

Life Force Foundation

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EASTERN SUBURBS • NORTHERN SUBURBS • INNER WEST

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Newsletter, March 2004

In this issue we continue our series on the benefits of different therapies in alleviating anxiety & stress and enhancing quality of life to encourage best possible outcomes for cancer patients and their carers.

Sharon Flanagan explores the psychosocial value of support groups, and we look at the wonderful benefits of guided imagery & meditation with Pat Woolford. (Notice also the upcoming art therapy workshops.)

And on page 2 you will find another article from familiar contributor to our newsletters, psychiatrist Dr. Mark Ryan, on the subject of emotional resilience.

Always remember that you can treat yourself to a nurturing weekend away at one of our fantastic LFF retreats. Autumn retreat May 21st.

Support Groups

Go to a support group? – You’ve got to be kidding!” I thought. But a little voice inside me reminded me that amongst the vast pile of literature I had read since being thrust on the cancer trail there were a number of studies that showed that “cancer recoverers” who attended a support group had a better outcome – on average – than those who didn’t. So.... having braved the surgeon’s knife and begun the awful roundabout of chemo – head-in-toilet–bowl–feeling–dreadful–for–weeks – just–starting–to–feel–human when bam! chemo again – head-in-toilet–bowl–feeling–dreadful....ad nauseum (excuse the pun)...I thought, well, I’m prepared to try anything.

Somewhere amongst all my reading I had seen a reference to Life Force – a cancer support group with meetings in Annandale a mere 10-minute drive from my home, so...no excuse not to go.

Headed out for my first group meeting (still feeling conspicuous in my scarf and hair-free head)....parked, watched people go into the building...strong urge to head back home (surely I must have left something on ... unlocked... untidy...). Somehow plucked up the courage to venture in. Bit scary, that first entrance! Relieved once I was seated and could just melt into the group and listen to others talk. Reassured to hear others who were relative newcomers, and inspired by those who were obviously many years down the track. By tea break, when we had the chance to chat one-to-one while we jostled for bikkies and teabags in the kitchen (looking desperately for a teabag with tea in it, not fruit peelings and “pip things” – my pre-herbal days!), the nerves had settled and I had a feeling that, maybe, just maybe, I would be back the next week....

And so, I discovered Life Force – and the wonderful “life force” that is Jilly Pascoe. I met some of the most inspiring, funny and courageous human beings I have ever had the privilege to know. I attended regular meetings throughout

my 6 months of chemo and beyond and during that time also attended a fun-packed weekend retreat in the country. The mix of people in the group changed over time, with an astonishing variety of personalities, backgrounds and work & family situations. I was surprised and delighted to meet up with an amazing young woman from my uni Zoology course (hi there, Lizzie!). There were individuals I particularly connected with and others I didn’t. But I came to respect them all and learned something from each one’s story.

And then one day I stopped going – everyday life just took over again. Now, nearly eight years down the track, I no longer attend weekly meetings, but I am thrilled to catch up with old friends from the groups at Christmas get-togethers and fundraising events, such as the wonderful poetry reading nights at The Wharf.

So what is it about the word “support group” that made me hesitate about entering the Neighbourhood Centre in Annandale all those years ago?

For me, cancer had been such a disempowering experience....from the time of my diagnosis it felt like I lost control over so much of my life... I felt like a pawn manipulated by other forces (doctors, nurses, drugs, pain, nausea...). Looking back, I think I dreaded being sucked into another “organisation” that would force me to undergo procedures that were uncomfortable or painful and where I had to conform to what others decided was best for me. What I found at Life Force was a community of people who shared similar experiences, and an arena in which each of us was encouraged and supported to take back control of our lives. I learned that there is no right way, or one way, to deal with the experience of cancer....there are no shoulds or should nots – whatever emotions you feel are valid...whatever things work for you are ok. I also learned about a range of things that may help – activities (eg, meditation, massage), information (eg, books, tapes), foods & supplements (yes, I even came to appreciate herbal tea!) – and I felt free to tap into those things if and when I chose. Most importantly, I learned that we each negotiate our own course and for most of us the way is made easier by sharing our experiences with others. We are sometimes “the leaner” or the learner and sometimes “the leaned on” or the teacher. By being encouraged and permitted to play both roles, I regained my sense of self, my sense of being in charge of my own life again.

