

# Provider Tools for Bridging the Gap

*A Resource Kit  
for Helping  
Newly Diagnosed  
Breast Cancer Patients©*

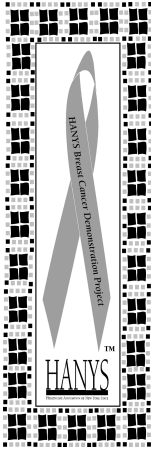
May 2003

**HANYS BREAST CANCER DEMONSTRATION PROJECT™**

Healthcare Association of New York State

One Empire Drive, Rensselaer, NY 12144

(518) 431-7600 ♦ [www.hanys.org](http://www.hanys.org)



DEAR HEALTH CARE PROVIDER:

When I cared for patients in my solo internal medicine practice, my busy work day often included times when I had to tell my next patient—the one sitting in my exam room or lying in a hospital bed—that he or she had cancer. I know about the challenges of helping survivors through those first minutes, hours, and days.

Unlike most clinicians, I also know what it is like to receive the shocking news, “You have cancer,” and to feel the fear and confusion that follow. As I have dealt with repeated courses of cancer treatment over the years, I have continued to learn about helping patients obtain sound knowledge, find and nourish hope, and act effectively. No longer able to practice medicine, I have devoted myself to helping patients by writing about survivorship.

Earlier this year, the Healthcare Association of New York State Breast Cancer Demonstration Project™ (HANYS BCDP™) asked me to consult on a project: developing a kit of materials to help health care professionals and their newly diagnosed breast cancer patients communicate. I did not hesitate because I believe that effective communication is essential to narrowing the gap between what we know of ideal cancer care and the care that patients receive.

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HANYS BCDP™ brought together a group of diverse and experienced professionals who have summarized for you some of the most useful information and resources regarding the care of newly diagnosed breast cancer patients. Many of the kit's elements are designed to help you, the health care professional, such as tip sheets on breaking bad news and helping your patients adjust. You will also find contact information for resources that allow you to pursue these topics more fully. Other components are intended for you to share with your patients, such as tip cards on adjusting to a new diagnosis. Patient resource lists can be copied, and most can be personalized for your practice. By giving these materials to your patients, you encourage them to benefit from the many excellent community and national resources for newly diagnosed patients with breast cancer. It is a tangible way to show that you care.

Your patients look to you for information, guidance, comfort, and hope. What you say and how you say it shapes the course of their survivorship. I wish I had a tool like this when I was in practice. It would have helped me fulfill my personal mission: helping others through the synergy of science and caring.

May this *Resource Kit* ease your workload, and make your visits with patients more fulfilling.

With hope,

Wendy S. Harpham, M.D.  
Author of *Diagnosis: Cancer.  
Your Guide To the First Months  
of Healthy Survivorship*  
(WW Norton and Co., third edition  
to be published June 2003)



# Provider Tools for Bridging the Gap

*A Resource Kit for Helping Newly Diagnosed Breast Cancer Patients*

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## CONTENTS

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This *Resource Kit* consists of templates that can be adapted and modified by hospitals for use, and sample resource items, publications, and media resources that may be obtained by hospitals to complement the tools within this kit. Many of the items in this Resource Kit are available for downloading at [http://www.hanys.org/quality\\_index/Breast\\_Cancer\\_Project/provgapresourcekit.htm](http://www.hanys.org/quality_index/Breast_Cancer_Project/provgapresourcekit.htm).

### **Introduction**

An overview of the *Resource Kit*.

### **HANYS BCDP™ Advisory Board Members**

### **Using the Kit**

Describes how the *Resource Kit* can be used by providers throughout your facility.

### **SECTION I: Sharing the Diagnosis**

Provides tips and strategies cards, resources, and tools to help health care providers with the multiple challenges of sharing a breast cancer diagnosis.

### **SECTION II: Supporting Initial Adjustment**

Provides tools, support resources, and samples to help health care providers support a patient's initial adjustment after hearing the news, including tips and strategies cards that providers can copy or download to give to patients.

### **SECTION III: Fostering Patient Autonomy**

Provides tips and strategies cards and tools and resources to help health care providers work collaboratively toward shared decision-making and assist patients to become informed partners.

### **SECTION IV: Guiding and Providing**

Provides tips and strategies cards and tools to help health care providers meet patients' information and support needs and help patients sort through information to access credible resources.

### **SECTION V: Overcoming Cultural Obstacles**

Provides resources and links to help health care providers overcome barriers that may be experienced by culturally diverse patients in accessing quality breast health care.

### **Bibliography**

Lists references and sources used in the development of this *Resource Kit* and related readings.

### **Order Form for Tips and Strategies Cards** (*Located in front pocket of binder*)

Use this form to order these pieces in bulk from HANYS.

#### **COLOR KEY:**

This kit is color coded to easily identify information designed to be used by providers or materials that the provider may pass on to the patient.

