Cancer Survivorship:
Management, role of repeated follow-ups, and self-management/rehabilitation

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<td>X</td>
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Overview

• Definition of cancer “survivor” & “survivorship”
• Brief history of the movement in survivorship care since 2005
• Key principles/standards of survivorship care
• Current guidelines for survivorship care with a focus on gynecologic cancers
• Progress made in the past 5 years
• Future challenges
Who is a cancer survivor?
Any patient with a history of cancer “from the time of its discovery and for the balance of life”.

- IOM
- ASCO
- NCCN
- ESGO
- CanCon
The number of cancer survivors is expanding dramatically.
Who are female cancer survivors? (U.S.)

American Cancer Society

3 gynecologic cancers are in top 10 prevalence of survivors

70% ≥ 60 years old
European picture (CanCon 2017)

- 9.17 million in 2012
- Increasing number of survivors due to:
  - Aging population
  - Progress in early diagnosis
  - Effectiveness of therapies
- Disparities in Survival
  - Lower in Eastern countries vs Western and Nordic
Cancer Survivor’s Bill of Rights

- Assurance of lifelong medical care
- The right to the pursuit of happiness
- The right to talk with their families and friends about their cancer experience
- The right to freedom from stigma,
- The fight to equal job opportunities
- The right to adequate health insurance

Evidence suggests that these needs are not yet being adequately met

- National Coalition for Cancer Survivorship
WHAT DO WE MEAN BY SURVIVORSHIP?

“Living with, through, and beyond a cancer diagnosis.”

- National Center for Cancer Survivorship 1986
Why is Survivorship Care Important?

- 58% with functional limitations (walking ¼ mile; standing or sitting for 2 hours)

- Depression/anxiety/PTSD and their consequences
  - Poor social functioning, more disability, functional impairment, sleep problems, fatigue, pain, poor illness monitoring & management, and poor health promotion.
    - “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” IOM, 2007

- Cancer has a serious impact on income/employment..... And mortality:
  - Two years after the diagnosis, 25.1% of people living with a cancer were below the poverty threshold compared with 14.3% of the general population
  - Cancer survivors more likely to be in debt (14%) and to file for bankruptcy (3%) than the general population
  - Survivors who file for bankruptcy are almost 2x as likely die compared to non-bankrupt survivors
    - Ramsey et al., JCO 2016
MODELS OF SURVIVORSHIP CARE
Model of Care: Living With and Beyond Cancer

U.K. National Cancer Survivorship Initiative
Ovarian Cancers: Evolving Paradigms in Research and Care (NAS, 2016)
KEY PROGRESS IN SURVIVORSHIP CARE

Cancer Survivorship Care: Anticipating the long-term needs of patients with cancer by Heidi Donovan
- Initiation of tumor registries
- Development of National/multi-national research cooperatives
- Cancer, psycho-oncology, palliative care, and survivorship associations developed
Cancer Survivorship Care Planning: Anticipating the long-term needs of your patients by Heidi Donovan

- Research
- Policy
- Action Plans
From Cancer Patient to Cancer Survivor: Lost in Transition (IOM, 2006)

• How to optimize survivors’ health and maintain QOL after active treatment?
• How to anticipate long-term/late effects of treatment?
• Cancer as a chronic disease? What does that mean?
• Tension between celebration of “completing cancer care” and feelings of isolation/abandonment by trusted providers
• How to support the “Warrior without a war”? 
Key IOM Recommendations

1. Recognition of survivorship as a distinct phase of the cancer care continuum.
2. Development and dissemination of survivorship care plans
3. Development of evidence-based guidelines for survivorship care
4. Development of Quality Measures of Survivorship Care & QA programs
5. Creation of demonstration projects to test models of care

6. Development, implementation, & evaluation of comprehensive cancer control plans that include survivorship

7. Provide education to health care providers and survivors

8. Eliminate discrimination & minimize untoward effects of cancer on employment
9. **Ensure access to affordable health insurance & reimburse for survivorship care**

10. **Increase support for survivorship research**
Key principles/standards of survivorship care

• Prevention of new and recurrent cancers
• Surveillance for recurrence; screening for 2nd cancers
• Assessment and intervention for late and long-term effects of cancer & treatment
• Coordination of Care
• Survivorship Care Plans
Special Needs: Why is a Survivorship Care Plan Necessary?

