

NCCS CPAT SYMPOSIUM JUNE 26, 2017

Improving Survivorship Care in
Your Local Community



Agenda

- Welcome and Introductions
- Session Goals
- Today's Plan
 - Update state of survivorship care with respect to 2006 IOM directives
 - Review specific guidelines related NCCS advocacy
 - What can be done locally
 - Examples from survivors
 - Discuss next steps

Goals for Improving Survivorship Care in Your Local Community

1. Provide an understanding of how survivorship care has evolved over the last 10 years
2. Share advocate-driven actions and programs that have changed survivorship care locally
3. Create initiatives to help you use guidelines to effect change in your communities
4. Provide ongoing communication vehicle so we continue to share ideas, successes and roadblocks with each other

2006 IOM Guidelines & Update on Survivorship Care

- A committee was established to examine the medical and psychosocial issues faced by cancer survivors and discuss ways to improve their health care and quality of life
- Some survivors experienced few late effects of their cancer but others suffered permanent symptoms

Essential Components of Survivorship Care

- **Prevention** of recurrent/new cancers and late effects
- **Surveillance** for cancer spread, recurrence, or 2nd cancers; assessment of late effects
- **Intervention** for consequences of cancer treatment; symptoms such as pain and fatigue; psychological distress; financial concerns
- **Coordination** between specialists and primary care providers to meet the needs of survivors

10 Recommendations

1. Raise awareness of the needs of survivors
2. Survivorship care plan
3. Identify & manage late effects of cancer and treatments
4. Quality survivorship care & quality assurance programs need to be monitored and improved upon
5. Organizations should support demonstration programs

10 Recommendations cont'd

6. Congress should support the development of survivorship care plans
7. Organizations should expand efforts to educate health care providers about survivorship issues
8. Survivors should not be discriminated against by their employer
9. Policy makers should ensure that all survivors have access to adequate and affordable health insurance
10. Organizations should support survivorship research

National Academy
of Medicine

National Cancer Policy Board

The Patient Experience

LISTEN → **PLAN** → **ACT**

- Describe experiences with survivorship care
- Identify gaps in survivorship care
- Illustrate challenges to improving survivorship care
- Suggest opportunities to address these challenges
- List shareholders who need to be engaged in improving survivorship care
- Describe the progress that has been made in survivorship care and service delivery

Physical Well Being

- Focus on:
 - Cross-cutting physical well-being concerns that are independent of treatment exposure and specific cancer.
 - Unique physical well-being concerns relevant to specific types of treatment and/or cancers
 - Host factors that predispose to greater risk for some symptoms
 - Preparation of survivors for potential long term physical sequelae of cancer and its treatment
 - Relationship of life style factors on physical sequelae

Psychosocial Well Being and Family Caregiving

- Focus on:
 - Addressing barriers to psychosocial care
 - Distinctions in psychosocial needs between age groups
 - Incorporation of psychosocial services into quality care standards
 - Integration of mind-body issues by health professionals
 - Identifying the organizations who should be taking an active role in advancing psychosocial services
 - Family caregiving as an important part of survivorship care

Socio-Economic – Employment and Insurance

- Focus on:
 - Health insurance
 - Covered benefits
 - Preexisting conditions
 - affordability
 - Access to care
 - Availability
 - Awareness
 - Employment challenges
 - Education challenges

Models of Survivorship Care

- Focus on:
 - Reviewing the expansion of survivorship care models by type of provider, type of location and type of services
 - Highlight unique community facilities
 - Identifying the challenges to the development and implementation of survivorship care
 - Developing the business case
 - Assessing the evaluation tools used to assess these models to date
 - Proposals for further evaluation of new models
 - Identifying mechanisms for care coordination between providers
 - Care plan status and evaluation

Policy Agenda

- Assess the role and actions of stakeholder communities in continuing to address the needs of cancer survivors. Fill in identified gaps.
- Work with and educate federal, state and local government representatives about the needs of cancer survivors.
- Enlist professional societies to become active in survivorship advocacy.
- Partner with other non-profit organizations on common issues.
- Educate survivors themselves about the issues in survivorship
- Educate survivors and providers about the importance of making change in local communities.

How Can We Support Recommendation 1?

Health care providers, patient advocates and other stakeholders should work to raise awareness of the needs of cancer survivors, establish survivorship as a distinct phase of cancer care and act to ensure the delivery of appropriate survivorship care.

What can you do? Raise awareness of the needs of cancer survivors through various means

How? Use NCCS resources to continue perfecting and communicating your story

Who are the stakeholders? Health care providers, your doctors, community outreach programs and anyone who can benefit from understanding the needs of survivors

How Can We Support Recommendation 2?

Patients completing primary treatment should be provided with a comprehensive care summary and a follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) who coordinated oncology treatment. This service should be reimbursed by a third party payers of health care.

What can you do? Talk to oncology care providers and other survivors to ask/educate on need for a survivorship care plans

How? Emphasize need for third party reimbursement and Encourage other survivors to become advocates

Who are the stakeholders? Oncologists, health care clinics and local representatives

How Can We Support Recommendation 3?

Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public and private sector efforts.

What can you do? Become a patient advocate at orgs such as ASCO, join a patient advisory board and/or AACR

How? Share recommendations from the IOM report. Participate in walks to raise awareness.

Who are the stakeholders? Health care providers, other patient advocates

How Can We Support Recommendation 4?

Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.

What can you do? Become active in your cancer center's patient support program. Vocalize concerns of care discrepancies to hospital patient/guest services.

How? Offer to share your story at hospital Grand Rounds. Become a patient member of a research hospital's Institutional Review Board

Who are the stakeholders? NCI, CDC, ASCO, Healthcare systems

How Can We Support Recommendation 5?

The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care

What can you do? Vocalize concerns of care discrepancies

How? Speak with leadership of supportive care and advocate for supportive care to be available for all cancer patients from diagnosis onward

Who are the stakeholders? Cancer support organizations, associations and others in the community

Other Ideas to Support Survivorship in Your Community

- **Education**

- Educate yourself about survivorship issues to improve your advocacy efforts
- Join research review boards to help navigate research

- **Community**

- Form partnerships with others to improve survivorship care
- Attend community health fairs and participate in community education

- **Policy**

- Attend your legislator's Town Hall meeting
- Contact your legislator about the ACA and the American Health Care Act
- Email your concerns to your legislators and interact with them through social media sites such as Facebook and Twitter

Next Steps

1. Working group will coordinate all input from today, organize relevant initiatives and send out to group
2. Set up a process to record the results of your successes and roadblocks in implementing ideas
3. Check in periodically to record and document your experiences

Our goal is to create a dynamic community with a set of resources to support your ongoing efforts

Questions?