**ITEMS IN BLUE:** *For the Provider*    **ITEMS IN MAROON:** *For the Patient*



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## Introduction

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**B**reast cancer is the second leading cause of cancer deaths in women, claiming the lives of more than 40,000 women in the United States each year. The American Cancer Society estimates that during 2002 alone, 203,500 women in the U.S. were diagnosed with invasive breast cancer, and another 54,300 women were diagnosed with pre-invasive breast cancer. One out of every eight women is expected to develop breast cancer in her lifetime. New York State has the second highest total incidence of breast cancer in the nation.<sup>1</sup>

Researchers acknowledge the critical role of physician-patient communication for women diagnosed with breast cancer and its importance in quality of care. At the time of diagnosis, women are often emotionally overwhelmed; yet, at the same time, they face the challenges of becoming educated and informed about their disease to make decisions regarding their treatment and care.<sup>2</sup>

These challenges pose quality of life concerns for newly diagnosed patients and for their physicians who seek to meet their complex needs while struggling with time constraints. Particular challenges for physicians include addressing patients' psychological and social needs while conveying distressing information, distinguishing individual patient preferences for information and decision-making roles, and overcoming cultural obstacles affecting patients' understanding of care.<sup>3</sup> Challenges that women newly diagnosed with breast cancer face include being overwhelmed by information, lacking coping skills for being confronted with a life-threatening diagnosis, and not knowing what to ask their physician.<sup>4</sup>

Effective communication between physician and patient is imperative if breast cancer patients are to achieve their desired level of participation in care, beginning with crucial treatment decisions. Most breast cancer patients must learn to manage their illness from an outpatient care setting, whether or not they choose more active roles in decision-making. To experience quality care, they need to have effective communication skills. Patients who become empowered through effective communication with their physician have reported experiencing a sense of control over their illness and a positive adjustment to the diagnosis of breast cancer.<sup>5</sup>

The purpose of this *Resource Kit* is to:

- assist health care providers in improving communication and establishing collaborative partnerships with patients newly diagnosed with breast cancer;
- link health care providers and patients with effective resources to decrease barriers that frequently occur at the time of diagnosis; and
- support empowerment of the newly diagnosed patient in communicating with physicians and health care providers and making informed choices about care.

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<sup>1</sup> Cancer Facts and Figures, American Cancer Society, 2002.

<sup>2</sup> Roberts, C., Cox, C., Reintgen, D., Baile, W., Gibertini, M. "Influence of physician communication on newly diagnosed breast patients' psychological adjustment and decision-making," *Cancer* (1994) 74:336-41.

<sup>3</sup> Vandekieft, G. "Breaking Bad News," *American Family Physician* (2001) 64: 12:1975-1978.

<sup>4</sup> Sepucha, K., Belkora, J., Mutchnik, S., Esserman L. "Consultation Planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians," *Journal of Clinical Oncology* (2002) 20:2695-2700.

<sup>5</sup> McWilliam, C., Brown, J., Stewart, M. "Breast cancer patients' experiences of patient-doctor communication: a working relationship," *Patient Education and Counseling* (2000) 39: 2-3:191-204.

The Healthcare Association of New York State Breast Cancer Demonstration Project™ (HANYs BCDP™) developed *Provider Tools for Bridging the Gap: A Resource Kit for Helping Newly Diagnosed Breast Cancer Patients* in response to a needs survey of HANYs BCDP™ Advisory Board members and requests from members. Responses in the initial survey identified the most challenging problem areas in communication between physicians and patients as sharing prognosis, breaking bad news, and patient understanding of treatment plans. This *Resource Kit* was developed to address the identified challenge areas and is organized under these five topics:

- Sharing the Diagnosis
- Supporting Initial Adjustment
- Fostering Patient Autonomy
- Guiding and Providing
- Overcoming Cultural Obstacles

This *Resource Kit* provides a set of user-friendly tools to help health care providers and patients enhance communication after a diagnosis of breast cancer is made. It consists of templates that you may adapt and customize to meet your facility's needs, sample resource items, and publication and media resources that hospitals may use as a complement to the templates within the *Resource Kit*.

This *Resource Kit* was made possible by grants from the New York State Assembly and the federal Centers for Disease Control and Prevention (grant number U57/CCU220149-01). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the New York State Assembly or the Centers for Disease Control and Prevention.

The Healthcare Association of New York State (HANYs) represents more than 550 non-profit and public hospitals, nursing homes, home care agencies, and other health care organizations throughout New York State. Founded in 1998, HANYs BCDP™ is a partnership with 14 participating hospitals and health care systems throughout New York State that are building best practice strategies that deliver exemplary care and enhanced quality of life for breast cancer patients. The Project's goal is to assist health care providers in developing effective strategies that decrease barriers to care and increase access for patients.

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## Using the Kit

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### **Who is the *Resource Kit* for?**

All health professionals caring for individuals diagnosed with breast cancer, including:

- ✓ oncologists, surgeons, radiologists, and primary care physicians, including obstetricians and gynecologists; and
- ✓ registered nurses and social workers.

### **What you'll find in the *Resource Kit*:**

- ✓ Tools designed specifically for providers **and** tools that health care providers may share with patients, including:
  - *Tips and Strategies Cards*,
  - *Checklist Tools* (for providers),
  - *Resource Lists*,
  - *Sample Resource Materials*, and
  - *Ordering Information for Resources*.
- ✓ Links to numerous resources for improving communication.

### **To Obtain Copies of this *Resource Kit*:**

- ✓ Visit the HANYS Web Site at [www.hanys.org](http://www.hanys.org), click on “Breast Cancer Project” and then “Resource Kits” to download this kit.

#### **The *Resource Kit* can help you:**

If you:

- ✓ Want evidence-based advice on helping your newly diagnosed patients.
- ✓ Deal with patients who are overwhelmed by their diagnosis.
- ✓ Have limited time to address all your patients' emotions.

#### **This *Resource Kit* can help you:**

- ✓ Enhance your communication with your patients.
- ✓ Deal with their emotional issues in timely and effective ways.
- ✓ Guide your patients to useful resources.

#### **The *Resource Kit* can help your patients:**

If your patients:

- ✓ Feel overwhelmed by their diagnoses.
- ✓ Feel unsure of how to make decisions regarding care.
- ✓ Do not know how to find and use the best information.