• Current method characterized by fragmented care. 

*By default: cancer survivors are high risk patients, but:*

• Too many cancer survivors are lost to follow-up.

• Primary Care Providers lack knowledge regarding guidelines for monitoring for new or recurrent cancers.

• Default is that no one is truly coordinating cancer survivorship plan of care.
Goals of Survivorship Care Planning

• Return cancer patients to as normal a life as possible
• Ensure optimal care
• Focus on patient needs
• Create standards: (What to expect; F/U care; Insurance; Fair employment practices; Hope for healthy future; Communication among HCPs)
Care Plan: Key Components
(IOM/ASCO)

Brief summary of cancer diagnosis and treatment
What is recommended for the future? Diagnostic tests? F/U? Special care
Stage; age; date; specific treatments
Late toxicity monitoring
Who is responsible for what
Psychosocial issues
Preventive behaviors and interventions necessary
The Treatment Summary: Essential Components

- Diagnosis (pathology and stage)
- Surgical procedures and dates
- Radiation treatment and dates
- Chemotherapy treatments and dates
- Endocrine therapy and dates
- Other therapies and dates
- Any complications experienced
- Relevant pathology and biomarker data
- Additional planned treatments
- Contact info for key treating physicians
Example of a Survivorship Care Plans (IOM, 2007)

| Risk of cancer recurrence and second cancer: Patient has high stage cancer with increased risk of recurrence. |
| Patient should report these signs and symptoms if persistent: Blood in stool, abdominal pain, change in bowel habits, cough that doesn’t go away, bone pain, new lumps, nausea, vomiting, loss of appetite, weight loss, fatigue |

| Recommended surveillance to detect recurrence/second cancer (specify frequency): |
| Clinical assessments: Every 3-6 months for the first three years after primary treatment, then every 6 months for years 4 and 5, and subsequently to be determined (ASCO, 2005) |

| Tests: Serum CEA every 3 months for at least 3 years after diagnosis, if the patient is a candidate for surgery or systemic therapy (ASCO, 2005); data not sufficient to recommend other tests such as CBC, LFT”s, and stool for occult blood |
| Imaging: Annual CT of the chest and abdomen for 3 years after primary therapy (for patients who are at higher risk of recurrence and who could be candidates for surgery with curative intent). |

| Other: Colonoscopy at 3 years after operative treatment; if results normal, every 5 years thereafter (ASCO, 2005); Genetic counseling for those who are high risk (colorectal cancer or polyps in a parent, sibling, or child younger than 60 or in two such relatives of any age or colorectal cancer syndromes in family) |
| This patient needs genetic testing due to young age and family history. |

| Potential late effects of treatment (e.g., cardiovascular, skeletal): Surgery: Bowel problems, such as diarrhea, fecal leakage/incontinence, constipation, bowel obstruction, hernia, pain, psychological distress |
| Chemo/Biotherapy: fatigue, peripheral neuropathy |

| Patient should report these signs and symptoms if persistent: Diarrhea, constipation, pain with urination, erectile dysfunction, painful intercourse, infertility, numbness or tingling in hands or feet |

| Recommended surveillance for late effects of treatment(s): monitor for recovery of peripheral neuropathy |

| Preventive care recommendations (e.g., osteoporosis prevention, weight management, smoking cessation, diet): This patient needs counseling about smoking cessation and weight loss. |

| Physician(s) who will monitor recurrence/second cancer, late effects, and preventive care: Dr. Adams will monitor for late effects and preventive care recommendations. Dr. Adams will monitor CEA and do endoscopy and imaging studies at prescribed intervals. |
Beyond Treatment Summaries and Medical f/u:

Financial/Social /Employment Worries

• Job loss

• Disability – loss of purpose/identity/social contact

• Obtaining insurance after cancer
  – Insurance coverage drives so many decisions

