

Life Force Foundation is a non-profit organisation providing emotional/psycho-social support for people dealing with the experience of cancer, through group therapy and meditation, counselling, special workshops and retreats.

Life Force Foundation

CFN 15707

ABN 61 068 056 682

DGR. 428809

EASTERN SUBURBS

NORTHERN SUBURBS

INNER WEST

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Gabi Hollows

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NEWSLETTER

Fifth World Congress of Psycho-Oncology 3-7 September, Melbourne, Australia

(from Jilly who attended the conference)

We often talk about the Cartesian split between mind and body, and how unfortunate it is that the society in which we live still maintains that concept, which is in turn reflected in our health care system. We are left with a system that does not honour the whole human being. Otherwise we would see the system putting more resources into the psycho-social area of cancer care - placing more value on this area of health care.

In fact, as Professor David Spiegel, Stanford University School of Medicine (one of the keynote speakers at the Congress) points out, psychological support for cancer patients and their families, particularly in the form of support groups, is extremely cost effective, requiring only the wages of a professional group facilitator, and a meeting room. Spiegel says: "If you compare the cost of that to even a minor surgical procedure, it's trivial. So what we need to do is to get ourselves back in balance so that helping a patient deal with illness through a support group of one kind or another is considered a routine, necessary part of health care, just like all the other aspects of health care."

Professor Jimmie Holland,
Memorial Sloan-Kettering Cancer

Centre New York, spoke of the 'dual stigma', the stigma of the illness and the stigma of psychological problems associated with the illness - people still feel that there must be something wrong with them when they experience psychological distress as a result of their illness, and consequently are still reluctant to ask for help.

It is important to reduce the stigma of psychological aspects of cancer. Attitudinal change is necessary - we need to change societal attitudes, the attitudes of colleagues, as well as institutional attitudes. We need to alter the conceptual framework to include the suffering of the mind when the body is seriously ill. The two cannot be separated.

She talked of the distress continuum "God knows anyone would be distressed who had cancer", and the importance of acknowledging this distress continuum which could extend to more severe degrees of depression and anxiety if undetected.

Some of the main issues to come out of this conference were: "To elevate the focus of psycho-social aspects of cancer care; to see this as an opportunity to refresh our humanity and our caring in what has become a highly technological field; to work

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2000

Please do not throw this newsletter in the bin. Pass it on to someone who may benefit from it, or give it to your doctor, dentist or other health professionals. You may wish to put the support group information up on a noticeboard. In this way you may be able to help someone in need. Thankyou.

Evening of Poetry & Prose

Our annual fundraiser was held at the Wharf Theatre on Sunday 23rd July to a packed house. What a wonderful night's entertainment!! Our presenters were just fantastic. Every year people comment on the marvellous atmosphere at our Poetry & Prose nights and this year was no exception.

Max Cullen, Arthur Dignam, Lisa Forrest, Gretel Killeen, Leah Purcell, Natasha Stott Despoja and Ewan McGregor were our guests - what a sensational line-up and what fabulous performances from these talented people. We are so grateful for their generosity in giving their time to support the work of LFF, and for providing us with such a delightful "evening of love and laughter".

An evening like this takes a lot of effort by many people. We are grateful to our wonderful team of LFF Angels who put so much into getting it all happening and contributed along with our usual permanent supporters -(the Giezekamp family, Pamela Chalmers, Anne Schofield, the Carroll family and our patron saint Gabi Hollows) - to the smooth running of the event. We thank The Sydney Theatre Company and The Wharf Restaurant for their ongoing support, and the many people listed below who made such generous contributions towards the event.

The evening was a great success both aesthetically and financially. About \$15,000 was raised on the

night. This means a great deal to us, as it helps to ensure that we can continue to provide the valuable programme of services that we offer to cancer patients and their families.

Many thanks to all our supporters. The Life Force team feel encouraged by that support, to continue the marvellous work they do in helping people deal with the impact of cancer on their lives. I want to thank all the wonderful members of our counselling team and Life Force therapists and group facilitators for the special love, compassion and dedication they bring to their work.

