir and Lifting Your
Spirits with Jan Alcoe
and Harvey Zarren

Book Review by Prof
Anthony Pinching

Judicial Review

Effects of Inflammation
on the Brain

Sara's Update

Humble Cake Wins a
Prestigious Award

Conference in Surrey
10th December

Coffee Mornings,
Feedback Sessions and
More - see back page for
details

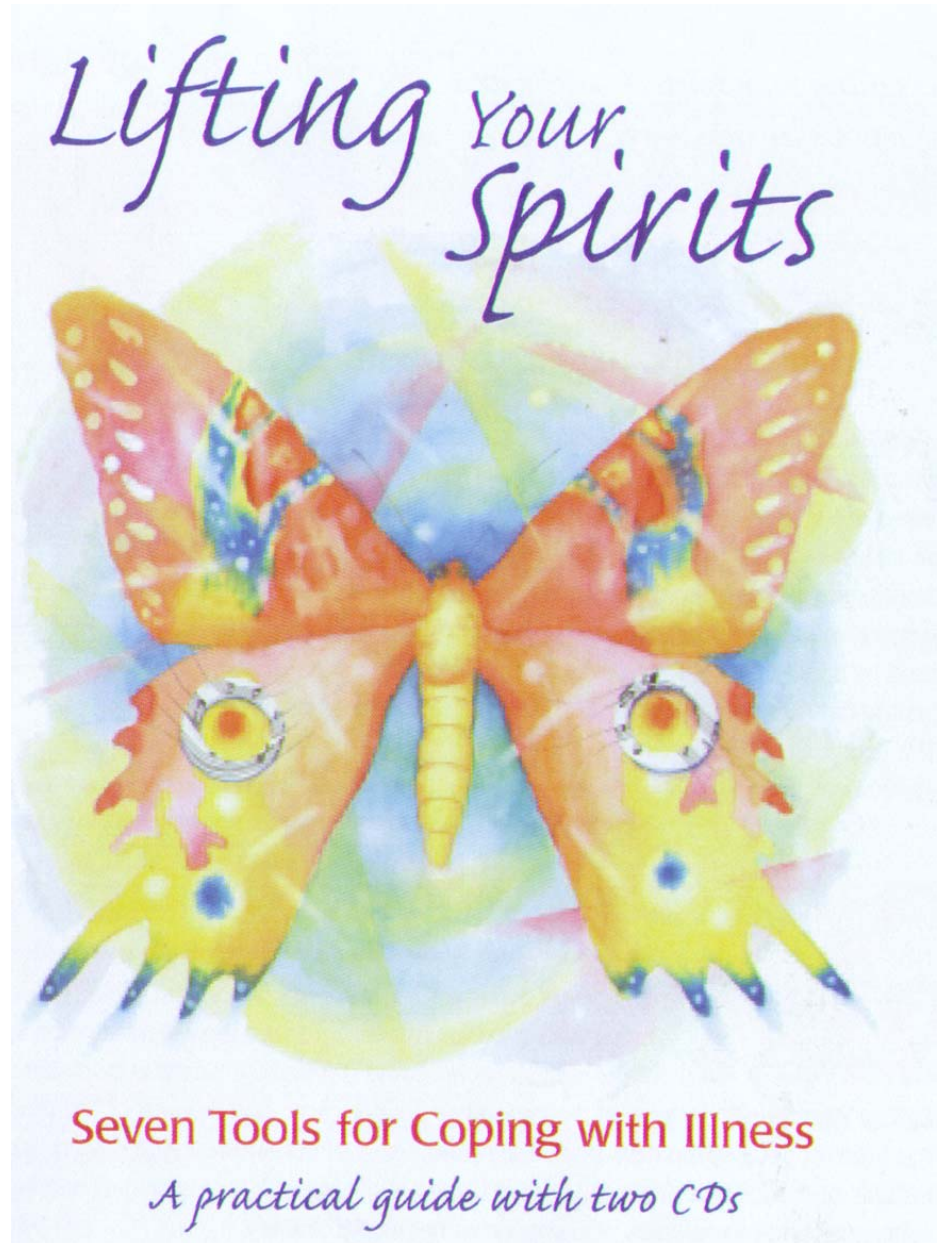
reMEMber
The Chronic
Fatigue Society

Registered Charity No 1077807

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(The Chronic Fatigue Society)

September 2008 Newsletter



*An essential companion for anyone struggling
with serious illness"*

Dr Craig Brown GP, Sussex

*See page two for details of how to order this
pack*

Lifting Your Spirits

Tools for Self-Healing

Jan Alcoe

Jan Alcoe is a writer and trainer in health and social care. She was diagnosed with cancer in the summer of 2005 and has completed a lengthy but successful treatment. Here she shares some tools for self-healing which she used to cope with her illness and to promote her recovery.