#### **This *Resource Kit* can help your patients:**

- ✓ Enhance communication with health care providers.
- ✓ Deal with their emotional issues in healthy ways.
- ✓ Find useful resources.
- ✓ Understand your concern for their well-being.

## **Using the Tools:**

You may copy or download from our Web site:

- ✓ Tips and Strategies Cards
  - *for providers*
  - *that providers may give to patients*  
(*may be customized with your facility name and/or logo*)
- ✓ Resource Lists
  - *for providers*
  - *that providers may give to patients*  
(*resource lists may be customized with your facility name and/or logo*)
- ✓ Checklist Tools for Providers
  - *Customize and adapt these for your facility's use*

## **To order any of the Resource Materials included in the kit:**

- ✓ See Resource Lists (in each section) for contact information.
- ✓ Use mail-in order cards where provided.
- ✓ Access the *Resource Kit* on HANYS' Web site for online links to organizations offering resource publications or online resources.

### SECTION I: **Sharing the Diagnosis**

*Section I, Sharing the Diagnosis*, provides strategies, tips, and tools to help health care providers with the multiple challenges of sharing a breast cancer diagnosis. Specifically, it includes:

- **TIPS AND STRATEGIES CARDS FOR PROVIDERS:**

- Sharing the Diagnosis
- Breaking Bad News
- Offering Hope
- Validating Crisis

*You may copy or download these tools.*

*To order Tips and Strategies Cards in bulk, see order form in front binder pocket.*

- **TOOLS FOR PROVIDERS:**

- **Resource Materials**

List of additional resources, organizations, contact information, and continuing education offerings

*The following materials are located in the pocket at the end of this section.*

- *Pocket Guide to Communication Skills in Clinical Practice*  
**Dr. Walter Baile, Dr. Robert Buckman**
- *On Being an Oncologist Workbook and Video* (located on inside back cover of binder)  
**MD Anderson Cancer Center, Dr. Walter Baile, Dr. Robert Buckman**
- Order information for *Communication Skills in Cancer Care*  
CD-ROM or Video Set  
**MD Anderson Cancer Center, Dr. Walter Baile, Dr. Robert Buckman**  
(If you place an order for any of the materials listed on this order form, you will receive a 20% discount when you mention you obtained the ordering information from the Healthcare Association of New York State.)

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For resources that may benefit patients,  
please see Section II: Supporting Initial Adjustment.



## Sample Tips and Strategies Cards For Providers

### SHARING THE DIAGNOSIS

#### For Health Care Providers

##### **Patient Issues**

Receiving a breast cancer diagnosis is an event that a patient will never forget. Patients often report remembering details about the setting, tone, and words used by health care providers.

##### **Setting the Stage**

As a health care provider, you can help prepare your patient for hearing the diagnosis by:

- ✓ ensuring privacy and quiet;
- ✓ seeking uninterrupted time;
- ✓ sitting near the patient and making eye contact;
- ✓ involving significant others;
- ✓ conveying warmth and caring;
- ✓ validating emotions and empathizing;
- ✓ listening for needs and concerns;
- ✓ using easy-to-understand language; and
- ✓ checking for understanding.

*Adapted from "SPIKES-A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer," by W. F. Baile, R. Buckman, R. Lenzi, G. Glober, E. A. Beale, and A. P. Kudelka, The Oncologist (2000) (5) 302-311.*

### BREAKING BAD NEWS

#### For Health Care Providers

##### **Patient Issues**

Patients have highly individual preferences, perceptions, coping skills, and needs for information.

Steps that you, as a health care provider, can take to help your patient cope with hearing the diagnosis include:

##### **Gather Information**

- ✓ Determine how much your patient knows and wants to know.

##### **Provide Information**

- ✓ Provide information in small amounts.
- ✓ Adjust pace of conversation to patient's preference and needs.
- ✓ Use simple terms and explanations; clarify and reinforce.

##### **Provide Support**

- ✓ Offer support for initial adjustment.

##### **Develop Plan Collaboratively**

- ✓ Encourage shared decision-making.

*Adapted from "SPIKES-A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer," by W. F. Baile, R. Buckman, R. Lenzi, G. Glober, E. A. Beale, and A. P. Kudelka, The Oncologist (2000) (5) 302-311.*

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Sample Tips and Strategies Cards For Providers

### OFFERING HOPE

*For Health Care Providers*

#### **Patient Issues**

Your patient's sense of hope is affected by her perception of the message you communicate during the initial consultation.

Hope helps many patients cope and move forward. As a health care provider, you can help your patient avoid feelings of hopelessness.

#### **Provide message of hope while delivering news of diagnosis:**

- ✓ Frame message in terms of positive aspects.
- ✓ Focus on positive, achievable goals.
- ✓ Use consistent approach in communicating.

#### **Enable sense of control:**

- ✓ Help patients recognize factors over which they have control.

#### **Offer support and resources that foster hopefulness:**

- ✓ Initiate early emotional support referrals as desired by the patient.
- ✓ Provide support resources.

### VALIDATING CRISIS

*For Health Care Providers*

#### **Patient Issues**

It is hard for patients to hear or process information after hearing the diagnosis. Patients may feel confused, overwhelmed, or in shock.

As a health care provider, you can use the following steps to enhance communication with your patient regarding the diagnosis.

#### **Acknowledge Crisis:**

- ✓ Normalize your patient's feelings.

