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Cancer Survivors: Key Advocates for a Better Future

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Office of Cancer Survivorship

National Cancer Institute • National Institutes of Health • DHHS

Tomatelo a Pecho
October 8, 2013
Mexico City, Mexico

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What I will cover…

- A brief history of the cancer survivorship 'movement'
- Who are our cancer survivors?
- What are survivors and (is) survivorship research telling us – *the lessons learned?*
- What are the implications of these findings for women's care?

"disproportionate" representation among refusers noted in the report under consideration appears less alarming.

MARY E.W. GOSS, PH.D.
New York, NY 10021 Cornell University Medical College

To the Editor: Dr. Stossel's observation, that low-status reviewers are nearly one-third more likely to provide editors of peer-reviewed journals with good reviews (and only half as likely to prepare poor reviews) as compared with reviewers with high status, should come as no surprise.

Low-status investigators are often honored to be asked to review a manuscript, particularly by a high-quality journal. Accordingly, they devote considerable time and effort to the review, checking the references and performing their own literature search.

As Dr. Stossel noted, high-status reviewers faced with greater demands on their time may either rely on their own expertise or pass the manuscript on to an unnamed junior investigator — unless it touches the subject of the high-status reviewer's current interest, in which case the result may be an extraordinarily thoughtful review.

If the manuscript is passed on to an unnamed junior reviewer, it is possible that the review may be written only to satisfy the hurried glance of the high-status reviewer.

Middle-level reviewers, often just reaching the peak of their publication productivity, are grateful for the efforts of those who have reviewed their own manuscripts, particularly for the high-quality reviews. They feel an obligation to reply to the editor with, if not a high-quality review, at the very least one of medium quality.

Editors can resolve many of the problems of poor reviews by insisting that the primary reviewers sign their names to the reviews and that reviews resulting from a hand-off by a high-quality reviewer to a subordinate be signed by both. I doubt that few who return reviews of high quality would object. It is possible that junior departmental members handed these tasks by high-status reviewers would devote more thought and effort to comments identified by their signatures.

As an example, the quality of the editorials in *The New England Journal of Medicine* reached their present pinnacle of excellence only after these became signed works.

HAROLD O. DOUGLASS, JR., M.D.
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The above letters were referred to Dr. Stossel, who offers the following reply:

To the Editor: Since the purpose of my article was to raise consciousness concerning an aspect of biomedical communication, I was glad to see the correspondence sent to the *Journal*, as well as a number of letters I received personally.

Drs. Douglass, Grunfeld, and Reinhart address possible reasons for the effects of reviewer status on review quality. Drs. Douglass and Reinhart ask whether reviews ascribed to high-status reviewers may actually have been done by someone else of lower status. High-status referees often indicate by name junior colleagues who have helped with reviews. It is my impression that such reviews tend to be of good quality, although I have not formally studied this point.

Dr. Grunfeld also speculates that low-status authors have difficulty getting papers published in prestigious journals and therefore try to curry favor with editors by providing good reviews. Whether this motivation is a factor that in part explains the findings requires examination, although if it is, it may be based on a false premise. A study of papers sent to a physics journal concluded that the relative status of authors and referees did not influence the fate of papers, although, not surprisingly, more papers were submitted by high-status physicists and more of those were published.[1] It would be virtually impossible to repeat this investigation in the biomedical-science field today, because most papers are multiauthored and have at least one high-status author.

Dr. Goss' letter is an example of a good review by a high-status person. The analysis underscores the point made in my article that "the majority of the 1600 reviews analyzed were of high quality," from which we can conclude that most participants in the peer-review system would like to see it work well.

The matter of anonymous reviewing has been debated for years,[2,3] but many editors think its advantages outweigh its drawbacks, an especially dangerous example of which has been described by M.R. James.[4] My own prejudice is that if we wrote fewer papers and were less hysterical about getting them published rapidly, reviewing might be a less onerous task, and there would be less justification for refusing to review or for doing it poorly.