Those who receive help and support from the team through what is a very difficult time, report feeling enormously encouraged, comforted and empowered by the presence of these "angels" in their lives. One patient who was visited in his home recently by members of the counselling team, summed it up, saying "I didn't know such kind people like you existed! I can't tell you how much better I feel."

However funding still continues to be a problem and any support from the community is greatly appreciated. Life Force Foundation is a public benevolent institution, registered charity number: CFN 15707. All donations \$2 and over are tax-deductible.

Poetry & Prose Acknowledgements

Sushi Bar Rashai • Lee's Hair Design
• Soula Petriziklas -The Ritz – Kogarah
• Craig Burton - XL Fitness • Bishops Enterprises Pty Ltd • O'Leary Electrical • Battaglia Plumbing Services • Annandale Carpet Centre • Express Glass
• Calendar Citi Carpet Cleaning
• Brian Sharkie – B S Roof Repairs
• JH Fisher & Sons • Tone's Paint & Decorating • All Pest Solution
• Suburban Maintenance Services
• Kaffee Klatsch - Annandale • The Half Price Cleaning • Hocking Hot Water Heater Co Pty Ltd • Stan and Sons – Croydon Park
• Vintage Cellars • Blue Oyster Restaurant – Double Bay • Clarence St Cyclery • East Sail Sydney • Echo Designs East Sydney • Energy Australia • Fighting Fit • Fox Studios • JAK Australia Pty Ltd • Maria Vaccaro Reflexologist • Reads of Woollahra • Sydney Theatre Company • Sony Australia • Kollage Catering • Patchetts Pies • Riteway Food Service • The Wharf Restaurant • Fox Creek Vineyards • Callaghers Real Estate • Action Man Cleaning Services - Bronte



Special thanks to the following people for their extraordinary effort: -

Gabi Hollows
Pamela Chalmers
Giezekamp Family
Anne Schofield
Tamara and Greg
Sue Adler
Tic, Tigger and Lucy
Life Force Angels – Stephanie Maraz, Jenny Gill, Margaret Brown, Rhonda Lee, Ann Christie, Georgie Guinness, Mandi O'Sullivan, Deb Wilson, Pamela Chalmers, Nicole Murray, Tamara Miller, Rachael Appleton, Ben Collier, Matt Lahood.

Winners of the Raffles were:-

Peter Reardon of Chifley First Prize - \$3,000 worth of furniture from Echo Designs – East Sydney
Cate Carey of Chatswood Second Prize - \$500 Women's clothing voucher from Reads of Woollahra
M Flor of Edgecliff - Third Prize – Health Assessment and Personal Training Program valued at \$300 from Fighting Fit.

Our thanks to all the people who so generously donated the wonderful raffle prizes.

Snapshots of our Evening of Poetry & Prose

Arthur Dignam

Ewan McGregor

Auction time with
Cary Gleeson

Sarah Holmes

Max Dillon

Natasha Elit Despoja

Lisa Forrest

Leah Purcell

Tom Keneally

— L F F A n g e l s —



Stephanie Maraz & Rosie Margaret Brown (left) with

Life after cancer

As I wrote in the June 1998 issue of the Life Force newsletter, "the end of treatment does not mean the end of cancer's effect on your life. The most critical stage of recovery is often overlooked - what happens when you leave the hospital to get on with your life?"

Some years ago a young man came along to our Inner West group. He was a little unsure as to why he had come along, as it was 16 years since he had undergone treatment for testicular cancer. Lee was grateful for the medical treatments that had rid him of his cancer but he had never felt the same since his cancer experience.

As he continued to come to the group meetings he began to realise that he had just been marking time for all those years. He began to explore for the first time the feelings that the cancer experience had evoked, and share that experience with other members of the group. We watched him blossom over that year, and he eventually went back to University, got his Masters and a few years ago he sent me his PhD thesis to read. He has been in a committed relationship with a lovely young woman for some years, which he says would have been unthinkable before.