The shock of a diagnosis like cancer causes major disturbance within all levels of our being – physical, mental, emotional and spiritual, as well as in relationships with family, friends, work and other spheres of living. Familiar footholds, in terms of our roles, routines, goals and plans, fall away as we are confronted with the big life issues which serious illness present – Why this? Why me? Why now? We may feel beset by a rollercoaster of emotions, we may feel alone and separate from normal life, we may feel out of control in terms of what is happening. However, each of us has a vast capacity to promote self-healing if we can access our inner selves and rediscover the qualities and resources we have forgotten we have. There are several healing tools we can use to do this. All of them help us to bypass our anxious, thinking minds and find a place of strength and stability within. We can use them to express our true selves and to heal on all levels.

The power of meditation

Many of us say that we can't meditate because we cannot still the mind. Instead of trying to stop thinking, just focus on peaceful thoughts. Even a minute spent in this way can take your mind off pain and anxiety and leave you feeling refreshed. It can also help us to surface some inner qualities, for example, love or patience, which can fill us up and make us feel strong. Sometimes it can be difficult to sit still, but you can still meditate while going about your everyday tasks or while walking.

'Following my diagnosis, I find it difficult to meditate. My mind teems with anxious thoughts and is drawn to what is going on in my body, in particular to the pain experienced from a fast-growing tumour. However, there are fleeting moments in which I can just observe my pain, as if I were detached from the physicality of my body. It is in these moments that I begin to experience a growing sense of peace, and with it, a reduction in pain and fear. I notice a settling in myself and a feeling of growing strength in just 'being' with the

confusion, the implications and the challenges of the illness and its treatment. As I begin to feel calmer, negative thoughts and emotions occur less frequently. More and more of the time I feel content in just being. Sometimes I even feel great waves of happiness and a sense of connection with everything.'

Healing pictures

Using our senses to visualise a healing scene can help us to cope with difficult treatments and procedures. Take a few moments to relax and picture in your mind a lovely wood or room you can visit whenever you need to. Create a beautiful chair you can imagine reclining on when you have a treatment or examination. See yourself calm and smiling, accepting the treatment with gratitude. You can picture a radiotherapy therapy treatment as a shaft of sunlight or add other, helpful details to support yourself. Practise going to this healing place before, during and after your treatments.

Giving thanks

It may sound odd to be grateful when we are experiencing serious illness. But giving thanks is like a plate of nourishing food. It is healing to ourselves and ensures that we receive many good wishes from others! Begin with yourself. Thank yourself every day for how well you are doing. Extend your thanks to those who are supporting you by telling them what a difference they have made. You may then feel ready to fully appreciate the treatment you are receiving, even if it is difficult. It is so much better to have good feelings in your body and mind, than feelings of bitterness and resentment. Of course, you can extend your appreciation into a spiritual practice by giving thanks to God, to the universe or to a greater consciousness.

Laugh and the world laughs with you

Cancer is a serious business, but there is no need for us to give up sharing moments of laughter and playfulness. In fact, laughter has many physical and mental benefits and is a great healer. Ask your friends to share their best jokes with you, watch a funny film, and allow your sense of playfulness to come to the fore. You will find that you are expressing your true self and that this will make you feel energised and alive.

Be creative!

Many people say they are not creative because they can't draw or paint. However, we are all

Lifting Your Spirits

creative beings and giving expression to our creative gifts helps us to heal. Some of us do turn to art or music during illness and discover abilities we didn't know we had. However, we can do most things in a creative way, whether it is arranging hair on a head, plants in a garden, words on a page, or food on a plate. Let your creativity have a voice without being judgmental or critical of what you produce. You will find it brings moments of deep, timeless peace, as well as a chance to discover who you truly are.