Of course none of this would have been possible without the skill and dedication of the group facilitator, Jilly. I am convinced that the success of any support group lies in the hands of the facilitator – someone who is sensitive to underlying fears and feelings, who can balance the (sometimes competing) needs of participants, who can inspire and encourage (ie, provide courage to) the more timid or despairing, and who can ensure it remains a safe and rewarding place for all. All of this with love, compassion and a terrific sense of humour! Thank-you, Jilly! Thank-you, Life Force!

Sharon Flanagan



On considering several different versions of resilience

Prepared by Mark Ryan, January, 2004

Unpacking emotional resilience

The dictionary definitions of resilience refer to a capacity to regain shape, maintain buoyancy, implying some inherent nature to resist or restore. The implication here is one of control, and in relation to emotional resilience, of bringing emotions back under control. In Western cultures emotions are implicitly seen as disruptive episodes which threaten a loss of control. There is the strong implication that one must bring and keep emotions under control. This emphasis on self-control stands in potential conflict with another bias in Western cultures, the view that self analysis is important in knowing what one is feeling and to verbally express those emotions. Thus a dilemma exists; one can express one's feelings, but not too much. The other implication in this account of resilience is that it is an inner attribute, something you possess to a greater or lesser extent, and the more the better in dealing with life's difficulties.

Additionally, positive emotions and thoughts are seen as causing good behaviour, whereas negative emotions and thoughts are seen as causing bad behaviour. As a result great efforts are made to teach and encourage people to be positive, to develop high self esteem, confidence and optimism. In therapeutic settings great efforts are made to help people control, reduce, eliminate or change negative emotions and thoughts. The presumption is that negative emotions and thoughts are abnormal or pathological and need to be got rid of to achieve health. It follows that any distress is likely to be labeled as pathological. Also in keeping with this theme of control is the frequent encouragement to "be positive" and to "fight this thing (the illness)".

In this article I will attempt to dismantle this dominant notion of emotional resilience, not with the intention to argue against being resilient or positive, but in the hope that by providing another perspective we might all be encouraged to hold our beliefs a little more lightly and to develop multiple perspectives and become more effective in dealing with uncertainty and not knowing.

Putting talk of emotional resilience in context

In the face of any adversity, including cancer, there is invariably a range of emotional states and thoughts. This range includes both the positive and the negative, often co-existing. At first glance this may seem surprising, and it often is to both the individual experiencing the predicament and to the researcher trying to distill the essence of coping.

What is someone doing when they talk about their health/ill-health and their feelings about the state of their health? The circumstances and the participants in this conversation will be very relevant to what is said and how it is talked about. Further, talk of illness is much more than talk about a physical condition. That is, talk about health and illness is also talk about that person's situation in the world whereby he/she is accountable to others, especially given that being sick entitles one to the "sick role" and to being excused from one's usual duties and obligations. However, these entitlements must be earned and this places the patient in a very ambivalent position. This person must both be ill and display healthiness or normality if they are to appear worthy of being granted those entitlements.

Put another way; good health is usually understood in relation to illness and being ill is understood in terms of the demands of the healthy. Thus people will use health beliefs to make themselves accountable to others and to articulate for others their own position in the world; the healthy will tend to talk about their illness experience while the ill tend to go to great lengths to show their "normality".