#### **Address Support Needs:**

- ✓ Encourage your patient to bring a family member or friend for support.
- ✓ Elicit your patient's biggest concerns.
- ✓ Initiate referrals as desired by your patient.

#### **Provide for Information Needs:**

- ✓ Provide starting point resources.
- ✓ Welcome questions that arise later.
- ✓ Consider scheduling a second visit to review the information and options so the patient has time to adjust to the diagnosis and process information.

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Tools For Providers

### Resource Materials

### Features

#### POCKET GUIDES

*The Pocket Guide to Communication Skills in Clinical Practice*

Dr. W. Baile, Dr. R. Buckman

Communication strategies:

- “SPIKES” protocol for breaking bad news
- “CLASS” protocol for medical interviews

**How to Obtain:** Medical Audio-Visual Communications, Call (800) 757-4868.

**American Academy on Physician and Patient**

*Tri-fold Card*

Communication strategies:

- relationship building
- information gathering
- patient education

**How to Obtain:** Call (703) 556-9222.

#### AUDIO-VISUAL RESOURCES

**University of Texas MD Anderson Cancer Center\***  
*Practical Guide to Communication Skills in Cancer Care*

*CD-ROM or video set*

Dr. W. Baile, Dr. R. Buckman

*Comprehensive course in communication skills relating to care of cancer patient. Demonstrates use of strategies and protocols within medical consultations. Offers menu of topic choices and multiple ways for providers to utilize resource.*

**How to Obtain:** Medical Audio-Visual Communications, Call (800) 757-4868.

**University of Texas MD Anderson Cancer Center\***  
*On Being An Oncologist*

*Video and workbook*

Dr. W. Baile, Dr. R. Buckman

*Dialogue on challenge issues identified by focus groups with oncologists. Includes eight focus group topics, “SPIKES” protocol, and annotated bibliography.*

**How to Obtain:** Medical Audio-Visual Communications, Call (800) 757-4868.

**American Society of Clinical Oncology (ASCO®)\***

*Doctor-Patient Communication: Confronting our Assumptions*

*CD-ROM or video*

*Program recorded live at 2002 ASCO Annual Meeting addresses need for communication skills training. Includes role-playing, implications for practice, practical tips, and patient experiences.*

**How to Obtain:** Call the Education, Science and Publications Department at (703) 797-1910 or order online at [www.asco.org](http://www.asco.org).

\* Continuing Medical Education credits available from these organizations.

*continued...*

## Tools For Providers (cont.)

### Resource Materials

### Features

#### EDUCATION MODULES

##### **The Education for Physicians on End-of-Life Care (EPEC) Project\***

Northwestern University  
School of Medicine

One of 12 program modules:  
*Communicating Bad News*

*Communicating Bad News* may be used for grand rounds, seminars, or workshops. Participant handbook is downloadable from Web.

**How to Obtain:** Call (877) 524-3732. May download module from Web site at [www.epec.net](http://www.epec.net).

##### **How to Give Bad News Lecture Kit** Includes materials by Dr. R. Buckman

*Instructor kit includes How to Break Bad News video, book, PowerPoint® presentation, and notes.*

**How to Obtain:** Available online at [www.patientcommunications.com/PtCmBadN.htm](http://www.patientcommunications.com/PtCmBadN.htm).

#### ONLINE RESOURCES

##### **Patient Communications Internet Links and Resources**

*Provides links to multiple online sites with resources for health care providers.*

**How to Obtain:** Available online at [www.eperc.mcw.edu/educate/flash/fastfact/98.htm](http://www.eperc.mcw.edu/educate/flash/fastfact/98.htm).

##### **End of Life Palliative Education Resource Center (EPEC)**

*Fast Fact and Concept Sheets:  
Delivering Bad News Part I and II*

*Downloadable fast fact sheets designed for educational purposes. Topic index includes several for communication issues.*

**How to Obtain:** Available online at [www.patientcommunications.com/PtCmBadN.htm](http://www.patientcommunications.com/PtCmBadN.htm).

\* Continuing Medical Education credits available from these organizations.

## Tools For Providers (cont.)

### RELATED ORGANIZATIONS

### ABOUT THE ORGANIZATION

#### **American Academy on Physician and Patient\***

*Society dedicated to research, education, and professional standards in patient-doctor communication. The Academy conducts communication courses, workshops, and forums, offers publications, maintains a Web site as a resource for providers interested in research and educational communication information. Featured on its Web site are monthly vignettes written by health care providers presenting communication dilemmas and suggested responses for enhancing communication with patients.*

**Contact Information:** 6728 Olde McLean Village Drive, McLean, VA 22101-3906; [www.physicianpatient.org](http://www.physicianpatient.org);  
Telephone: (703) 556-9222; Fax: (703) 556-8729; E-mail: [AAPPatient@degnon.org](mailto:AAPPatient@degnon.org)

#### **Bayer Institute for Health Care Communication, Inc.\***

*Institute dedicated to enhancing the quality of health care by improving the communication between providers and patients through education, research, and advocacy. The Institute offers communication workshops and training programs for clinicians, and a research-based coaching kit for patients. Its Web site features several annotated bibliographies on research in communication.*

**Contact Information:** 400 Morgan Lane, West Haven, CT 06516; [www.bayerinstitute.com](http://www.bayerinstitute.com);  
Telephone: (800) 800-5907; Fax: (203) 812-5951; E-mail: [bayer.institute@bayer.com](mailto:bayer.institute@bayer.com)

#### **End of Life Palliative Education Resource Center (EPERC)**

*Offers training materials, publications, and conferences.*

*Supported by Robert  
Wood Johnson Foundation  
located at Medical College  
of Wisconsin*

**Contact Information:** Call: (414) 456-4353; [www.eperc.mcw.edu](http://www.eperc.mcw.edu).

\* Continuing Medical Education credits available from these organizations.