Time for reflection

Experiencing cancer is often described as a journey. It can make us look at our lives and

ourselves in new ways, bringing surprising insights and valuable learning. It can help to capture some of this by keeping a journal, making a collage of pictures or writing a poem. Always try to focus on how far you have come, not how far you have to go. You will then experience feelings of achievement and satisfaction in your own strength and qualities.

These healing tools can be described as 'spiritual' tools because they connect us with the essence of who we really are, and with a wider sense of belonging. If you practise them and play with them you will discover the power of your own self-healing.

Not drowning but waving!

I walked sure-footed
along the beach
where the sand was packed-down hard
and the curve of its whiteness set out my path ahead.

A rogue wave washed me into the sea
and I struggled in the swell of an ocean
without form or limits,
my feet floating free of any surface below.

I tried to swim towards the shore
but the currents took hold of my body
and kept me apart
from all I had known.

Alone in a vastness of being,
as I floated in the bottomless blue,
everything I thought I was, thought I did,
began to sink away.

I tried to plan my return to the known-ness of land
but my mind stayed full of a thousand thoughts
without direction or intent,
while I trod the waters of past suffering.

As the tides closed over and around me
I felt an enormous peace and stillness within.
I was, after all, not alone,
not separate, but a spark of light in a great, teeming sea of life.

Not drowning, but waving!

Jan Alcoe

LIFTING YOUR SPIRITS

London 10th July 2008

The launch of Jan Alcoe's package "Lifting Your Spirits", published by the Janki Foundation for Global Health Care, took place at the Waterloo Campus of Kings College, London on Thursday 10th July. Janice, Bill, Sally Roberts and Dr Willy Weir attended on behalf of reMEMber.

Before Jan spoke Dr Harvey Zarren of the United States, a cardiologist who is also a holistic practitioner, gave a short talk explaining that wellness was not just to do with the body. There were mental, emotional, spiritual and social dimensions all of which can make your illness feel worse. Conventional and complementary medicines and self-healing techniques can all be of great help. Jan's package was an excellent model for this.

In her presentation Jan covered all the points made in her article "Tools for self-healing" which precedes this report. The seven tools are set out here.

Tool 1 – Meditation. Jan said she had found meditation good for general health, relief of pain and stress and connection with spiritual peace. She admitted it could be difficult to remain in silence but the benefits made it worthwhile.

Tool 2 – Visualisation. This was about picturing good health, and using all our senses to visualise. Visualisation would help us to relax and boost resilience and immunity. It had helped her to deal with radiotherapy and chemotherapy. She had shunned negative words like "toxic" and "burning" and had visualised her chemotherapy as a beautiful golden liquid, helping to heal her cells.

Tool 3 – Appreciation – giving thanks. Jan said "I am grateful for just being here today". She said that when she appreciates herself and others it creates an atmosphere of mutual respect. She even showed deep gratitude to all her medication. This helps to form a virtuous circle.

Tool 4 – Creativity. This was about learning to express ourselves. Art therapy and music therapy were being used in health care now. You can lose yourself in your creativity. She had taken up sculpture. When working at it she felt like a wholly creative being; all other thoughts and feelings disappeared.

Tool 5 – Listening. Jan explained that by this she meant deep listening; deepening our connection with others. This requires calm and respect for the listener, an atmosphere of tolerance, mutual caring etc.

Tool 6 – Play – enjoying the benefits of fun and laughter. It takes us out of our normal roles, relaxes us, reduces stress and helps us deal with pain. Laughter therapy is now being used in rehabilitation programmes.

Tool 7 – Reflection. Jan described this as "Making time for meeting ourselves". To see our illness as part of life's journey. It can help us to let go of the past, and to accept and enjoy whatever we do.

Jan concluded by talking about the pack. It had arisen out of a talk she had given to about seventy health care professionals about a year before. They had asked if she could supply them with some notes on the subject. The pack was the result. It consists of two CDs and a booklet with simple exercises you can do. It could be of benefit to anyone with an illness or disability, and also to



carers. Jan then read her poem "Waving". In response to a question she confirmed that she is well now. All signs of cancer had gone.