Given that talking is always to someone in a context, the status, including the health status of the other is relevant to what is talked about and how it is said. Usually the other person in the conversation is a "healthy" healthcare professional which contributes to the creation of a context in which there will necessarily be concerns about blame which generates attempts to legitimate. This follows the fact that issues of health and illness are directly connected with those of employment and earning money and other social duties. That is, those who are ill and/or suffering from disability need to do more than just claim to be unwell or suffering from disability; they must also justify claims to be unable to work and be granted other concessions of the sick role.

Thus the challenge for the person talking of their illness is that they must not only justify their condition and disability but also indicate their attempts to recover their normality. The risk here is also that they might be seen as a malingerer or a complainer. This risk is even greater in chronic illness and psychological conditions as accounts of such states are always at risk of being met with potential criticisms and imputed personal shortcomings.

Usually the sick are encouraged by the healthy to redefine their misfortune in positive ways, thus avoiding embarrassment and other discomforts (for the healthy). In doing this successfully, the sick will be accorded attributes such as strength of character and/or emotional resilience. By being strong of character and/or emotionally resilient they can be credited with being worthy to be looked after, as if too much weakness should be insupportable. Thus the sick must make manifest their difficulties while showing how they either have borne it or have or are overcoming it. This makes the social dimension of being ill even more complicated and rather fraught and it is thus not surprising that healthcare – patient interactions are potentially so difficult for all concerned.

It is important to note that such talk is a joint production, the "work" of all participants in the conversation. And such conversations also occur in the larger contexts of subculture and culture. The medical model which implicitly shapes medical discourse and interactions is still a largely mechanical understanding of the person. It is concerned with control. Not surprisingly such concerns with control mirror the cultural bias about emotions talk and displays. A "good" patient will thus tend to speak in terms of their normal functions and be careful to be appropriately subdued in their expression of emotional distress. That is, they can reveal their difficulties while showing how they are bearing it or have overcome it. They will be performing in ways that are likely to be labeled as resilient. Such people will be more likely to receive care from the healthcare professional.

However there are other contexts in which one gives an account of one's illness. In more private situations there is usually more trust and no longer the concern with the healthcare professional against whose criteria their statements will be judged. These more "private" conversations can occur, in time, with a health professional, but often don't. They are likely to occur when one shares experiences with others in the same position. In such contexts there is more opportunity for more open disclosure of emotional states and concerns and the assessment of whether one is emotionally resilient or not is less likely to come up or be relevant. We know that the opportunity to make such disclosures, either in conversation or in writing, is associated with better psychological adjustment in cancer patients. We also know that attempts to eliminate negative emotions and thoughts generally makes them more intense, more frequent and more intrusive and may worsen mental and physical health outcomes and set up a range of problematic avoidance habits and behaviours

From the perspective that I have outlined, resilience is not some inner attribute but reflects how one is positioned and positions oneself in conversations with healthcare professionals and others, including the conversations one has with one's self.

The importance of talk

Notwithstanding the above mentioned difficulties, talk is nevertheless central to developing an adjustment to an illness experience. The trauma of a life threatening illness like cancer is profoundly disruptive but also presents a potential turning point in one's life. Not surprisingly, strong emotions and existential disorientation and uncertainty will be manifest. Initially at least one will feel alienated and isolated from one's sense of self-in-the-world. The process of coping and moving on involves changes in what we say about our self-in-the-world. That is, one's usual self-talk or self-narrative, needs review and revision. Because talk about self involves a balance between autonomy and commitment (thereby describing one's uniqueness), such talk necessarily involves talk of self in relation to others as well as what is personally important, what matters in one's life. The process involves both telling ourselves as well as talking with others. And talking with others in the same or similar predicament can be greatly beneficial; amongst other things one can discover that they are also experiencing existential confusion and isolation, a necessary early stage in the process of evolving one's self-narrative towards a new way of describing one's self-in-the-world, i.e., a new sense of self. As our circumstances change we need to "re-make" ourselves. This is a process of change, not of control and may be a more helpful and generative way of understanding resilience.

