

Cancer Survivorship Research: Recovery and Beyond

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Marriott Wardman Park Hotel

Washington, D.C.

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Research • Educate • Support

Cancer affects us all...

Supporters

- ACS – American Cancer Society
- NCI – National Cancer Institute
- NIH – National Institutes of Health
- DHHS – Department of Health and Human Services
- LIVESTRONG
- CDC – Centers for Disease Control



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Decision to attend survivorship conference



- During 2010 it was decided by the CEO that she and Dr Albrecht would team up in the US, after he addressed the WTE in Las Vegas, and then attend a major conference on cancer survivorship in Washington D.C. from 17-19 June, 2010.
- The reason for this, is the growing realisation world-wide that more and more cancer patients are surviving for 5 years and longer and need special attention in order to deal with the delayed side-effects of a cancer diagnosis as well as cancer treatment and enjoy a reasonable quality of life.
- Furthermore, such cancer survivors needed information on how to reduce the increased risk of another cancer diagnosis, i.e. maximum protection.
- It is estimated that there are now about 13 million cancer survivors in the US as a result of a survival rate of 65%. The number of survivors in South Africa is unknown. With a South African population of 50 million vs. the 350 million in the US there could be about 1.85 million survivors. With a more realistic cure rate of 45% , compared to 65% in the US, the number of survivors could be **1.28 million**.
- Many of these cancer survivors are attracted to CANSA sponsored Relay For Life events and their demographics are trapped in computers.
- The hypothesis is that these cancer survivors could be enthused to form a Cancer Survivor Support Group in South Africa that could be of great value.

Who is a cancer survivor?

- A cancer survivor is anyone who has ever been diagnosed with cancer and is living today. Because of major advances in diagnosis and screening as well as better treatment for many types of cancer, many people are living longer with cancer. Approximately 12 million people in the United States have a history of cancer. Of these, over 60 percent were diagnosed 5 or more years earlier and 14 percent were diagnosed 20 or more years ago. Further, because cancer tends to affect older adults, about 60 percent of survivors are over the age of 65



cassie, 34
cancer survivor



Mona Brooks
photographer

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What is cancer survivorship?

- Cancer survivors may face **physical, emotional, social, spiritual,** and **financial** challenges as a result of their cancer diagnosis and treatment. Public health professionals strive to address survivorship and quality of life issues such as the coordination of care, patient-provider communication, health promotion, support services, and fertility preservation. In light of these concerns, public health initiatives aimed at understanding and preventing secondary disease, recurrence, and the long-term effects of treatment are essential.
- (<http://nihseniorhealth.gov/lifeaftercancer/faq/faq3a.html>).



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What can be done to promote survivorship?

- **Promoting Health After a Cancer Diagnosis**
- Cancer survivors are at greater risk for recurrence and for developing second cancers due to the effects of treatment, unhealthy lifestyle behaviors, underlying genetics, or risk factors that contributed to the first cancer. The following factors can help maintain health and improve survival and quality of life after a cancer diagnosis:
- **Quitting Tobacco Use**
 - Smoking is a preventable risk factor for cancer recurrence and additional cancers.
- **Being Active and Maintaining a Healthy Weight**
 - Obesity may be related to poorer survival after breast, prostate, and colorectal cancer.
 - Regular physical activity may improve quality of life after a cancer diagnosis.
- **Discussing Follow-up Care with a Health Care Provider**

Important topics to discuss:

 - A follow-up plan of care that includes a schedule of recommended follow-up visits, screenings, and medical tests and specifies which providers will be responsible for care.
 - Possible delayed effects of treatment.
 - The importance of seeking timely care in response to certain signs or symptoms.
 - Emotional wellness after cancer and identifying available resources for additional support, if necessary.
 - Lifestyle changes recommended for improving health and well-being after cancer.
 - Developing an effective support system that meets survivors' medical and emotional needs. (http://www.cdc.gov/cancer/survivorship/basic_info/index.htm)



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Main challenges of survivorship

- Sequelae of:
- Cancer
- Treatment
- Ageing
- Lack of exercise
- Poor diet
- Poor mental health
- Lack of finances

Specific messages from the conference



- **Exercise:**
- Numerous examples were presented that illustrated a beneficial effect of exercise on survivors.
- Kathryn Schmitz focused on 234 breast cancer survivors. Twice-weekly strength training positively impacted self-perceptions of appearance, health, physical strength, sexuality, relationships, and social functioning (Breast Cancer Res Treat, 2010, 121, 421).
- A number of speakers highlighted research results showing a 40-50% reduction in cancer risk (breast, prostate, colon) in survivors involved in exercise. (For review see: **“Cancer prevention, aerobic capacity, the physical functioning in survivors related to physical activity: a recent review”**, Cancer management and Research, Wiggins MS and Simonavice EM, 2010, 2, 157-164.)