Chichester 20th July 2008

Jan delivered her presentation again for reMEMber at the Continuing Medical Education Centre, St Richard's Hospital, Chichester on Sunday 20th July. Dr Harvey Zarren was again present, and he followed Jan's presentation with a short talk on "wholeness". He began by saying that there was "no ME in the United States –

because there you are given a diagnosis of either CFS or fibromyalgia”. He explained that Jan had suffered from ME at one time but had recovered. She could find no trace of ME or cancer now. This, he believed, was due to her holistic approach.

Dr Zarren went on to say that all the bad feelings you get when ill – pain, troubled mind, emotional problems etc – are related. To combat them you need some energy, but CFS/ME/fibromyalgia leave you with not much energy. The holistic approach means making use of conventional and complementary/alternative therapies and self-healing techniques, including correct nutrition. He ran heart disease and cancer support groups. They did well on correct nutrition. He said that those who take lots of drinks like coca cola and eat a lot of meat and dairy products will feel unwell. These foods can cause inflammation, he said, which can lead to blocked arteries and this causes pain, suffering and bad emotions to get worse. He recommended CFS/ME/fibromyalgia patients to try a mainly vegetarian diet and to cut out foods with flavouring additives such as monosodium glutamate (MSG). Try cutting out dairy and citrus products for a while and see if you feel any better – and then try putting them back to see if it makes a difference. He had found that this approach had an impact on most people.

The Emerging Research

Dr Zarren was followed by Dr Willie Weir who gave a re-run of the presentation he had given at Burgess Hill earlier this year on the research studies of Dr Jonathan Kerr. Dr Weir began by saying that he was first alerted to ME when he worked as a junior doctor at the London School of Tropical Medicine. There he saw patients who had been successfully treated for various tropical diseases, but they “didn’t get better” – they were left with pain, nausea, fatigue etc. Conventional medicine’s explanation was that the condition was psychosomatic. It had taken him many years to convince colleagues that it was a physical illness. Research by Dr Kerr and others was now unravelling the genetic nature of this illness.

Dr Kerr’s Observations on CFS/ME

He describes it as a disease characterised by neuro-immune features and virus infection. The symptoms are unexplained fatigue lasting over six months, impaired memory and concentration, sore throat, tender lymphadenopathy, muscle pain, multi-joint pain without swelling or redness and unrefreshing sleep. Dr Weir emphasised that the symptoms need to be treated.

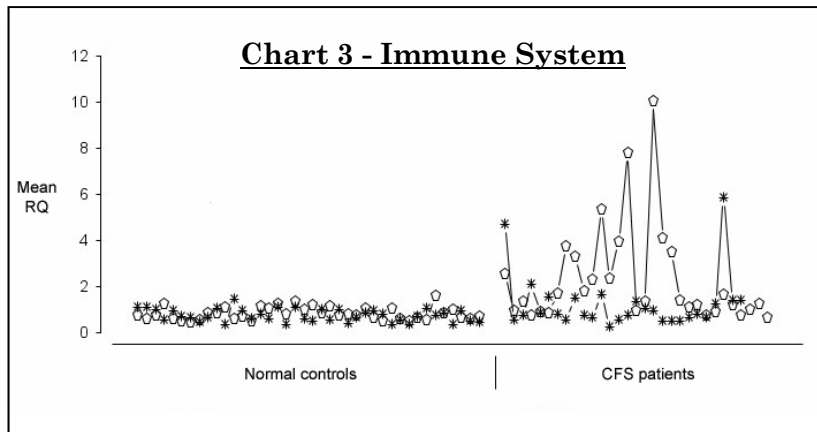
There is an estimated prevalence of 0.5% in the population and the illness is more common in females (3:1 or higher). Although it often follows a virus infection it can also follow bacterial infection or exposure to toxins, chemicals, pesticides or vaccination. It can also follow physical trauma such as a road accident or surgery. Studies of the pathogenesis of CFS/ME have shown a number of abnormalities. These include cytokine dysregulation, chronic immune activation, infection and abnormalities of the nervous, cardiovascular and endocrine systems. Studies with twins have shown there is a genetic predisposition. Dr Kerr’s hypothesis, which his team is testing with their studies, is that although there are many different initial “insults”, such as infection, they all lead to a few “common pathways” to CFS/ME. It is these pathways they are examining.