• Debt – even for the well-insured

• Guilt for the patient
Key guidelines in Survivorship Care released in the past 5 years

• Practice Guidelines
  – 2013 - National Comprehensive Cancer Network (NCCN) guidelines for survivorship care

• Policy Guidelines
  – 2017 – CanCon *European Guide on Quality Improvement in Comprehensive Cancer Control*, including:
    • CanCon WP-8: [Survivorship and rehabilitation](#)
GUIDELINES FOR SURVIVORSHIP CARE WITH A FOCUS ON THE NEEDS OF GYN CANCER SURVIVORS

(NCCN, 2017)
POST-TREATMENT SURVEILLANCE FOR RECURRENT DISEASE

Based on established guidelines for each cancer type
Cervical
- Follow up exam (with Pap)
  - Every 3-6 months for 2 years
  - Every 6-12 months for 3-5 years
- Imaging and labs as needed based on symptoms or exam
- Patient education re:
  - Symptoms of recurrence
  - Health promotion behaviors
  - Sexual health (e.g. dilators)
  - Potential long-term and late effects

Ovarian
- Follow up exam (with pelvic exam and Ca-125)
  - Every 2-4 months for 2 years
  - Every 3-6 months for 3 years
  - Annually after 5 years
- Imaging and labs as needed based on symptoms or exam
- Refer for genetic risk evaluation if not already done
- Patient education re: long-term wellness care
Screening for 2nd cancers

• Based on screening guidelines for cancer prevention in general population
  » e.g. U.S. Preventive Services Task Force guidelines https://www.uspreventiveservicestaskforce.org/

• Special guidelines for those with known germline mutations (e.g. BRCA; Lynch syndrome)
Assessment at regular intervals

• Ensure Care Coordination
• Weight & Health Behaviors
• Reversible or contributing causes of symptoms
  – Current disease status
  – Functional/performance status
  – Medications
  – Comorbidities
  – Prior cancer treatments
  – Family history
  – Psychosocial factors
MANAGEMENT OF LATE & LONG-TERM PSYCHOSOCIAL AND PHYSICAL PROBLEMS

Focus on those most salient to Gynecologic Cancers
Anxiety, Depression & Distress

- Routine Screening at regular intervals
  - In the past 2 weeks on more days than not, have you:
    - Had worries or fears related to your cancer?
    - Felt worried or nervous about other things?
    - Had less enjoyment or interest in activities than usual?
    - Felt sad or depressed?
    - Had difficulty performing daily activities because of these feelings?
    - Had trouble sleeping?
    - Had difficulty concentrating?
- Further evaluation and referral for PTSD/Safety if indicated
Anxiety, Depression Distress

- Non-pharmacologic interventions for all survivors:
  - Address treatable contributing factors
    - Sleep, pain, fatigue, comorbidities, substance use
  - Provide reassurance that these feelings are common and can be treated
  - Support and education to survivor and family regarding normal recovery phases after treatment, common worries/stressors and strategies for coping
  - Provide resources for social support networks and specific social, emotional, spiritual, intimacy resources
  - Develop a plan for regular physical activity and health nutrition
Pharmacologic Interventions

- Selective Serotonin Reuptake Inhibitors (SSRI’s)
- Serotonin Norepinephrine Reuptake Inhibitors (SNRI’s) (if also have pain and/or hot flashes)
- Monitor for side-effects
- Patient education:
  - 2-6 weeks time to take effect
  - Potential for withdrawal if stop suddenly
- Referral to mental health provider if no response to initial treatment
Cognitive Function

COGNITIVE FUNCTION ASSESSMENT

Focused history:
- Focal neurologic deficits
- High risk or known metastatic disease/brain primary
- Onset, temporality
- Age (a risk factor for developing cognitive deficiency)
- Trajectory over time
- Cancer treatment history
- Prescription medications/OTC medications and supplements
- Education attainment
- Caregiver assessment of cognitive function
- Nature of impairments per patient; clarifying questions may include:
  - Do you have difficulty paying attention? Multitasking?
  - Do you frequently leave tasks incomplete?
  - Do you have difficulty finding words?
  - Do you have difficulty remembering things?
  - Do you need to use more prompts like notes or reminders than you used to?
  - Does it take you longer to think through problems; does your thinking seem slower?
  - Do you notice an impact on functional performance? Job performance?
- Assessment of medical history that may impact cognitive function