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Specific messages from the conference



- **Psychological help**

- Loge has reported that up to 40% of breast cancer survivors suffer from chronic fatigue which is related to body mass index, current psychological distress and pain in the treatment area. Attempts should be made to reduce these three fatigue-inducing factors. (J Cancer Surviv, 2010, 4, 405.)
- Partner-assisted emotional disclosure (PAED) is a novel, couple-based intervention designed to help patients disclose cancer-related feelings to their partners and partners to respond empathically. Data from a recent RCT indicated that the intervention led to improvements in relationship quality and intimacy for couples in which patients initially reported holding back from discussing cancer-related concerns (Abstract 52: **Reactions to a Partner-Assisted Emotional Disclosure Intervention: Direct Observation and Self-Report of Patient and Partner Communication**, Laura S. Porter)



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Depression and sexual dysfunction (Abstract 66).



- Kristen et al. showed that effective treatment of depression in cancer survivors might have an important secondary benefit of improving sexual outcomes , offering a potential avenue for addressing sexual difficulties – one of the most under-recognised and undertreated survivorship issues.



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Cancer survivors website which was activated during 2010

<http://www.cancersurvivorlink.org/>

Welcome to SurvivorLink

SurvivorLink has been designed to:

Increase awareness and knowledge about the life-long healthcare needs of pediatric cancer survivors

Increase **communication** about the specific healthcare needs of individual survivors between:

- Survivor and Family
- Cancer Survivor Team
- Primary Care Provider
- Healthcare Subspecialist

On SurvivorLink, over the next three years we plan to develop portals targeting three areas of the survivor care community:

Patient Portal, which will provide access to the patient's Survivor Healthcare Plan (SHP) including:

- Cancer Treatment Summary
- Individualized Late Effects Risk Profile
- Individualized Surveillance Plan for the detection of late effects

Provider Portal, which will give providers access to:

- CME educational material about survivorship
- Links to useful resources to assist in providing care for pediatric cancer survivors
- Access to your patients' Survivor Healthcare Plan* which will assist you in identifying existing medical problems in your patient, late effects they are at risk for, and recommended screening for your patient

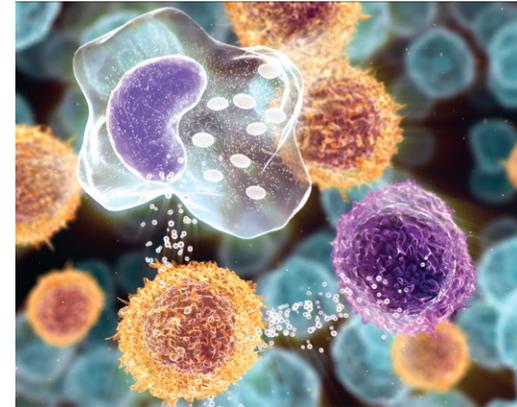
Research Portal, which will be used to:

- Perform IRB-approved studies to better understand the frequency of late effects
- Design interventions to prevent the long-term health consequences of late effects of cancer therapy



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Cancer Survivorship and systemic inflammation



- There is growing evidence that cancer survivors have systemic inflammation.
- This could be due to the original cancer, treatment or subsequent unhealthy lifestyles.
- There is a hypothesis that systemic inflammation could increase the risk of a recurrence of cancer.
- CRP (C-reactive protein) is an inflammatory marker
- CRP has been found to be increased in A-bomb survivors
- Increasing CRP (>1mg/L) has been correlated with 5% recurrence of cancer or cardiovascular disease, 9-11 years after curative treatment.
- Among breast cancer survivors, a better-quality diet seems to be associated with lower levels of CRP chronic inflammation.
- It has also been shown that exercise can cause CRP to decrease by 1. 39 mg/L.



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Treatment sequelae

- Sequelae = abnormal bodily condition or disease related to or arising from a pre-existing disease.
- Anthracyclines: subclinical cardiac dysfunction
- Delayed neurological complications, such as cognitive decline, progressive myelin disruption and brain atrophy.
- Pre-counseling of prostate cancer patients starting (neo-)adjuvant LHRHa therapy must include fatigue, mainly physical fatigue, in particular in men aged 65 years or younger.
- Patients who receive brain radiation therapy may have both short and long-term memory problems, often referred to as *chemobrain*.
- Adult survivors of childhood cancer, especially those treated with cranial irradiation, are at increased risk of developing the metabolic syndrome.



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Vision for survivorship in South Africa

- Database built on forms filled in at Relay for Life events.
- Epidemiological survey and needs assessment.
- Create SOP (Standard Operating Procedures) on paper.
- Empower survivors to constitute a Cancer Survivors Group.
- Empower group to operate procedures
- SOP's:
 - 1. Governance
 - 2. Exercise routines
 - 3. Psychological support
 - 4. Referral re sequelae
 - 5. CRP testing
 - 6. Information dissemination (Internet)