THOMAS P. STOSSEL, M.D.
Boston, MA 02114 Massachusetts General Hospital

1. Zuckerman H, Merton RK. Patterns of evaluation in science: institutionalization, structure and functions of the referee system. Minerva 1971; 9:66-100.
2. Knox FG. No unanimity about anonymity. J Lab Clin Med 1981; 97:1-3.
3. La Follette MC. On fairness and peer review. Science Tech Hum Values 1983; 8:3-5.
4. James MR. The ghost stories of an antiquary. 2nd ed. London: E Arnold, 1974:516-38.

ONE DRUG COMPANY'S SALES TECHNIQUES

To the Editor: A sales representative for a drug company inadvertently left a copy of a page from his manual of selling techniques in our office. I found it most enlightening and think that it may be of general interest. Among the devices recommended as "attention getters" were cookies with the shape and color of drug capsules, pizzas with drug initials picked out in pepperoni, Easter baskets containing eggs painted to resemble drug capsules, and Halloween baskets containing free samples and decorated with little ghosts made from Dum-Dum suckers and tissue. These last are to be accompanied with a little joke about haunting the doctor to write the correct prescriptions.

The instructions go on to say that any of the above can be made into "an annual event, and they really enjoy them." Furthermore, they advise the representatives that it is vital to make the maximal impact in the limited time available. This is done by handing the doctor candy bars labeled "Powerhouse." Any initial mystification is quickly dispelled by then handing him one or two nostrums that are recommended as "powerhouses" for the treatment of common, chronic, and incurable conditions, such as chronic bronchitis and arthritis (type unspecified).

The original of this document, which I shall be glad to show to anyone interested, contains grammar and spelling that suggest that the standard of education among this company's sales force cannot be high. But sales techniques are not used unless they work. This drug company, and perhaps others, obviously regard us as idiots who respond to Easter baskets and italicized pizzas by prescribing more of their products. Could it be that they are right?

PATRICK A. MURPHY, M.D.
The John Hopkins University
Baltimore, MD 21205 School of Medicine

OCCASIONAL NOTES

Seasons of Survival: Reflections of a Physician with Cancer

WHEN I was given a diagnosis of cancer, my first thought was not, Will I die? but rather, How can I beat this? Like a youngster who flunks a big test, I immediately began to worry about what to do to pass the course. I was 32 years old at the time, a physician, a husband, a parent, and a son. I had been healthy, athletic, and free of pain, but with the diagnosis, I became formally sick. My mind and my hopes riveted

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Fitzhugh Mullan, N Engl J Med 1985; 313:270-273

