

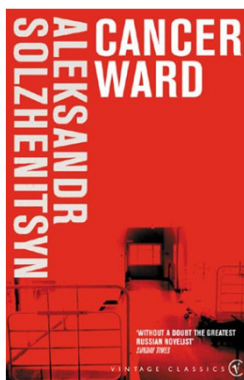
# *How can survivors change the world?*

Prof Bogda Koczwara  
Flinders Medical Centre Flinders University  
Adelaide, Australia  
August 2011

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# The world of cancer is changing

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# 1971 - The War on Cancer



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# Susan Sontag "Illness as a Metaphor"

"Cancer patients are lied to, not just because the disease is (or is thought to be) a death sentence, but because it is felt to be obscene -- in the original meaning of that word: ill-omened, abominable, repugnant to the senses."



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# Cancer survivors have changed the world already!

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## Cancer survivors:

- Change what cancer survival means
- Change what care means
- Change how care is planned

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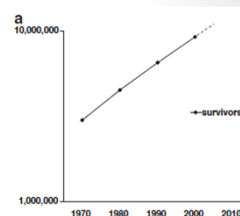
## National Cancer Institute Office of Cancer Survivorship definition:

- "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition."

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## Demographics

- 30 mln of survivors globally
- 12 mln in USA (3 mln in 1971)
- 700, 000 in Australia
- ? 130, 000 in NZ
- Growing by 2.5% per year
- Approximately 15% diagnosed more than 20 years ago.
- Most cancer survivors today are age 65 or older.



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## Phases of survival

- active treatment
- recovery from treatment
- health maintenance
  - prevention of recurrence
  - prevention of second primary
  - prevention of treatment toxicity
  - health maintenance – diet, exercise, stress management



Acute Survival

Diagnosis  
Treatment  
(Months to yrs)

Extended Survival

From completion/remission  
(5-10 years)

Permanent Survival

Normal life pattern  
(beyond 10 years)

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## Challenges of surviving cancer

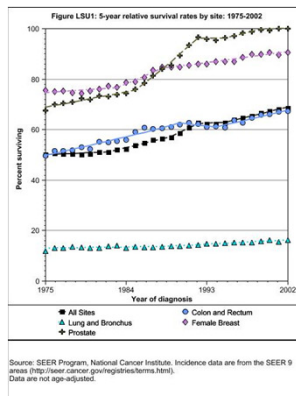
- Multiple domains – physical, psychological, spiritual, social
- Specific concerns
  - Second cancers
  - Cardiovascular morbidity
  - Fertility
  - Bone health
  - Cognition
  - Mental health
  - Financial health and employment

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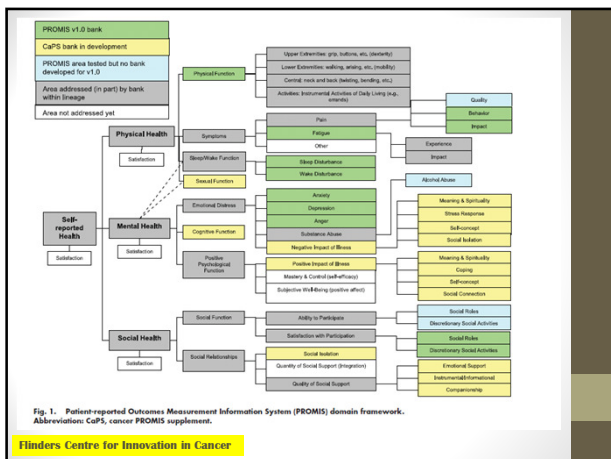
## What can be done

- Second cancers
  - Screening
  - Risk reduction – prevention
  - Risk avoidance – smoking, diet, exercise
- Cardiovascular
  - Cardioprotectants ? B blockers
  - Risk modification - manage BP, cholesterol, weight
- Fertility
  - prevention, IVF
- Bone
  - Vit D/Calcium, weight bearing exercise, no smoking
- Other
  - screen for problems (ie depression)
  - alerts re specific toxicities
  - Rehabilitate – physical and occupational
- Reinforce healthy lifestyle message