Assessment of contributing factors:
- Medications/side effects
- Emotional distress
  - Depression/anxiety (See SANXDE-1 and NCCN Guidelines for Distress Management)
- Symptom burden
  - Pain (See SPAIN-1)
  - Fatigue (See SFAT-1)
  - Sleep disturbance (See SSD-1)
- Comorbidities
- Use of alcohol and other agents that alter cognition

SPECIALIZED EVALUATION

Neuroimaging

See Cancer-associated Cognitive Dysfunction Interventions (SCF-3)
Cognitive Function Interventions

- Patient/Family Education: validation, reassurance that it is not generally progressive, self-management strategies

- General strategies:
  - Organizational strategies
  - Timing of high-demand tasks with high energy times
  - Relaxation and stress management; yoga; meditation
  - Physical activity
  - Limit use of alcohol
  - Good management of pain, fatigue, sleep, depression, comorbidities
Cognitive Function Interventions

- Neuropsychiatric evaluation
- Cognitive Rehabilitation:
  - Occupational Therapy
  - Speech Therapy
  - Neuropsychology
- Physical Activity Program
- Consider psychostimulants
Fatigue

- Routine screening on a 0-10 scale
- Full evaluation for those with moderate to severe fatigue (>4).
  - Goal is to identify treatable, contributing factors:
    - Medication side effects, pain, emotional distress, anemia, sleep problems, nutritional problems, comorbidities
Fatigue Interventions for survivors

- Patient/Family education re:
  - Monitoring of fatigue
  - Energy Conservation:
    - The 4 P’s: Planning, Prioritizing, Pacing, Positioning
  - Physical Activity
  - Others:
    - Psychosocial interventions (CBT, expression)
    - Nutrition
    - CBT for sleep
    - Accupuncture
  - Consider psychostimulants after failure of all others
Menopause-related symptoms

- Screening for
  - signs and symptoms of menopause
  - related health risks (osteoporosis, cardiovascular disease)
Treatment of menopausal symptoms

Vasomotor symptoms (ie, hot flashes/night sweats) disruptive to quality of life in females

- Non-hormonal pharmacologic treatments
  - Categories include low-dose antidepressants, anti-convulsants, neuropathic pain relievers, and certain anti-hypertensives
- Non-pharmacologic treatments
  - Acupuncture
  - Exercise/physical activity (See SPA-1)
  - Lifestyle modifications (See HL-1)
  - Weight loss if overweight or obese (See SNWM-1)
  - Integrative therapies including cognitive behavioral therapy (CBT), yoga, and hypnosis

Vaginal dryness

- Non-hormonal treatments
  - Vaginal moisturizers, vaginal gels, oils, topical vitamin D or E (category 2B)
  - Lubricants for sexual activity
- Local estrogen treatment (rings, suppositories, creams) (category 2B)
  - Limited data in breast cancer survivors suggest minimal systemic absorption with rings and suppositories. Therefore, if estrogen based treatment is warranted, rings and suppositories are preferred over creams for survivors of hormonally sensitive tumors.
- Other topical prescriptions (ie, testosterone)
- Consider referral to appropriate specialist for management
Sexual Function

• Screening

BRIEF SEXUAL SYMPTOM CHECKLIST FOR WOMEN

Please answer the following questions about your overall sexual function:
1. Are you satisfied with your sexual function?
   __ Yes  __ No
   If no, please continue.