Here is his story:

My experience with the Life Force cancer support group

Lee Anderson Brown

8th December, 1994

"I'm somewhat different from the others in the group in that my experience with cancer was in 1977-78. Despite being so many years ago, I still felt I had a lot of unresolved issues from my experience with cancer. So when I saw the Life Force pamphlet I decided to see if I could resolve some of those issues.

I developed cancer at the end of a long process of treatment for a congenital condition - Partial Androgen Insensitivity Syndrome - which had seen me undergo a series of hospitalisations for surgery throughout my childhood; the first was when I was three and the last when I was eighteen. It was a shock therefore to be back in hospital little more than a year later. At the time my family, with the consent of the doctor, didn't tell me that it was cancer. Rather they told me I had problems with cysts developing in my body. It was only when the first round of radiation treatments failed to stop the cancer and I needed to undergo extensive chemotherapy that I was finally told.

After six months of chemotherapy (with all the standard effects of hair and weight loss, constant vomiting and the other 'joys' of treatment) I was finally given the all clear and told I was in remission.

Thankfully the cancer has not returned in the many years since.

At the time of my treatment, a social worker at the hospital tried to start a support group for cancer patients, which I went to a few times. However I soon left the group because after my many years experience with hospitals, the last place I wanted to be was in a hospital talking about my experience of the hospital system. This does not mean that I had resolved many of the issues raised, simply that I found them impossible to deal with in such a situation.

Only someone who has had cancer, or been close to someone with cancer, really knows the complex mix of emotions: fear, anger, grief, helplessness, resignation, feelings of betrayal by your own body, and a sense of being cheated by life when there is so much more to be done. It is a period of great physical and emotional trauma, and to survive it is a truly transforming experience.

The experience of cancer really brings into focus questions of life and death and it forced me to only consider the here and now: the next treatment, the next checkup or test. Thinking about the future was only to worry whether there would be a future for me, while thinking about the past was to be worried about many of life's mistakes and the things left undone. By only concerning myself with the present I was able to deal with the immediate issues of treatment, the reactions of friends and family to my condition and my own whirlpool of emotions.

The experience also made me value every small scrap of beauty and joy in life. Where once I had considered my family distant without much love, when they rallied around me it made me understand, and even clearly see for the first time, how much they really loved me as they struggled to find their own ways of expressing their love. I have never doubted their love since that time even though we are still a family that doesn't show it often.

Also early in my chemotherapy when every day, literally, may have been my last, I finally found the simple truth of the phrase: look for the good and beautiful in each and every experience. It is sometimes difficult to find, and sometimes isn't there (especially with some of the more unpleasant aspects of hospitalisation) but since the time of my treatment this simple saying has enriched my life far more than it would ever be possible to put into words.

However while my experience with cancer taught me the value of life it also left some deep emotional and spiritual scars. As I was undergoing treatment, my friends were out discovering the world as young adults; as I was facing the questions of life and death, they were facing questions of career, sexuality,

Life after cancer (Continued)

family, and relationships. I felt so changed by my experience that my friendships with my former peers became more and more distant because they could never understand all the things I'd been through. They continued discovering all the normal things life offers to twenty year olds and went their way while I started to feel isolated and depressed.

It has continued that way for many years. On one hand, I valued all that life could offer in the everyday; on the other I was filled with despair and wondering if I would ever again feel at home or be able to fit in with a group of people. I have seen counsellors and other health professionals in an attempt to deal with this dilemma. But until I started going to the Life Force group, I had never really felt comfortable expressing, or dealing with, the wide range of emotions which are a legacy of my experience with cancer. Finally I had found a group of people who could understand feelings I have kept hidden for so long.

The ability to share another's pain and grief, especially when it reflects much of my own experience, is a privilege and honour. To share another's tears is to finally express the tears I repressed so long ago; to share another's fear is to feel the strength of a common bond; to be touched by another's pain is to feel my own pain lessen because it no longer seems so absolutely mine. In a real sense being able to share the experience of cancer with the group has freed me from the need to share it with anyone else. Having a safe space, where all my feelings about my cancer will be understood, has allowed me to leave my cancer experience behind with the group, and once again start to relate to people outside the group on matters which I have in common with those people.