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## Support group needs – Gralla 2011

- 3728 participants - recruited from NexCura, website, 70% women, 20 cancer types
- Treatment choices ranked highest
  - Treatment side effects ranked second .... then
    - Living with cancer
      - Making decisions
        - Talking with doctors
        - Anxiety and depression
        - Uncertainty of cancer
        - Stress
          - Navigating the system
- Information ranked higher than support

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## Women “survivorship” research priorities

- 835 women – postal survey

  1. The physical risk of cancer recurring
  2. The long-term impact of medical treatment on physical health
  3. Lymphoedema
  4. The fear of cancer recurring
  5. Access to good follow up care
  6. Long-term bone health
  7. Long-term provision of information and support
  8. Long-term care planning
  9. Nutrition and Exercise
  10. Long term cognitive difficulties

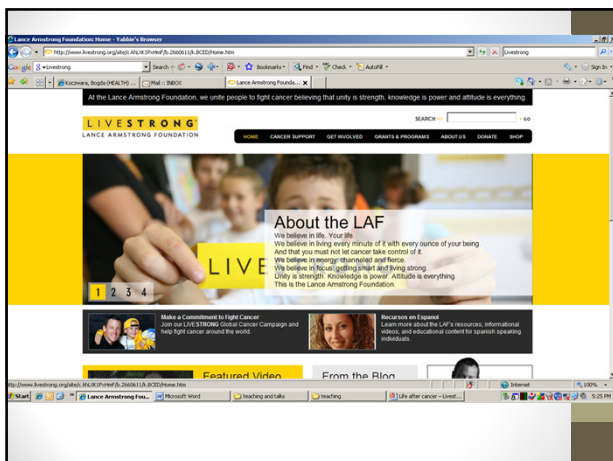


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## What is care?



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# Livestrong.org

- Empower people affected by cancer
- Practical information and tools for people to live life on their own terms
- Take aims at the gaps between what is known and what is done
- Unite people to fight cancer
- Focus on prevention, access, improved QOL of survivors, investment in research

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## Short history of survivors care

- 1986 – National Coalition of Cancer Survivorship
- 1997 – Lance Armstrong Foundation
- 2003 – Livestrong.org launched
- 2004 – ASCO Survivorship Taskforce
- 2005 – National Coalition, IOM, ASCO joint Symposium on Survivorship
- 2006 - Institute of Medicine Committee – *From Cancer Patient to Cancer Survivor: Lost in Transition*.

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## IOM Recommendations

1. Raise awareness, establish survivorship as a distinct phase, act to ensure delivery of care
2. Survivorship care plan
3. Develop evidence practice guidelines, tools,
4. Develop quality of survivorship care measures
5. Test models of care delivery
6. Include survivorship in cancer control plans
7. Educate providers
8. Address employment concerns
9. Ensure access to insurance
10. Invest in research

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**Table 3** Information and service needs (n=210), frequency (percent)

	Total need	Unmet need
Information about cancer	205 (98.1)	21 (10.2)
Internet sites	200 (95.2)	53 (26.5)
Diet and nutrition information	186 (89.4)	85 (45.7)
Exercise information	180 (86.1)	89 (49.4)
Complementary/alternative health care services	169 (80.5)	84 (49.7)
Assistance with health insurance, disability or social security	168 (80.8)	68 (40.5)
Camps, retreats	164 (78.5)	121 (73.8)
Mental health counseling	158 (76.3)	61 (38.6)
Infertility information	138 (65.7)	59 (42.8)
Counseling related to sexuality or intimacy	118 (57.3)	97 (82.2)
Family counseling	111 (53.4)	72 (64.8)
Religious/spiritual counseling	104 (49.8)	34 (32.7)
Adoption services	90 (43.5)	78 (86.7)
Infertility treatment/services	85 (40.9)	53 (62.4)
Transportation assistance	58 (27.8)	40 (68.9)
Child care	36 (17.5)	23 (63.9)
Alcohol or drug abuse counseling	8 (3.8)	6 (75.0)