Support Needs for Primary Caregivers of People with Cancer

Would you be willing to participate in a study looking at primary caregivers of people with cancer?

This study aims to examine the well-being and needs of cancer caregivers. We are looking for primary caregivers of a person with cancer, who would be willing to complete a questionnaire about their experience as a caregiver.

The Cancer Council NSW and the University of Western Sydney are jointly funding this project. Please contact the Research Coordinator, Mirjana Petrovic, on (02) 9772 6766 for more information about the study.

Guided Imagery

"Circle of Health"

Article which appeared in The Sun-Herald, April 16, 2000:

"Cancer patients can gear up their immune systems merely by imagining their bodies waging war on the disease, psychologists said yesterday. The dramatic finding emerged from a study in which women with breast cancer were asked to visualise white blood cells destroying tumour cells. Researchers found that the patients had higher numbers of T-cells - specialised white blood cells that play a vital role in fighting disease - while "killer" cells, which destroy cancerous cells, became more active.

Four previous studies had suggested that psycho-social intervention not only enhances quality of life but also prolongs cancer survival.

But the scientists could not say whether the immunological changes they observed would have any effect on recovery or survival.

Professor Leslie Walker, from the University of Hull in England, who led the study, said: "Our results show that relaxation and guided imagery can bring about measurable changes in the body's own immunological defences."

Research, such as that mentioned in the newspaper article above, as well as that done by David Kissane in Melbourne and many other studies, confirm the value of relaxation therapy, meditation and guided imagery in supporting the immune system. Caro Jonas has worked with Life Force Foundation since its inception ten years ago. Caro uses meditation and guided imagery in helping people on the healing journey.

Following is Pat Woolford's description of her experience of guided imagery during her time at the Annandale support group.

I had been attending the Annandale Support Group for a while which, as those of you who know the groups, includes a meditation. In the last term of 2003 we had a Native American Medicine Wheel "Circle of Health" for our meditation focus. This was divided into 8 sections corresponding to the 8 weeks of term, with a ninth central part to finish off. Week 1 was "Black Sun - Despair" and it progressed in a clockwise direction. This meant there was a different theme each week.