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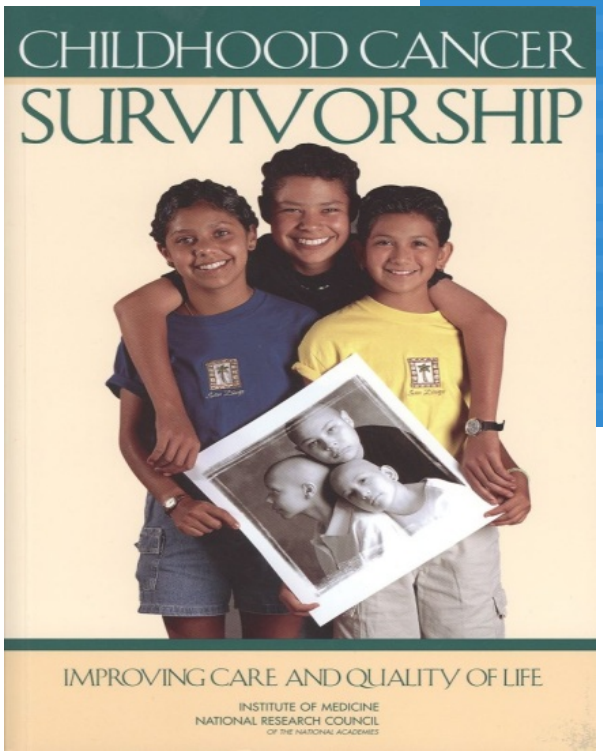
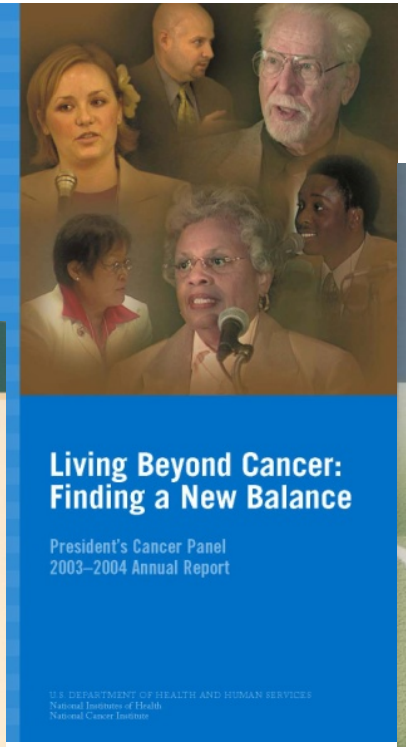