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## Physical Activity and Survival After Breast Cancer Diagnosis

Michelle D. Holmes, MD, DrPH  
Wendy Y. Chen, MD  
Diane Finkelstein, ScD  
Candace H. Kroenke, ScD  
Graham A. Colditz, MD, DrPH

**Context** Physical activity has been shown to decrease the incidence of breast cancer, but the effect on recurrence or survival after a breast cancer diagnosis is not known.

**Objective** To determine whether physical activity among women with breast cancer decreases their risk of death from breast cancer compared with more sedentary women.

**Design, Setting, and Participants** Prospective observational study based on responses from 2987 female registered nurses in the Nurses' Health Study who were diagnosed with stage I, II, or III breast cancer between 1984 and 1995 and who were followed up until death or June 2002, whichever came first.

**Main Outcome Measure** Breast cancer mortality risk according to physical activity category (<3, 3-8.9, 9-14.9, 15-23.9, or ≥24 metabolic equivalent task [MET] hours per week).

**Results** Compared with women who engaged in less than 3 MET-hours per week of physical activity, the adjusted relative risk (RR) of death from breast cancer was 0.80 (95% confidence interval [CI], 0.60-1.06) for 3 to 8.9 MET-hours per week; 0.50 (95% CI, 0.31-0.82) for 9 to 14.9 MET-hours per week; 0.56 (95% CI, 0.38-0.84) for 15 to 23.9 MET-hours per week; and 0.60 (95% CI, 0.40-0.89) for 24 or more MET-hours per week (P for trend = .004). These MET-hours is equivalent to walking at average pace of 2 to 2.9 mph for 1 hour. The benefit of physical activity was particularly apparent among women with hormone-responsive tumors. The RR of breast cancer death for women with hormone-responsive tumors who engaged in 9 or more MET-hours per week of activity compared with women with hormone-responsive tumors who engaged in less than 3 MET-hours per week was 0.50 (95% CI, 0.34-0.74). Compared with women who engaged in less than 3 MET-hours per week of activity, the absolute unadjusted mortality risk reduction was 6% at 10 years for women who engaged in 9 or more MET-hours per week.

**Conclusions** Physical activity after a breast cancer diagnosis may reduce the risk of death from this disease. The greatest benefit occurred in women who performed the equivalent of walking 3 to 5 hours per week at an average pace, with little evidence of a correlation between increased benefit and greater energy expenditure. Women with breast cancer who follow U.S. physical activity recommendations may improve their survival.

JAMA. 2008;299:2479-2486

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## Lifestyle switches disease genes 'on, off'

By Will Dunham in Washington

Comprehensive lifestyle changes, including a better diet and more exercise, could lead not only to a better physique, but also to swift and dramatic changes at the genetic level, United States researchers said yesterday. In a small study, the researchers tracked 30 men with low-risk prostate cancer who decided against conventional medical treatment such as surgery and radiation or hormone therapy.

published in the journal *Proceedings of the National Academy of Sciences*. The research was led by head of the Preventive Medicine Research Institute in Sausalito, California, and a well-known author advocating lifestyle changes to improve health Dean Ornish. "It's an exciting finding because so often people say, 'Oh, it's all in my genes, what can I do?' Well, it turns out you may be able to do a

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## Individuals can change the world..

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## Senate Inquiry 2005 (on request of Sen Peter Cook)

- Reasonably, doctors tend to stick with scientifically proven treatments, whereas patients are often desperately looking for the most promising options in order to improve their odds. This dichotomy and the dismissive attitude conventional medicine often exhibits towards less conventional treatments can leave patients worried and confused about what to do.