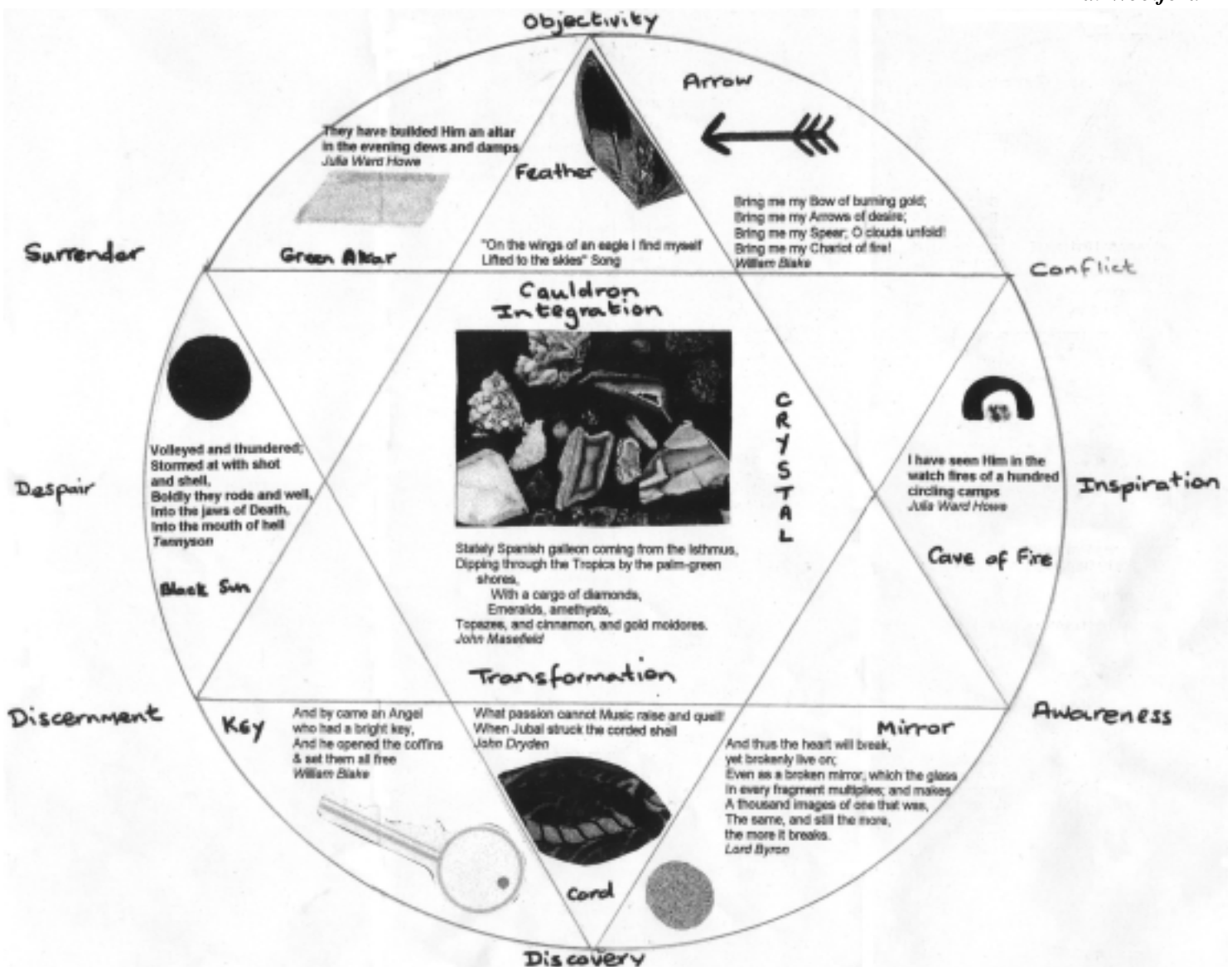
Using the week's theme as a guide, at home, I looked through my poetry books and found short sentences and stanzas that seemed to fit that theme and then placed that in the space provided in the circle. I then added a cut out picture (collage) or drew a simple picture in colour. It therefore grew in shape and form, from week to week, and in this process I became very attached to it as its meaning grew for me. The poetry samples would stare out of the pages as if waiting for me to find them! It was quite uncanny.

When I completed the circle I had it laminated and I use it to take to difficult medical appointments. In between appointments I place it on a special table at home as I have become very attached to it as it has become something personal.

The meditation focus changes each term and means different things to different people which I feel is the beauty of it - being able to attach personal meaning to a shared experience.

I have no artistic background but found that wasn't necessary and just enjoyed being creative in a way that had meaning for me.

Pat Woolford



The Creative Journey



The Creative Journey is a series of 4 art therapy workshops designed to help cancer patients improve their lives by developing their own personal creativity. Through guided art making activities, participants are offered new ways to express, contain and transform the difficult experience of cancer diagnosis and treatment.

It is not intended only for "creative" people, but may also be helpful for those who feel stress, anxiety and depression as a result of their cancer experience. No artistic talent is necessary.

These four week workshops are run by Fiona Fitzpatrick, B.ED, M.A. (Art Therapy), in collaboration with the Life Force Cancer Foundation.

When: Wednesdays May 5, 12, 19, 26 2004 6pm - 7.30pm
Where: Annandale Neighbourhood Centre 79 Johnston St. Annandale
Cost: \$20 per workshop. All art materials and refreshments provided.

