

## SURVIVORSHIP

Debbie Moore  
Support Services Coordinator  
Auckland & Northland  
19 September 2009

Leukaemia & Blood Foundation  
Vision to Cure - Mission to Care

## WORLD LYMPHOMA AWARENESS DAY

- World Lymphoma Awareness Day is held globally every year on 15 September
- Lymphoma is the sixth most common cancer in New Zealand with around 800 people being diagnosed every year
- LBF, in collaboration with the International Lymphoma Coalition, is aiming to raise awareness about this little known cancer

Leukaemia & Blood Foundation  
Vision to Cure - Mission to Care

## OVERVIEW

- Redefining cancer survivorship
- Stages of survivorship
- Challenges facing cancer survivors
- Finding your new normal
- Summary
- References

Leukaemia & Blood Foundation  
Vision to Cure - Mission to Care

## SURVIVORSHIP

- What is survivorship?
- Who is a survivor?
- When are you a survivor?

Leukaemia & Blood Foundation  
Vision to Cure - Mission to Care

## SURVIVORSHIP

- Cancer patient – sufferer or victim
- If cancer did not reoccur in the 5 years following either diagnosis or treatment, patients were considered to have become survivors
- Anyone who has been in remission for one year post diagnosis or treatment
- Anyone who has finishes their "active" cancer treatment

Leukaemia & Blood Foundation  
Vision to Cure - Mission to Care

## LANCE ARMSTRONG



## SURVIVORSHIP DEFINITION

### LIVESTRONG – LANCE ARMSTRONG FOUNDATION

- Survivorship begins at diagnosis, the moment your battle with cancer begins, and continues through your treatment and beyond
- A survivor is anyone battling with cancer; the person with cancer, a spouse or partner, a child, a friend, a parent or caregiver



## SURVIVORSHIP DEFINITION

### NATIONAL INSTITUTE OF CANCER (USA)

- Individuals who have been diagnosed with cancer and the people in their lives who are effected by the diagnosis, including family members, friends and caregivers



## STAGES OF SURVIVORSHIP

1. Acute –Begins with diagnosis and spans the time of further diagnostic and treatment effects
2. Extended – begins when the survivor goes into remission or has completed treatment
3. Permanent – cured

End of life issues can occur during any of these 3 stages



## PEPSI CHALLENGE

- Physical
- Emotional
- Practical
- Spiritual
- Interpersonal



## PHYSICAL

- Fatigue
- Changes in sexual functioning and/or interest
- Cognitive distortions and frustrations ( i.e. chemo brain and/or stress related memory problems)
- Greater risk of late effects and new cancers
- Infertility
- Premature menopause
- Various other issues



## EMOTIONAL

- Fears of recurrence
- Sense of loss, abandonment and insecurity on leaving the safety of the treatment centre/team
- Post cancer trauma, stress, anxiety, grief, confusion and/or depression
- Facing check ups and the fears and painful memories they may conjure up each time
- Learning to trust your body again
- Harboring survivors guilt
- For those whose illness is not curative, coming to terms with the mantle 'terminal' and its implications



## PRACTICAL

- Vocational problems
- Re-adjusting to the 'real world' and its trivial concerns and focuses
- Possible financial hardship from reduced income during the treatment and recovery period
- Your ability to get loans and insurance is impeded



## SPIRITUAL

- Any life threatening condition can open questions such as 'why me?' and 'what does this all mean?'
- Many question their faith or a cancer diagnosis can draw people back to their faith
- Uncertainty about what you want out of life now; even how you feel about what mattered to you before cancer



## INTERPERSONAL

- Changed role within the family
- Others expectations of you now you are 'well' can be at odds with your need for time, space and reflection
- Relationship difficulties with family and friends
- Vocational problems



## SURVIVORSHIP IS A JOURNEY TO YOUR 'NEW NORMAL'

- It's not so much "getting back to normal" as it is finding out what is normal for you now

National Cancer Institute ( USA )




## MOVING FORWARD


- Returning to "normal" everyday life
- It is usual for you and your family to look forward to the end of treatment
- This transition and adjustment period can be difficult – facing a life threatening illness makes you rethink your priorities



"The challenge is not to return to your pre-diagnosis self, but rather to accept and build on your new reality"



Pam McGrath, Living with Leukaemia, Lymphoma and Myeloma. A guide for patients and their families. 2008.




### HELPFUL HINTS FOR CREATING A NEW NORMAL

- Accept Limitations
- Learn to pace yourself
- Reconnect with previous or find new satisfying activities
- Find time & space for personal reflection
- Foster meaningful connections with others who understand your journey
- Sadness, grief & a sense of loss are normal
- Share your emotions with someone who will understand



"After my very last radiation treatment for cancer, I lay on a cold steel table hairless, half-dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing. At the time I wasn't sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned and terrified. This was the rocky beginning of cancer survivorship for me."

Dr Elizabeth McKinley, MD



### VIDEO

[From Cancer Patient to Cancer Survivor: Lost in Transition](#)



### LBF CAN HELP

- Emotional support
- Education and information
- Online support [www.lifebloodlive.org.nz](http://www.lifebloodlive.org.nz)
- Education & support programmes
- Financial assistance




The screenshot shows the LifeBloodLive website interface. At the top, there is a navigation bar with the Leukaemia & Blood Foundation logo and the text "LifeBloodLive The online support and information forum". Below this, there are sections for "Discussions" and "Diagnosis specific". The "Discussions" section lists various topics such as "General discussion", "Cares, family and friends", and "Compliments or comments". The "Diagnosis specific" section lists topics for different types of leukemia, including "Acute lymphoblastic leukaemia", "Chronic lymphocytic leukaemia", "Acute myeloid leukaemia", and "Chronic myeloid". On the right side, there are links for "Home", "Forums", "Ask the experts", "News", and "Contact us". At the bottom right, there is a "Support!" button.

## A FINAL THOUGHT

"Cancer victims and cancer survivors are people in the same situation with a different frame of mind. Focus on what you still have and have gained rather than what you've lost."

Wendy Schlessel Harpham



## REFERENCES

1. Centres for Disease Control and Prevention. CDC (online). Available at: [www.cdc.gov/cancer/survivorship/what\\_cdc\\_is\\_doing/action\\_plan.htm](http://www.cdc.gov/cancer/survivorship/what_cdc_is_doing/action_plan.htm)
2. The National Action Plan for Cancer Survivorship; page last updated April 29, 2009
3. Lance Armstrong Foundation. LAF (online). Available at: [www.laf.org](http://www.laf.org)
4. National Cancer Institute. NIA (on-line). Available at: [www.cancer.gov](http://www.cancer.gov)
5. National Coalition for Cancer Survivorship. NCCS (online). Available at: [www.canceradvocacy.org](http://www.canceradvocacy.org)
6. The Cancer Council Victoria 2007. Life after cancer: a guide for cancer survivors, Melbourne, Australia, The Cancer Council Victoria
7. "Life, Happiness... & Cancer", Phil Kerslake (2006)
8. The National Cancer Institute: Facing forward series: 'Life after cancer treatment' Available at: [www.cancer.gov/cancertopics/life-after-treatment](http://www.cancer.gov/cancertopics/life-after-treatment)
9. Living with Leukaemia, Lymphoma and Myeloma. A guide for patients and their families, Pam McGrath (2008)

Acknowledgements to the Leukaemia Foundation of Australia for sharing much of their materials from a recent Survivorship workshop held in South Australia.



## QUESTIONS OR COMMENTS