## **SECTION II: Supporting Initial Adjustment**

*Section II, Supporting Initial Adjustment*, provides tools, support resources, and samples to help health care providers support a patient's initial adjustment after hearing the news, including tips and strategies cards that providers can copy or download to give to patients.

### ● **TIPS AND STRATEGIES CARDS FOR PATIENTS**

- Coping with Diagnosis
- Finding Hope  
Includes contact information for accessing resources

*You may copy or download and customize these materials with your logo.*

*To order Tips and Strategies Cards in bulk, see order form in front binder pocket.*

### ● **RESOURCES FOR PATIENTS:**

- Resources for Patients  
List of resources/contact information to obtain supplies

*You may copy or download and customize these materials with your logo to give to patients.*

*The following materials are located in the pocket at the beginning of this section.*

- National Coalition for Cancer Survivorship *Cancer Survival Toolbox® and Order Card*
- National Alliance of Breast Cancer Organizations: *NABCO Breast Cancer Resource Cards<sup>SM</sup>* (English and Spanish)
- New York State Department of Health Booklet: *A Woman's Guide to Breast Cancer Diagnosis and Treatment*
- American Cancer Society Booklet: *After Diagnosis: A Guide for Patients and Families*
- Order information for Woman-to-Woman Video: *Initial Discovery and Diagnosis of Breast Cancer*

*To obtain supplies of resource items, see Resources for Patients List for contact information, or use tear-off order cards where provided.*

### ● **TOOLS FOR PROVIDERS:**

- Patient Support Services  
A template which lists the support services that may be available to help your patients (will need to be customized to your facility).
- Patient Preferences for Support  
A checklist to help keep track of patient preferences for support.
- Follow-up Tool: Information and Support  
A checklist to help track support and information given to each of your patients.

*You may copy or download these materials.*



## Sample Tips and Strategies Cards for Patients

### COPING WITH DIAGNOSIS

#### For Patients

It is hard to hear or process information after hearing the diagnosis.

- ✓ Having a family member or friend with you for support can help.
- ✓ It is normal to feel confused, helpless, or overwhelmed.
- ✓ Take time to collect yourself, gather information, and consider obtaining a second opinion before making important decisions. Ask your doctor how much time you have for making decisions.

#### Finding Support

- ✓ There are many excellent resources and support services available to help you cope after diagnosis. See the list on this card for places to start.
- ✓ Know that you are not alone.
- ✓ It is okay to ask for help and get the support you need. You can call or visit Web sites of the organizations listed on this card to get help.

### FINDING HOPE

#### For Patients

#### Nurturing Emotional Well-Being

A cancer diagnosis can challenge your sense of emotional well-being.

- ✓ Try support groups for sharing with others or talking to another cancer survivor. Reaching out and connecting with others can help.
- ✓ Talk to your doctor about mind/body/spirit approaches to encourage well-being.
- ✓ Web sites of national cancer organizations offer valuable resources. A list of some of these organizations is included.

The following is a list of organizations, toll-free help lines, and Web sites that can help.

#### RESOURCES

##### **National Coalition for Cancer Survivorship Booklet: *You Have the Right to be Hopeful***

To order, call (877) 622-7937; [www.canceradvocacy.org/online\\_store.html](http://www.canceradvocacy.org/online_store.html)

##### **National Alliance of Breast Cancer Organizations**

Link to information resources and support groups; (888) 806-2226 or [www.nabco.org](http://www.nabco.org)

##### **American Cancer Society: *After Diagnosis: A Guide for Patients and Families***

To order, call (800) 227-2345.

#### ORGANIZATIONS: Help Lines and Web Sites

**American Cancer Society:** (800) 227-2345; [www.cancer.org](http://www.cancer.org)

##### **Y-Me National Breast Cancer Organization:**

(800) 221-2141; [www.y-me.org](http://www.y-me.org)

##### **National Coalition for Cancer Survivorship:**

(877) 622-7937; [www.canceradvocacy.org](http://www.canceradvocacy.org)

**Cancer Care:** (800) 813-4673; [www.cancercare.org](http://www.cancercare.org)

##### **Susan G. Komen Breast Cancer Foundation:**

(800) 462-9273; [www.komen.org](http://www.komen.org)