Gene Expression

Dr Weir explained that our bodies are made up of cellular units all containing genes inherited from our parents. Most of them are subject to a very tight control system which ensures that, for example, the thumb doesn’t manufacture liver cells. However, immune system genes differ from the rest – they need to be able to change so that they can combat the different infections which may attack us. If we get measles, for example, the immune system will be activated, bring the disease to an end and, in most cases, ensure we don’t get it again. The immune system then switches off.

But in the case of CFS/ME the immune system appears not to switch off. Dr Kerr’s team has therefore been examining the activity of a number of genes, comparing those in CFS/ME patients with those in healthy control subjects. The results of one of his studies are shown in the chart on page 12. They clearly show that in the healthy controls the immune system has switched off, whereas in the CFS/ME patients it appears to have gone berserk! Dr Weir likened this to a riot squad which, having dealt with the troublemakers, did not know when to stop and carried on beating innocent bystanders!

Dr Weir explained that Kerr’s team had also looked at the clinical sub-groups of people with CFS/ME (eg those with mainly fatigue, those with mainly muscle pain) and had distinguished seven different genetic subtypes. They had found variations in subtypes in different geographic regions but the study samples were small and



they will be doing more work in this area. They will also be looking for gene abnormalities common to CFS/ME and Gulf War Illness.

Dr Weir concluded his talk by saying that Dr Kerr's team would be continuing and extending all their studies. He was sure that their work would lead to a definitive test for the illness soon and, in due course, to a cure. He also mentioned that one of Dr Kerr's collaborators, David Tyrrell of the Common Cold Unit, had found that this illness, like many others, was worsened by psychological stress. "If you want to help your immune system calm down, bring your mind to it" he said. "That is the basis of the meditation I recommend".

(For a more detailed report of Dr Weir's presentation, see our March 2008 Newsletter, pages 14 to 17)

Further Points

Dr Weir was then joined by Jan Alcoe and Dr Harvey Zarren for a short question and answer session. Dr Zarren mentioned that inappropriate diet can be a cause of inappropriate behaviour of cytokines (protein molecules, released by cells when activated by antigens, that are involved in cell to cell communication).

Q. What is the difference between CFS and ME?

Dr Weir; I worked with Dr Malcolm Ramsey who chose the name Myalgic Encephalomyelitis. It has been argued that this is not an accurate description. Some recent studies have shown brain inflammation, but many patients have not got myalgia – ie pain in the muscles. The term CFS was coined, largely by psychiatrists, in the 1980s to describe the same condition. My view is that CFS is an umbrella term – it covers ME and other fatigue states.

Q. I have been ill for twenty years. What advice have you for me?

Dr Zarren; "You can turn back". Dr Weir; "You can do this by visualising calming down your immune system".

Q. I need a good diet balance. How can I find it?

Dr Zarren; Consult a good nutritionist (he explained that in the USA "nutritionist" and "dietician" are the same

thing. In the UK dieticians are registered, nutritionists are not, so only dieticians can be accessed in the NHS). There is a heart disease reversal diet called the Dean Ornish diet which is available as a book.

Q. Can holistic treatment (eg nutrition) be given in the NHS?

Jan; The Penny Brohn Cancer Care Charity will give diet sheets: Helpline - 0845 123 13 10 or helpline@pennybrohn.org also www.pennybrohncancercare.org

Several people said that their GPs were not very helpful to them over ME. Dr Weir said unfortunately many GPs are still not familiar with this illness, even though the NICE report on CFS/ME went out to GPs last year. Incidentally, the NICE report has many critics and is now the subject of a Judicial Review- see opposite page

Q. What sort of food supplements may be helpful?

Dr Zarren; The recommendations for heart disease and cancer patients are healthy nutrition, not supplements. I'm not aware of any supplement that helps unless you're deficient in something.

Q. My ME followed a road accident. What is the cause of a numbness I can't explain?

Dr Weir; this may or may not be part of your ME. Unfortunately sometimes medical doctors can't explain these things either.

Q. What you have spoken about are ways of managing illness, not cures?

Dr Weir and Dr Zarren; Yes, there is no cure yet for CFS/ME. But managing your illness can help you to feel considerably better.