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Herb	Concurrent chemotherapy/condition (suspected effect)
Echinacea	Caution with camptothecin, cyclophosphamide, TK inhibitors, epipodophyllotoxins, taxanes, and Vinca alkaloids (CYP3A4 induction)
Ephedra	Avoid with all cardiovascular chemotherapy (synergistic increase in blood pressure)
Ginkgo	Caution with camptothecin, cyclophosphamide, TK inhibitors, epipodophyllotoxins, taxanes and Vinca alkaloids (CYP3A4 and CYP2C19 inhibition), discourage with alkylating agents, anti-tumour antibiotics and platinum analogues (free-radical scavenging)
Ginseng	Discourage in patients with oestrogen-receptor positive breast cancer and endometrial cancer (stimulation of tumour growth)
Green tea	Discourage with erlotinib (CYP1A2 induction)
Japanese arrowroot	Avoid with methotrexate (MCC and GAT inhibition)
Soy	Avoid with tamoxifen (antagonism of tumour growth inhibition), and treatment of patients with oestrogen-receptor positive breast cancer and endometrial cancer (stimulation of tumour growth)
St. John's wort	Caution with tamoxifen (CYP2C9 inhibition), cyclophosphamide and temiposide (CYP2C19 inhibition)
Valerian	Avoid in all patients with pre-existing liver disease, with evidence of hepatic injury (herb-induced hepatotoxicity) and/or in combination with hepatotoxic chemotherapy, caution with camptothecin, cyclophosphamide, TK inhibitors, epipodophyllotoxins, taxanes and Vinca alkaloids (CYP3A4 induction)
Xiao-hua	Caution with camptothecin, cyclophosphamide, TK inhibitors, epipodophyllotoxins, taxanes and Vinca alkaloids (CYP3A4 induction), and with alkylating agents, anti-tumour antibiotics and platinum analogues (free-radical scavenging)

Abbreviation: TK, tyrosine-kinase.

De Jong EJC 2008

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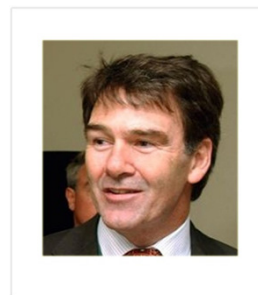
## Cancer Journey. Informing Choice.

- Dedicated funding stream into research from NHMRC
- Collaboration of providers
- Access to information
- Cancer services should provide therapies that improve QOL and make them more accessible

[http://www.aph.gov.au/Senate/committee/clac\\_ctte/completed\\_inquiries/2004-07/cancer/report/index.htm](http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/cancer/report/index.htm)

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## Chris O'Brien and the Lifehouse




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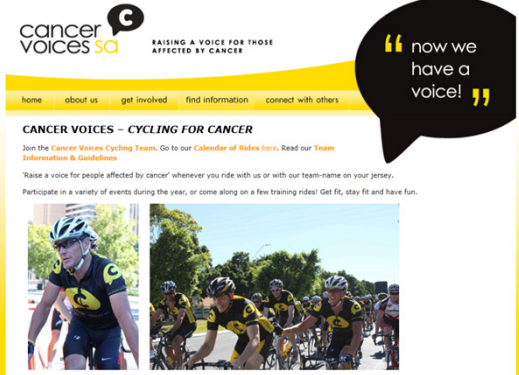
**LifeSupport** is your guide to handling the nitty gritty of daily life with cancer.

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Unity is strength, knowledge is power and attitude is everything

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“now we have a voice!”

**CANCER VOICES – CYCLING FOR CANCER**

Join the Cancer Voices Cycling Team. Go to our Calendar of Rides here. Read our Team Information & Guidelines

‘Raise a voice for people affected by cancer’ whenever you ride with us or with our team-name on your jersey. Participate in a variety of events during the year, or come along on a few training rides! Get fit, stay fit and have fun.

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It is a different “C” word...

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