##### **SHARE: Self-Help for Women with Breast or**

**Ovarian Cancer:** (866) 891-2392; [www.sharecancersupport.org](http://www.sharecancersupport.org)

##### **Adelphi University NY Statewide Breast Cancer**

**Hotline:** (800) 877-8077; [www.adelphi.edu/nysbreastcancer](http://www.adelphi.edu/nysbreastcancer)

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Resources for Patients

Resources for Patients	Features
<b>New York State Department of Health:</b> <i>A Woman's Guide to Breast Cancer Diagnosis and Treatment</i>	Guide offers information on breast biopsy, diagnosis and treatment of breast cancer; includes suggestions on coping, where to find help, and questions to ask the doctor. Available in Spanish and English.
<b>How to Obtain:</b> Available free of charge. Call (518) 474-5370 or write to: Publications, New York State Department of Health, Box 2000, Albany, NY 12220 Available online at <a href="http://www.health.state.ny.us/nysdoh/breast_cancer/home.html">www.health.state.ny.us/nysdoh/breast_cancer/home.html</a>	
<b>American Cancer Society:</b> <i>After Diagnosis: A Guide for Patients and Families</i>	Booklet offering suggestions on coping with a cancer diagnosis; includes general information on cancer, where to find help, information on treatment options, questions to ask your doctor, and more.
<b>How to Obtain:</b> Available free of charge. Call (800) 227-2345; or log on to <a href="http://www.cancer.org">www.cancer.org</a> (type the publication title into the search engine at this site).	
<b>National Alliance of Breast Cancer Organizations</b> <i>NABCO Breast Cancer Resource Card<sup>SM</sup></i>	List of major breast cancer support organizations, available in Spanish and English.
<b>How to Obtain:</b> Available free of charge. Call (888) 806-2226; or log on to <a href="http://www.nabco.org">www.nabco.org</a> .	
<b>Woman-to-Woman Video:</b> <i>Initial Discovery and Diagnosis of Breast Cancer</i>	Features breast cancer survivors sharing their experiences—the goal is to offer emotional support to newly diagnosed women and reduce their sense of isolation. Comes with resource guide, list of breast cancer organizations, and a glossary. Three additional videos in this series are available: <i>Family Support</i> , <i>Intimacy</i> , and <i>Chemotherapy</i> .
<b>How to Obtain:</b> Call (877) 859-6626; or log on to <a href="http://www.womantowomanvideos.org">www.womantowomanvideos.org</a> .	
<b>National Cancer Institute</b> <i>What You Need to Know About<sup>TM</sup> Breast Cancer</i>	Booklet offering suggestions on detection, symptoms, diagnosis, and treatment of breast cancer; includes suggestions on questions to ask the doctor and where to find help.
<b>How to Obtain:</b> Available free of charge. Call (800) 422-6237; available online at <a href="http://www.cancer.gov/cancerinfo/wyntk">www.cancer.gov/cancerinfo/wyntk</a> .	
<b>National Coalition for Cancer Survivorship</b> <i>You Have the Right to be Hopeful</i>	Fifty-eight page booklet offering tips on attaining and maintaining hopefulness after cancer diagnosis.
<b>How to Obtain:</b> Cost: \$5.00; Call (877) 622-7397; or log on to <a href="http://www.canceradvocacy.org/online_store.html">www.canceradvocacy.org/online_store.html</a> .	

*This list is provided as a starting point for resources that may be provided to support initial adjustment. It is not intended as a comprehensive listing of resources.*



## Tools for Providers

Please customize this template form per services available at your facility.

### SAMPLE: PATIENT SUPPORT SERVICES

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#### Support Service

#### Type of Service

**American Cancer Society:**  
*Reach to Recovery Volunteer*

*Links women with a trained breast cancer survivor to provide support.*

**Initiating the Referral:** Call (800) 227-2345

Or local chapter: [FILL IN THE PHONE NUMBER OF YOUR LOCAL CHAPTER HERE.]

Local chapter contact: [FILL IN THE CONTACT NAME OF YOUR LOCAL CHAPTER HERE.]

---

#### Social Work

*Professional counseling support.*

**Initiating the Referral:** Your facility contact: [FILL IN THE CONTACT NAME AT YOUR FACILITY HERE.]

Telephone: [FILL IN THE PHONE NUMBER OF YOUR FACILITY CONTACT PERSON HERE.]

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#### Pastoral Care

*Spiritual care needs.*

**Initiating the Referral:** Your facility contact: [FILL IN THE CONTACT NAME AT YOUR FACILITY HERE.]

Telephone: [FILL IN THE PHONE NUMBER OF YOUR FACILITY CONTACT PERSON HERE.]

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#### Patient Navigator

*Patient navigator programs are available at increasing numbers of hospitals. The navigator assists with a variety of patient needs associated with navigating the health care system following diagnosis, including coordinating breast health care, assisting with access to appropriate social and financial services, and providing emotional support.*

**Initiating the Referral:** Your facility contact: [FILL IN THE CONTACT NAME AT YOUR FACILITY HERE.]

Telephone: [FILL IN THE PHONE NUMBER OF YOUR FACILITY CONTACT PERSON HERE.]

**For information on patient navigator programs, log onto [www.hanys.org](http://www.hanys.org) and click on “Breast Cancer Project” and then “Resource Kits” to access the HANYS Breast Health Patient Navigator Resource Kit©.**

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#### Breast Cancer Coalition Patient Advocate

*Available at some facilities, this program provides a support person who assists women with a variety of needs associated with navigating the health care system; accessing resources, emotional support—similar to patient navigator program.*

**Initiating the Referral:** Your facility contact: [FILL IN THE CONTACT NAME AT YOUR FACILITY HERE.]

Telephone: [FILL IN THE PHONE NUMBER OF YOUR FACILITY CONTACT PERSON HERE.]

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#### Support Groups

*Various types:*

*Support groups led by cancer survivors: (1) Breast cancer support group, (2) General cancer support group*

*Support groups led by professional facilitators: (1) Breast cancer support group, (2) General cancer support group*

**Initiating the Referral: Provide information**

Meeting: [PROVIDE MEETING DATES AND TIMES HERE.]

Call American Cancer Society, (800) 227-2345 for local contact/listing.

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## Tools for Providers (cont.)

