Survivorship Care Plans: The Key to Survivorship Care



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About Me

- Mark Gorman
- Director of Survivorship Policy
- National Coalition for Cancer Survivorship
- Long-term survivor (12+ years) metastatic melanoma



About NCCS

- Founded in 1986
- Mission: Advocate for Quality Cancer Care
- Survivor led: Bylaws require majority of BoD have personal diagnosis;
 25% of staff now
- Created concept and language of "cancer survivorship" as alternative to "patient" or "victim".

FOR CANCER SURVIVORSHIP

Advocacy Continuum

- Public interest anchors one end.
- Community, such as this Conference
- Personal, or self-advocacy, anchors the other end.
- All necessary to bring about systemic change in delivery of cancer care.
- NCCS active throughout.



What is Quality Cancer Care?

Elements

- Patient-centered
- Effective
- Timely
- Safe
- Efficient
- Equitable

In Practice

- Shared decisionmaking
- Empowered patients
- Ongoing communication
- Treatment planning and patient involvement



The power of survivorship, The promise of quality care

Comprehensive Patient-Centered Care

- Survivors need integrated, comprehensive, patient-centered care.
- Acute phase of active treatment
- Transition from active treatment
- Long-term, late effects



The Survivorship Continuum

Pre-Treatment

During Treatment Transition:
Post-Treatment

Transition: End of Life

Plan for treatment and management of symptoms and side effects Monitor treatment and management of symptoms and side effects

Treatment summary and plan for follow-up care

Plan for end-oflife care



IOM: 2005



From Cancer Patient to Cancer Survivor: Lost in Transition

Calls for treatment plans during treatment, treatment summaries at conclusion of treatment, survivorship care plans for post-treatment survivorship



Summary & Plan Contents

- Cancer type, treatments received, and their potential consequences;
- Specific information about the timing and content of recommended follow-up;
- Recommendations regarding preventive practices and how to maintain health and well-being;
- Information on legal protections regarding employment and access to health insurance; and
- The availability of psychosocial services in the community.



Physician Responsibility

This "Survivorship Care Plan" should be <u>written by the principal</u> <u>provider(s)</u> who coordinated oncology treatment. (emphasis added) (From Cancer Patient to Cancer Survivor, Recommendation 2, p. 4)



Journey ForwardTM

- Free software for clinicians to build customizable treatment summary and follow-up survivorship care plan
- Survivors can also use medical history builder
- Partnership between NCCS, UCLA
 Cancer Survivorship Center,
 WellPoint, Inc., and Genentech
- www.journeyforward.org



Journey ForwardTM

- Based on ASCO's templates and follow-up guidelines
- Generic template just launched in addition to breast and colon templates
- www.journeyforward.org





Targets for Change: How to Help

- Physician behavior
- Survivor expectations: Survivor "demand"
- Help us get the care we need and deserve



Thank You!

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