But the group is not only about sharing negative feelings. I was amazed at the way people in the group nodded their heads when I talked about how I had to cheer up my visitors in hospital. Sometimes I

think that being the patient is the easiest part of the cancer experience. The feelings of fear, frustration and helplessness for the people close to a person with cancer seemed to be at times overwhelming for those friends and family who came to visit. It became important to show them that, despite the ordeal of the cancer and treatment, I was still the person you could share a joke or laugh with; I was still friend or family.

But also there can be a lot of humour in the group generally. Parts of the cancer therapy can be the source of very funny anecdotes and it is more than a gallows humour of the 'if you don't laugh you cry' type. Rather, it is a genuine celebration of the fact that we have survived, or are surviving, a deeply traumatic time. By laughing at incidents which were very painful when we experienced them, we don't make light of the deep pain we felt, we are actually acknowledging that the painful time has passed and we are able to enjoy life again with a renewed vigour.

Finally, what I've learnt most from my time with the Life Force group is a new way of looking at my experience with cancer. I've long understood it as a medical condition and even understand the purpose of many of the treatments which were so painful at the time. However, only with the group have I been able to deal with issues other than the physical ones and see how the cancer affected me emotionally and spiritually. And by using meditation and other 'alternative' techniques I've been able to bypass the 'mind' which thinks about cancer and simply be able to let my body, heart, and soul, express the range of feelings I've repressed for so long. I will always be grateful to the medical profession for providing the treatments which rid me of the cancer but I know that those treatments only healed a part of me. It is only when I started going to the group that I was finally able to begin healing many of the other scars left by my cancer experience.

Lee's story highlights the need for ongoing support...
p.t.o.

Acknowledgments

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Sue Fisher,
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Ian Hunter,
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Linking Hospital & Community Care

Linking hospital and community care for cancer patients and their families is vitally important. Life Force Foundation groups were originally set up over seven years ago to provide support for people after hospital care. This is a time when people often feel particularly vulnerable, and we believe that they need to be offered ongoing care, in the wake of an extreme event in their lives, in order to help them re-engage with life, rebuild their lives.

We lose a lot when we get cancer, and it is important to acknowledge the losses and the attendant grief, and to be supported through this process.

Our consumers are letting us know that they would like their oncologists or surgeons to routinely advise them of what support is available in the community to help them on an ongoing basis, once they leave the hospital system. Indeed they believe their doctors have a duty of care to do so, and this notion is supported by the NHMRC clinical practice guidelines which state that clinicians have a responsibility to

advise their patients of available psycho-social support.

"We at LFF are working towards forging stronger links with metropolitan hospitals so that there is continuity of care for cancer patients as they leave the treatment stage to resume life in the outside world once more, when, as Jane Gillespie says, the regime of regular appointments no longer provides a focus. This is a very vulnerable time for most people and it is ongoing.

LFF group members, if you would be available to speak to health professionals about your experiences, please let us know, as this could be a helpful way of forging those links.

Health professionals likewise if you would like some of our people to give talks at your hospitals to staff members, please get in touch." (from newsletter June '98)

Fifth World Congress of Psycho-Oncology (cont'd)

towards a holistic and integrated approach and a better co-ordination of care for cancer patients and their families, with the inclusion of consumers and carers across all areas, so as to foster a sense of personal control which in turn is vital in fostering better outcomes; to strengthen the role of the patient in the course of their illness.

A highlight of the Conference was the inclusion of The Humanities in cancer medicine, with a conversation between Australian author and broadcaster Robert Dessaix and Professor Martin Tattersall of the University of Sydney, as well as - "Journey into Illness" - a philosophical discussion, chaired by Professor Sidney Bloch of the University of Melbourne. There was also a dramatisation by Jack Hibberd of the Leo Tolstoy short story - "The Death of Ivan Illych" , followed by a dialogue with playwright, director and cast.

The theme of the conference was stated thus:

With the dawning of a new millenium, this international congress provides a wonderful opportunity to promote the psychosocial care of the person with cancer, something which is at the very heart of all successful treatment of patients with cancer.