### SAMPLE: PATIENT PREFERENCES FOR SUPPORT

**Patient Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

<b>Patient would like Support Referral</b> <input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Not at this time	<b>INFORMATION GIVEN/DATE</b>	<b>REFERRAL MADE/DATE</b>
ACS Reach to Recovery Volunteer		
Social Worker		
Pastoral Care		
Patient Navigator/ Breast Cancer Coalition Patient Advocate		
Support Group		
<b>Patient would like Support Materials</b> <input type="checkbox"/> YES <input type="checkbox"/> NO <input type="checkbox"/> Not at this time		
Literature		
Tapes or CDs		
Videos		
Culture-Specific Support Materials		







## **SECTION III: Fostering Patient Autonomy**

*Section III, Fostering Patient Autonomy*, provides tips and strategies cards and resources to help health care providers work collaboratively toward shared decision-making and assist patients to become informed partners.

### **● TIPS AND STRATEGIES CARDS FOR PROVIDERS**

- Fostering Autonomy
- Promoting Collaboration
- Educating for Informed Choice
- Advocacy Support

### **● TIPS AND STRATEGIES CARDS FOR PATIENTS**

- Sharing What is Important to You
- Gathering Information  
Includes contact information for accessing resources.

*You may copy or download and customize these materials.*

*To order Tips and Strategies Cards in bulk, see order form in front binder pocket.*

### **● RESOURCES FOR PATIENTS**

- Patient Resources List  
Contact information for obtaining materials including online resources.

*You may copy or download and customize these materials with your logo to give to your patients.*

- See Section II Pocket for National Coalition for Cancer Survivorship  
*Cancer Survival Toolbox® and Order Card*



## Sample Tips and Strategies Cards For Providers

### FOSTERING PATIENT AUTONOMY

#### *For Health Care Providers*

##### **Patient Issues**

Preferences for participation in decision-making vary among patients; however, the opportunity to participate in this decision-making has been linked to patient satisfaction.

##### **Identify your patient's preferred level of participation (and comfort) in decision-making roles:**

- ✓ Support your patient in gaining access to preferred amounts of information:
  - at her preferred pace; and
  - using the patient's preferred mode of learning.
- ✓ Address impact of the diagnosis and treatment options on your patient's:
  - lifestyle;
  - work and family roles; and
  - financial situation.
- ✓ Seek your patient's agenda and respect patient choices.

### PROMOTING COLLABORATION

#### *For Health Care Providers*

##### **Patient Issues**

Some patients may need to hear it is okay to ask questions and express their concerns or needs.

As a health care provider, you can foster good communication through the following steps.

- ✓ Encourage patients to openly discuss needs and concerns.
- ✓ Encourage patient participation by:
  - asking questions,
  - taking notes, and
  - asking for clarification as needed.
- ✓ Give your patient a notepad to encourage questions and note taking.
- ✓ Foster collaboration by inviting your patient to have a two-way exchange and sharing of information.

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Sample Tips and Strategies Cards For Providers

### EDUCATING FOR INFORMED CHOICE

#### *For Health Care Providers*

##### **Patient Issues**

Patients may become overwhelmed with information and may need clarification and review.

As a health care provider, you can assist your patient by:

- ✓ encouraging your patient to inform you about what information she desires and/or needs for decision-making;
- ✓ informing your patient about all options for care and checking the patient's understanding;
- ✓ summarizing options;
- ✓ clarifying information;
- ✓ providing reinforcement literature;
- ✓ telling your patient where she can go to get more information;
- ✓ offering to review American Cancer Society/National Comprehensive Cancer Network *Breast Cancer Treatment Guidelines* with your patient, if she desires; and
- ✓ if appropriate, reviewing information about options for clinical trials.

### ADVOCACY SUPPORT

#### *For Health Care Providers*

##### **Patient Issues**

Patients may be overwhelmed after diagnosis, unable to process information, or may lack adequate support networks for managing cancer related issues.

- ✓ Encourage your patient to bring a family member or friend with them to consultations and/or treatments for support.
- ✓ Consider offering your patient, in advance of the visit, an option to tape record the consultation.
- ✓ *Patient Navigator Program*: Identify a staff person to assist your patient in navigating the health system from diagnosis through treatment and to assist with multiple needs for support.
- ✓ *Breast Cancer Coalition*: May offer a support advocate to go to visits with patient if needed.
- ✓ *ACS Reach to Recovery Program*: This program offers trained volunteers who are breast cancer survivors to support patients.

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Sample Tips and Strategies Cards for Patients

### SHARING WHAT IS IMPORTANT TO YOU

#### *For Patients*

Remember: Honest communication will help your doctor meet your needs.

- ✓ Decide how much detail you want to know about your diagnosis, prognosis, and treatment options.
- ✓ Let your doctor know how much (or how little) you want to know.
- ✓ Discuss your concerns with your doctor.
- ✓ Share information about what is important to you when making choices about your care with your doctor.
- ✓ Ask your doctor how you can communicate questions or concerns that arise between visits.
- ✓ Keep a list of questions or concerns that you can bring to talk about at your next visit.

### GATHERING INFORMATION

#### *For Patients*

Take time to collect yourself and gather information before making important decisions. **Ask** your doctor how much time you have for making decisions.

- ✓ Bring a list of questions with you that you want to ask the doctor.
- ✓ Bring a friend or family member with you to your doctor visits—someone who can help you listen, ask questions, or take notes.
- ✓ If you do not understand something, ask your doctor to explain it or to explain it in a new way.
- ✓ If you need to, ask your doctor to give you examples or to draw or show you pictures so you can understand.
- ✓ Ask your doctor where you can get more information to help answer your questions.

This card lists organizations, toll-free help lines and Web sites that can help.

#### RESOURCES

**National Coalition for Cancer Survivorship (NCCS): Cancer Survival Toolbox®**

To order, call: (877) 866-5748. Available online at [www.cancersurvivaltoolbox.org](http://www.cancersurvivaltoolbox.org). Free.