It is necessary to register your interest in the Creative Journey program. To do this please ensure that you phone the facilitator, Fiona on mobile: 0416 199 804. The deadline for registration is Wednesday 28th April.

all about Jane

Sunday 14th March

7pm Start

374 Liverpool Rd., Ashfield

starring members of:

Andy 500

Whiteliners

Satellite 5

Slowhand

Spurs for Jesus

Happenin' Thang

50 Million Beers

Benny & the Fly By Neters

COMBO & the Flaming Stars



Ladies please frock up in pink or orange

Doors open at 6.30 p.m. for a 7.30 p.m. start
\$10 at door or donation
Proceeds go to Life Force Foundation
(cancer support)

People attending must be a member of Ashfield RSL Club or live more than 5 kms away from the club, otherwise a \$2.20 membership is available for the nite.
For the information of members and their guests.

Acknowledgements...

Our thanks to the following people for their recent donations to Life Force Foundation:



Deirdre Aronson, Avis Australia, Katie Barton, Judy Bentzen, Trevor & Michelle Brentnall, Pamela Chalmers, Agnes Chan, Margaret Cody, Gary & Sue Connelly, Maree D'Arcy, Julie Darge, Richard de Carvalho, Jan Driscoll, Fiona Fitzpatrick, Lynette Elsinger, Trish Evans, Richard Galey, Jack de Groot, Aurora Hammond, Lawrence Hinchliffe, Angel Ioannou, Arnold & Val Javen, Gloria Jones, Gary Kastanias, Vernon Katz & Barbara Cohen, Gabrielle Prest & The Leukaemia Foundation NSW, Mary Maraz, Annette Marfording, Kerry May, Marie McMillan, Nicole Murray, Sally Murray, Alexa Gilbert - Obrart, Rosalie Pencharz, Sue Penny, Manfred & Beverley Perlstein, Marian & Peter Phelan, Gabrielle Prentice, Libby & Gerald Raichman, M. K. & Y. R. Rawack, Ros Robertson, Bert & Pauline Rosenberg, Mark Ryan, Anne Schofield, Carol Segal, Erm & Jenny Slobedman, Jody Somogy, Libby Stow, John Thacker, Leona Watson, Robin Woods.

Life Force Foundation Support Groups

2004 Term Dates

Note: It is important to register for all support groups, before turning up, in order to check on numbers and confirm that details are correct. Phone Caro Jonas on: (02) 9564 3289. To register for the Carer's group please phone Jo Dewar on (02) 9517 9018

Eastern Suburbs

meets weekly at:

St. Joseph's Parish Centre
10 Albert St, Edgecliff

Monday evenings: 5:45pm - 7:45pm

Term 1	Feb 2 to March 22 (8 weeks)
Term 2	May 3 to June 28 (8 weeks)
Term 3	July 26 to Sept 13 (8 weeks)
Term 4	Oct 18 to Dec 6 (8 weeks)

Northern Suburbs

meets weekly at:

Mosman Art Gallery & Community Centre
Cnr Short & Myahgah Sts, Mosman

Tuesdays: 1 pm - 3pm

Term 1	Feb 3 to March 23 (8 weeks)
Term 2	May 4 to June 22 (8 weeks)
Term 3	July 27 to Sept 14 (8 weeks)
Term 4	Oct 19 to Dec 7 (8 weeks)

Inner West

meets weekly at:

Annandale Neighbourhood Centre
79 Johnston St, Annandale

Thursday evenings: 5:45pm - 7:45pm

Term 1	Feb 5 to March 25 (8 weeks)
Term 2	May 6 to June 24 (8 weeks)
Term 3	July 29 to Sept 16 (8 weeks)
Term 4	Oct 21 to Dec 9 (8 weeks)

Family & Carers Group

meets weekly subject to numbers at:

Annandale Neighbourhood Centre
79 Johnston St, Annandale

Tuesday evenings: 5.45pm - 7.45 pm

Term 1	Feb 10 to March 30 (8 weeks)
Term 2	May 4 to June 22 (8 weeks)
Term 3	July 27 to Sept 14 (8 weeks)
Term 4	Oct 19 to Dec 7 (8 weeks)