2. How long have you been dissatisfied with your sexual function?

3a. The problem(s) with your sexual function is:
   (mark one or more)
   __ 1 Problem with little or no interest in sex
   __ 2 Problem with decreased genital sensation (feeling)
   __ 3 Problem with decreased vaginal lubrication (dryness)
   __ 4 Problem reaching orgasm
   __ 5 Problem with pain during sex
   __ 6 Other:

3b. Which problem is most bothersome? (circle)
   1 2 3 4 5 6

4. Would you like to talk about it with your doctor?
   __ Yes  __ No
Treatment of Sexual Problems

**SYMPTOMS**

- Symptoms of menopause (See SMP-1), vaginal dryness, or other issues related to vaginal health (eg, discomfort, discharge, pain)
- Global symptoms of distress, anxiety, depression, or other psychological concerns
- Symptoms of pain with sexual activity
- Problems with orgasm (eg, less intensity, difficulty achieving)
- Low or lack of desire, libido, or intimacy
- Multiple issues identified

**TREATMENT OPTIONS**

- See SMP-5
- Anxiolytics
- Antidepressants
- Integrative therapies (eg, yoga, meditation)
- Topical vaginal therapies (See SMP-5) (OTC or prescription)
- Vaginal dilators
- Ospemifene
- Prasterone
- Pelvic physical therapy
- Topical anesthetics (OTC or prescription)
- Discussion of options including vibrator or clitoral stimulatory device with referral to appropriate specialist
- Pelvic physical therapy
- Discussion of available drugs (ie, androgens, bupropion, buspirone, flibanserin)

**FOLLOW-UP**

- Concerns regarding sexual function improved or resolved
- Re-evaluate at regular intervals
- Ongoing concerns regarding sexual function
- Refer to appropriate health care provider for further evaluation, workup, and/or treatment:
  - Primary care
  - Gynecology
  - Psychology (may include couples counseling)
  - Sexual health specialist
PREVENTIVE HEALTH

General principles:

• Achieve and maintain a healthy lifestyle: Physical activity, diet, weight
• Health Lifestyles
  • Increase health & QOL
• May reduce the risk of recurrence and death
Counseling and Support for Health Promotion

- Attain normal BMI
- Develop regular physical activity
- Maintain a healthy diet
- Minimize Alcohol
- Avoid Tobacco
- Sun Safety
- Regular visits to PCP for preventive screenings and immunization
  - Annual flu shot
  - Pneumococcal vaccin
  - Tetanus (TD/TDAP)
  - HPV for those ≤26 y.o.
  - Shingles (zoster) for survivors >60 who are not immunocompromised
LOOKING FORWARD
Overarching Needs Going Forward

- Disparities
- Education to all
- Symptom care plans as a tool; not an end in itself
- Coordinate care
- Risk stratified approach
European perspective: CanCon’s 2017 GuideSurvivorship & Rehabilitation (Ch. 7)

Main messages/challenges going forward:

1. Survivorship needs must be anticipated, personalized and implemented into care pathways, with active participation of survivors and relatives.

2. Requires improvement of:
   1. early detection of patients’ needs
   2. survivor access to rehabilitation, psychosocial and palliative care services is required
   3. integrated and multiprofessional care approach with a coordination of community care providers and services to implement a survivorship care plan that enhances patient’s self-management and quality of life.
CanCon Survivorship & Rehabilitation (cont’d)

4. For children, adolescents and young adults survivors, **late health and psychosocial effects** of cancer and its treatments need to be anticipated and addressed.

5. **More research** in the area of survivorship is needed to provide data on late effects, as well as the **impact and cost-effectiveness** of supportive care, rehabilitation, palliative and psychosocial care intervention.
US Perspective on Future challenges (NCI)

- Aging populations
- Ethnic diversity
- Better tailored & coordinated care to decrease preventable morbidity and mortality
- Personalized risk analysis (e.g. omics) to ID host factors that put some individuals at greater risk and r/t specific treatments
- Implementation of best practices into a wide range of real-world settings (under-served, low resource)
• Evaluate effects of various state/country control plans; share progress among state/countries

• Need for increased focus on financial toxicity & impact of cancer on employment – especially among young survivors

• Ensure a focus on equitable access to affordable survivorship care

• Work to preserve funding stream for survivorship research

• Rowland et al; Beyond Lost in Transition, JCO 2017
# NCCN Resources for Providers