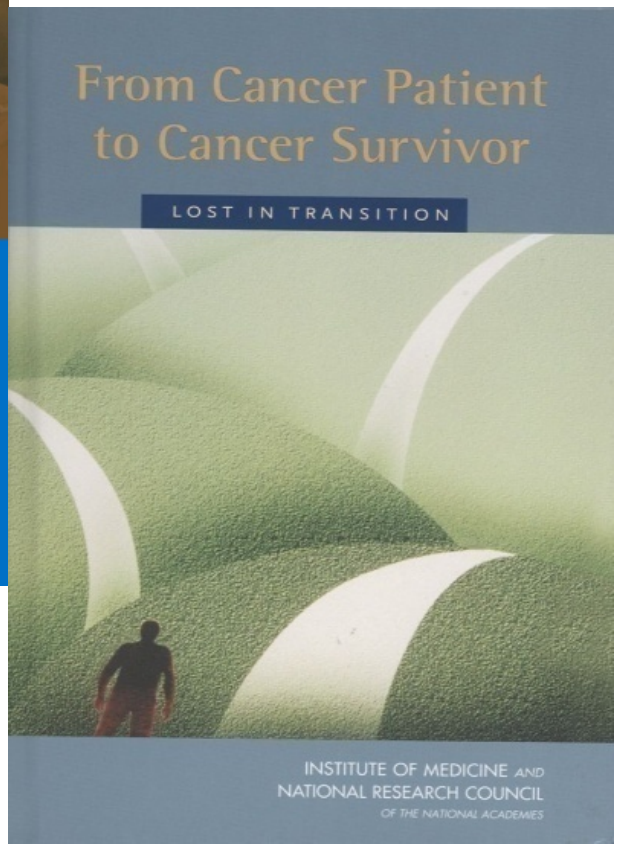
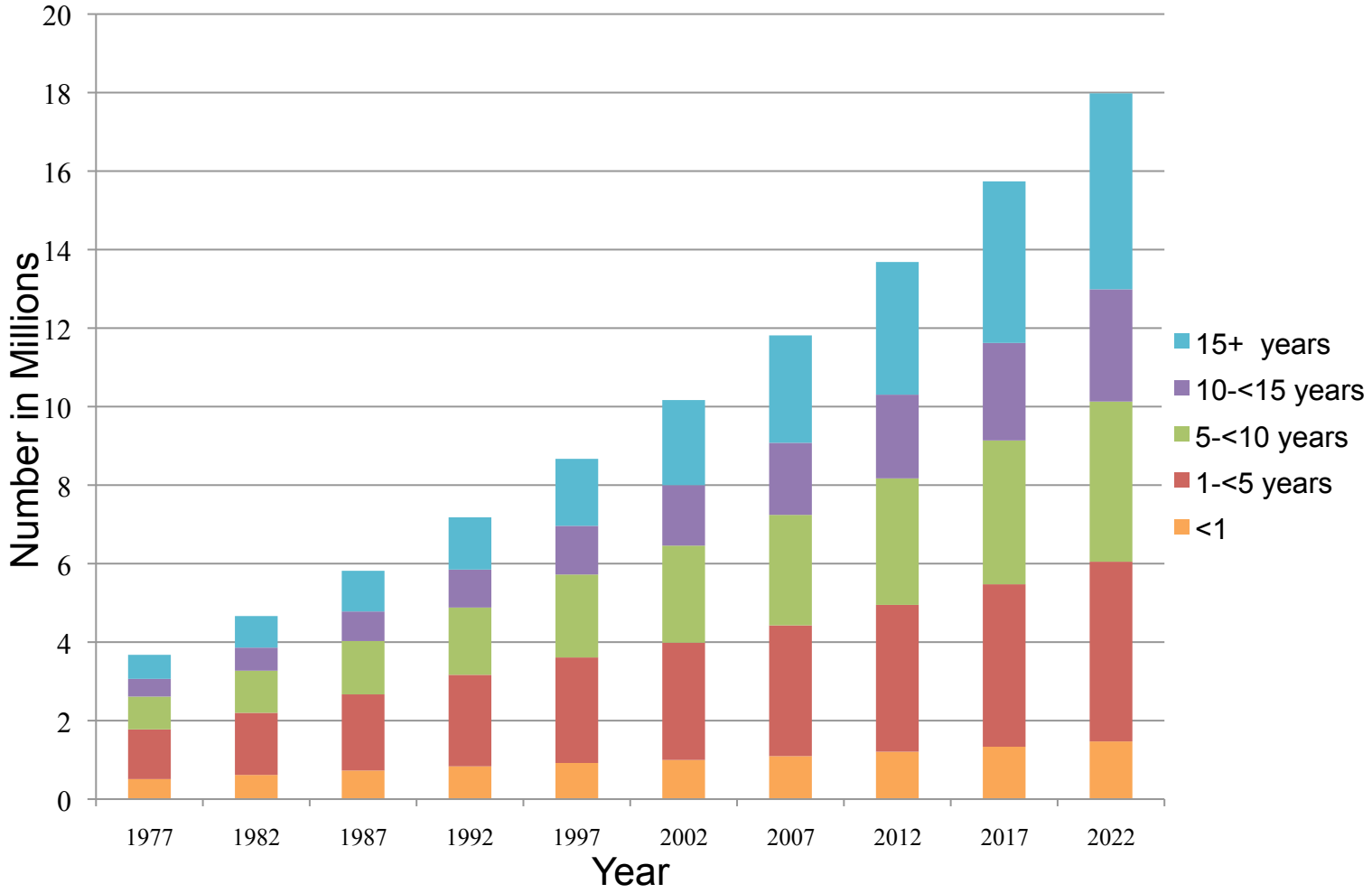
Visibility of Cancer Survivorship at the National Level in the U.S.