The scope of psycho-oncology is indeed broad, spanning prevention, screening and diagnosis, management including surgery, radiotherapy, and medical oncology, survivorship, progression, palliative care and bereavement. It is both patient- and family-centred. It is the responsibility of every treatment team and must be grappled with by all disciplines. It is of vital concern to consumers.

Emphasizing our theme of "A New Momentum", we hope this Congress will lift the awareness of psychosocial issues in all our institutions and their care-providers so that a truly multi-disciplinary effort will result in the enhanced care of patients with cancer and their families.

DON'T FORGET

23rd October
is
Australia's Breast
Cancer Day

** Reminder **

Saturday, October 14 2000
"Making a difference in NSW 2000"
The 2nd NSW Breast Cancer Consumer Forum.

To register contact
Liz Palmer (02) 9326 9328

Spring Retreat

Our next retreat will be held on the weekend of the 3rd to 5th of November at our beautiful retreat premises in the Kandos Valley. Give yourself a real treat, an opportunity for a very special experience, restore your vitality, enhance your sense of wellbeing with life-affirming activities such as vision quest, creativity workshop, massage, yoga and meditation, as well as delicious food and lots of fun.

To book phone 9389 3834 asap.

Consumer & Community Participation Implementation Group - CCPIG

Jilly Pascoe and Jane Mills are members of the Consumer and Community Participation Implementation Group reporting to NSW Health over a period of 6 months in order to represent the needs of our consumers, ie. all people dealing with the experience of cancer - cancer patients and their families. The aim is to set up best model of consumer and community representation at all levels of health care. Jane Mills, herself a cancer survivor, is particularly well placed to represent us, having worked in Health and Community Services for many years.

Family & Carers Group

The role of carer is a difficult and stressful one, and this group offers an opportunity to share thoughts and feelings with others in a similar situation.

Mutual understanding and caring, experiencing a common predicament is very supportive and a powerful component of healing. Sadness and anxiety can be put in perspective by sharing in a supportive environment.

The next series of sessions of the Family & Carers Group will commence on October 12 (Thursday) at the Annandale Neighbourhood Centre, 79 Johnston St, Annandale from 5.45pm to 7.45pm. For further details and to register, phone 9389 3834.

Telephone Counselling

In addition to our regular telephone counselling service from 10am to 4pm daily on the Life Force office number - 9389 3834, we now can offer phone counselling **each Wednesday evening from 6pm to 10pm**. Georgina Guinness will be available during those hours to take calls on: **(02) 9569 0885**

Georgie, a registered nurse, is trained in telephone counselling, and has herself been a cancer patient and a former member of LFF's Inner West support group some years ago. Help is available at the end of the line. Do give Georgie a call.

Life Force Foundation Support Groups

2000 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. Telephone the LFF number: **9389 3834**.

Eastern Suburbs

meets weekly at:

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

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

Term 4 Oct 16 to Dec 4 (8 weeks)

Northern Suburbs

meets weekly at:

**Chatswood Church of Christ Hall
365 Victoria Ave, Chatswood
Jane Gillespie: 9960 3213**

Friday mornings 10.30am - 12.30pm

Term 4 Oct 13 to Dec 1 (8 weeks)

Inner West

meets weekly at:

**Annandale Neighbourhood Centre
79 Johnston St, Annandale**

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

Term 4 Oct 12 to Nov 30 (8 weeks)

Family & Carers Group

meets weekly at:

**Annandale Neighbourhood Centre
79 Johnston St, Annandale
Thursday: 5:45pm - 7:45pm**

The next series of sessions for family and carers will begin on **October 12**.

Please call Life Force office on **9389 3834** for more info.

S O S ... S O S ... S O S ...

We urgently need extra admin. support at the Life Force office.

If anyone can help out, please telephone **9389 3834** ASAP. Thanks.

if you would like to become a part of the extended family, and help the foundation, you can send any donations to:

Life Force Foundation
P.O. Box 1663
Bondi Junction 1355

Donations are tax deductible.