## NCCN Guidelines Version 2.2017

### Survivorship

**Survivorship Resources for Health Care Professionals and Patients**

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<thead>
<tr>
<th>General Online Information</th>
<th>URLs</th>
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<tbody>
<tr>
<td>National Coalition for Cancer Survivorship (NCCS)</td>
<td><a href="http://www.canceradvocacy.org/">www.canceradvocacy.org</a></td>
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<tr>
<td>American Association for Cancer Research (AACR)</td>
<td><a href="http://www.aacr.org/">www.aacr.org</a></td>
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<tr>
<td>• A six-part podcast series about survivorship in partnership with CR Magazine and The Wellness Community</td>
<td><a href="http://www.crrmagazine.org/archive/CrPodcasts/Pages/SurvivingThriving.aspx">www.crrmagazine.org/archive/CrPodcasts/Pages/SurvivingThriving.aspx</a></td>
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<tr>
<td>American Cancer Society (ACS)</td>
<td><a href="http://www.cancer.org/">www.cancer.org/index</a></td>
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<td>• Survivorship information</td>
<td><a href="http://www.cancer.org/treatmentsurvivorshipduringandaftertreatment/index">www.cancer.org/treatmentsurvivorshipduringandaftertreatment/index</a></td>
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<td>• Cancer Survivors Network</td>
<td><a href="http://osn.cancer.org">osn.cancer.org</a></td>
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<td>• National Cancer Survivorship Resource Center</td>
<td><a href="http://www.cancer.org/SurvivorshipCenter">www.cancer.org/SurvivorshipCenter</a></td>
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<tr>
<td>• Physical Side Effects information, including sexual function</td>
<td><a href="http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/index">www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/index</a></td>
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<tr>
<td>• Survivorship information</td>
<td><a href="http://www.aicr.org/patients-survivors/after-cancer-treatment.html">www.aicr.org/patients-survivors/after-cancer-treatment.html</a></td>
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<td>• Tools and resources for oncology providers</td>
<td><a href="http://www.cancer.org/">www.cancer.org/index</a></td>
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<td>Cancer Care: Free, professional support services for anyone affected by cancer</td>
<td><a href="http://www.cancer.org">www.cancer.org</a></td>
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<tr>
<td>LIVESTRONG</td>
<td><a href="http://www.livestrong.org">www.livestrong.org</a></td>
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<tr>
<td>• Facing Forward series, designed to educate cancer survivors, family members, and health care providers about the challenges associated with life after cancer treatment</td>
<td><a href="http://cancercontrol.nci.nih.gov/ocs/resources/ffseries.html">cancercontrol.nci.nih.gov/ocs/resources/ffseries.html</a></td>
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<td>National Comprehensive Cancer Network (NCCN)</td>
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<td>• Life After Cancer: Patient and Caregiver Resources and Information</td>
<td><a href="http://www.nccn.org/patients/resources/life_after_cancer/">www.nccn.org/patients/resources/life_after_cancer/</a></td>
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<tr>
<td>Oncology Nursing Society: Putting Evidence Into Practice</td>
<td><a href="http://www.ons.org/practice-resources/pep">www ons org practice resources pep</a></td>
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<td>American Psychosocial Oncology Society</td>
<td>1-866-276-7443</td>
<td><a href="http://www.aspos-society.org">www.aspos-society.org</a></td>
</tr>
<tr>
<td>Cancer Support Community</td>
<td>1-888-793-9355</td>
<td><a href="http://www.cancersupportcommunity.org">www.cancersupportcommunity.org</a></td>
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<tr>
<td>LIVESTRONG SurvivorCare</td>
<td>1-855-220-7777</td>
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<tr>
<td>National Cancer Institute’s Cancer Information Service</td>
<td>1-800-4-CANCER</td>
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<tr>
<td>National Suicide Prevention Lifeline</td>
<td>1-800-273-TALK</td>
<td><a href="http://suicidepreventionlifeline.org">suicidepreventionlifeline.org</a></td>
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Contact information

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