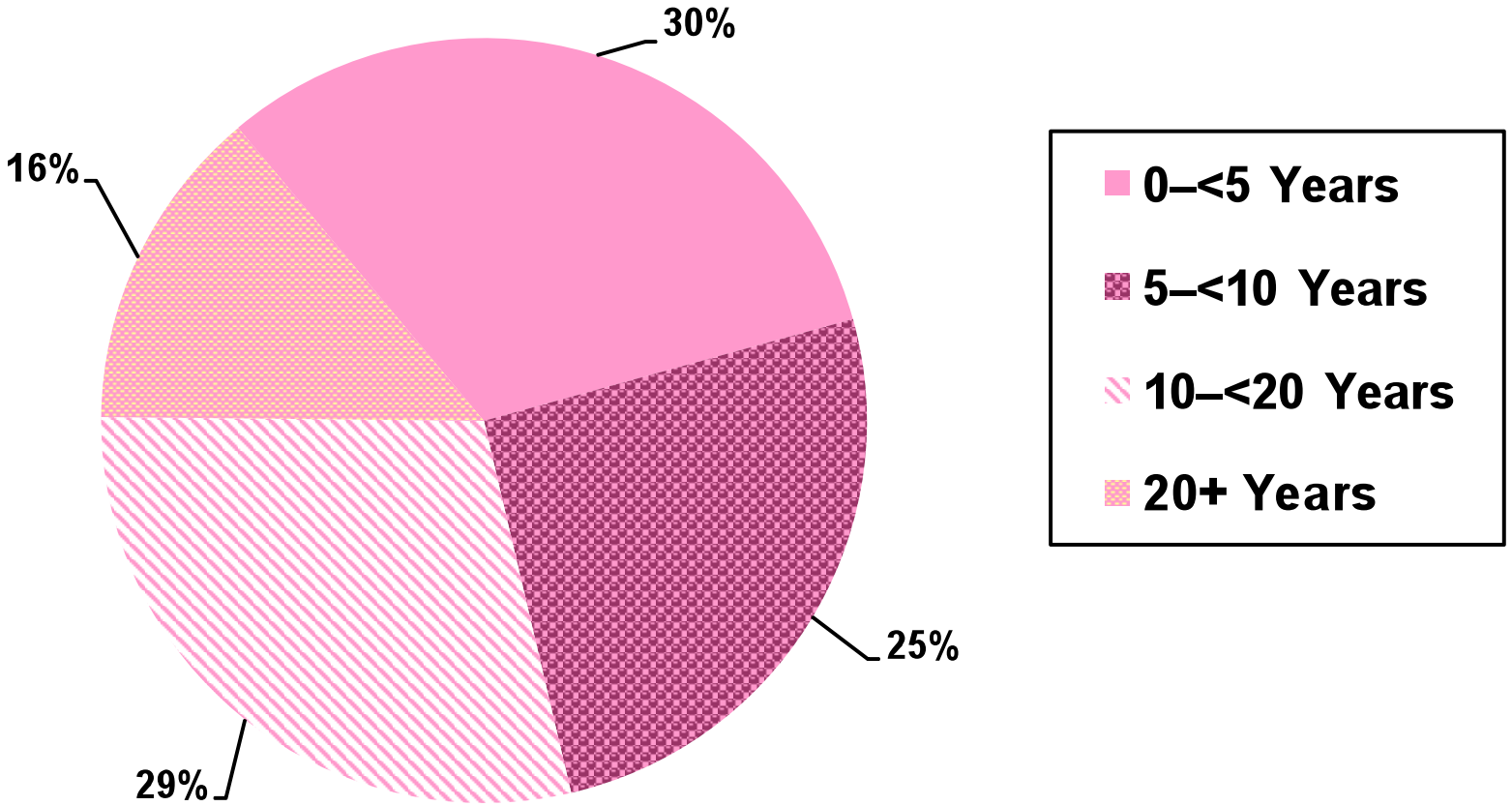


Estimated and Projected Number of Cancer Survivors in the US from 1977-2022 by Years Since Diagnosis



de Moor et al, *CEBP*, in press March 2013

Women Alive Diagnosed with Breast Cancer by Time Since Diagnosis (N = 2.6 Million Survivors)



Based on 2008 data; Howlader et al. *SEER Cancer Statistics Review, 1975-2008*, National Cancer Institute. Bethesda, MD, **http://seer.cancer.gov/csr/1975_2008/,** based on November 2010 SEER data submission, posted to the SEER web site, 2011.

"[Survivors] have special psychological, physical, and health care counseling needs that we are only beginning to understand…the [OCS] will support the much needed research that will help cancer survivors deal with the problems they face even after their cancer is cured." ***President Clinton, October 27, 1996, at the Rose Garden ceremony to formally announce the launch of the Office of Cancer Survivoship.***

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Office of Cancer Survivorship (OCS)

- **The mission of the OCS is to enhance the length *and quality of survival* of all cancer survivors**
- **We accomplish this mission through:**

1. **Support of research** that seeks to a) identify and prevent if possible or address if not, the long-term and late effects of cancer; b) provide an evidence base for optimal post-treatment care; and c) guides efforts at health promotion after cancer
2. **Promotion of training** of professionals to conduct research among cancer survivors and to provide clinical care to this population
3. **Communication of research findings** to professionals who deal with cancer survivors, the public, and cancer survivors themselves and their family members.

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What have we learned from survivors?

Lesson # 1:

Language is important

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Definitional Issue:
Who is a **Cancer Survivor?**

- **Philosophically, anyone who has been diagnosed with cancer is a survivor— from the time of diagnosis to the end of life**
- **Caregivers and family members are also cancer survivors**

(Source: NCCS, 1986)

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What's in a name?

- It provides hope
- It informs care – it changes the dialogue!
- It is NOT a label, although it is meant to replace the term:

VICTIM

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Lesson # 2:

Being cancer free does not mean being free of cancer

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Long-Term and Late Occurring Effects of Cancer & Cancer Treatment

- **Physical/Medical** (e.g., second cancers, cardiac dysfunction, pain, lymphedema, sexual impairment)
- **Psychological** (e.g., depression, anxiety, uncertainty, isolation, altered body image)
- **Social** (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/ loss, return to school, financial burden)
- **Existential and Spiritual Issues** (e.g., sense of purpose or meaning, appreciation of life)

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Lesson # 3:

Planning for recovery is important!

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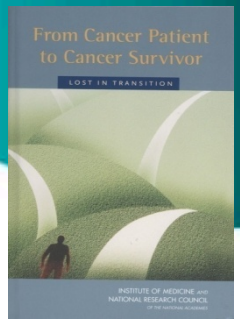
Follow-up Care Plan (per IOM) Main Domains to Cover:



1. Surveillance for recurrence or new cancer
2. Assessment and treatment or referral for persistent effects (e.g., pain, fatigue, sexual dysfunction, functional impairment, depression, employment issues)
3. Evaluation of risk for and prevention of late effects (e.g., second cancers, cardiac problems, osteoporosis); health promotion
4. Coordination of care (e.g., including frequency of visits, tests and who is performing these)

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Lesson # 4:

Despite risk, survivors manifest remarkable *resilience* with respect to and even the potential to *find benefit* from the cancer experience

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Benefit Finding… (post-traumatic growth)

- "I do not worry about the little things any more."
- "I take time now to stop and smell the roses….I don't take my family for granted any more."
- "Having cancer made me realize that there were still things I wanted to do, places I wanted to go."

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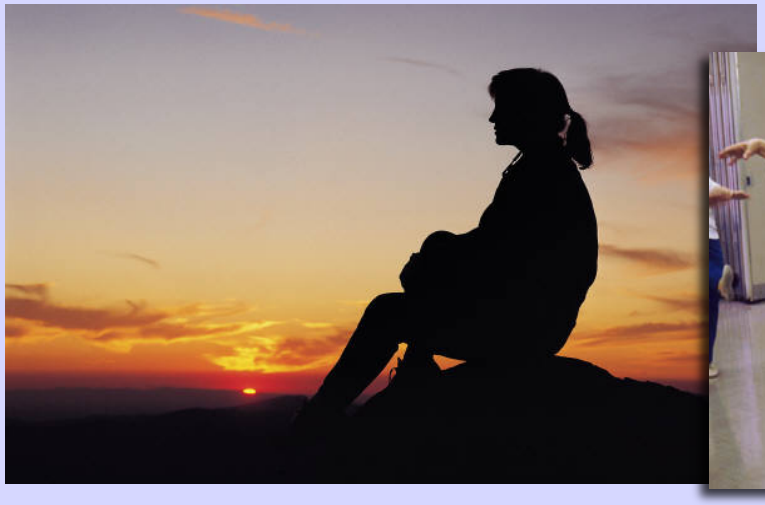
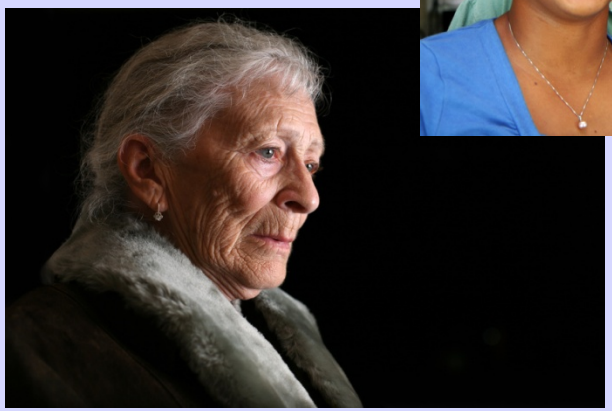
Lesson # 5:

We need to ***LISTEN*** to what survivors are telling us!

In spite of the uncertainties, there can still be good quality of life after cancer!





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Opportunities

- Growing attention to survivors' long-term well-being and follow-up care (as reflected in recent reports)
- Commitment of growing numbers of researchers and clinicians to this area of cancer control science and practice
- Articulate and effective advocacy community: The power of survivors' voices!

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Gracias!

http://survivorship.cancer.gov

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