**NCCS: Teamwork: The Cancer Patient's Guide to Talking with Your Doctor**

To order, call: (877) 622-7937.

**American Cancer Society (ACS)/National Comprehensive Cancer Network:  
Breast Cancer Treatment Guidelines for Patients**

Available online at [www.cancer.org](http://www.cancer.org) (type the publication title into the search engine at this site) or call ACS at (800) 227-2345.

**ACS: What Are Some Questions I Can Ask My Doctor?**

To obtain this list, go to [www.cancer.org](http://www.cancer.org) and type "doctor" and "breast" in the search box.

**ACS: Talking with Your Doctor**

Available online: [www.cancer.org](http://www.cancer.org)

**National Cancer Institute Cancer Information Service**

(800) 422-6237 or [www.cancer.gov](http://www.cancer.gov)

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Resources for Patients

### Resources for Patients

### Features

#### SKILL BUILDING TOOLS

#### **National Coalition for Cancer Survivorship (NCCS):**

*Cancer Survival Toolbox®*

*Self-learning audio program designed to help newly diagnosed patients develop skills to cope with the challenges of cancer diagnosis.*

*Available in English on compact disc set, in Spanish on cassette tapes, and in Chinese in book form.*

**How to Obtain:** Available free of charge. Call (877) 866-5748.

Available online at [www.cancersurvivaltoolbox.org](http://www.cancersurvivaltoolbox.org).

(See order card included in kit.)

#### **NCCS:**

*Teamwork: The Cancer Patient's Guide to Talking with Your Doctor*

*Book developed by cancer survivors and health care professionals as a practical tool for patients to use in communicating with their doctor. Provides sample questions and checklists for patients.*

**How to Obtain:** First copy is free (\$2.00 fee to cover shipping and handling).

Call (877) 622-7397.

Available online at [www.canceradvocacy.org/online\\_store.html](http://www.canceradvocacy.org/online_store.html).

#### INFORMATION RESOURCES

#### **American Cancer Society (ACS)/ National Comprehensive Cancer Network (NCCN):**

*Breast Cancer Treatment Guidelines for Patients*

*Updated guidelines for treatment of breast cancer produced collaboratively by the ACS and NCCN.*

**How to Obtain:** Available free of charge. Call ACS: (800) 227-2345 or NCCN: (888) 909-6226.

Available online at [www.cancer.org](http://www.cancer.org) (type the publication title into the search engine at this site).

#### **National Cancer Institute (NCI):**

*Cancer Information Service*

*The Cancer Information Service (CIS), a national information and education network, is a free public service of NCI. It offers toll-free telephone service or live online assistance for general cancer questions or assistance in navigating the NCI Web site. The NCI Web site offers extensive resources including information on cancer treatment, clinical trials, coping, and support (English or Spanish).*

**How to Obtain:** To speak with a cancer information specialist, call: (800) 422-6237 Monday-Friday from 9 a.m. to 4:30 p.m. (EST). To contact an NCI cancer information specialist online from 9 a.m. to 10 p.m., go to [www.cancer.gov](http://www.cancer.gov). Recorded information is available by telephone 24 hours a day, seven days a week.

#### **Oncolink—University of Pennsylvania Cancer Center Resource**

*Online service provides comprehensive information on cancer. Can link to NCI's PDQ® Patient Statement for Breast Cancer and NCI's Cancer Literature.*

**How to Obtain:** Available online at [www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)

*This list of patient resources offers a selection of available resources that may be provided to help patients become partners in their care. It is not intended as a comprehensive listing of resources.*



## **SECTION IV: Guiding and Providing**

*Section IV, Guiding and Providing*, provides tips and tools to help health care providers meet patients' information and support needs and help patients sort through information to access credible resources.

- **TIPS AND STRATEGIES CARD FOR PROVIDERS:**

- Meeting Patient Information and Support Needs

- **TIPS AND STRATEGIES CARD FOR PATIENTS:**

- Finding Good Information  
Includes contact information for accessing resources

*You may copy or download and customize these materials with your logo.*

*To order Tips and Strategies Cards in bulk, see order form in front binder pocket.*

- **TOOLS FOR PROVIDERS:**

- Summary of Publication Resources  
Topic chart/contact information to obtain supplies

- **RESOURCES FOR PATIENTS:**

- National Cancer Institute: *Cancer Facts: How to Evaluate Health Information on the Internet: Questions and Answers*

*You may download or copy this NCI fact sheet to share with your patients. To download, go to the NCI Web site at [www.cancer.gov](http://www.cancer.gov), click on "Cancer Information" and then "Support Services."*

*To order resources for patients,  
see Publication Resources Chart (this section) for contact information.  
See also: Resources for Patients (located in Sections II and III).*



### MEETING PATIENT INFORMATION AND SUPPORT NEEDS

#### *For Health Care Providers*

##### **Patient Issues**

Patients often feel overwhelmed by information overload and may not know how to find useful, credible resources.

As a health care provider, you can steer your patient toward reliable sources of information.

##### **Providing Information in Stages**

- ✓ Avoid initial information overload.
- ✓ Provide starting point resources and recommend a resource list (books, publications, online resources, and tapes).
- ✓ Tailor provision of information per patient preferences and needs.
- ✓ Document information resources that are available and those that you have provided to the patient.
- ✓ During follow-up visits, inquire if patient needs clarification on any information read in the literature provided at a previous visit.

##### **Following Up on Needs Over Time**

- ✓ Assess at regular intervals if more information is needed or desired.
- ✓ Inform patients where they can access more resources as needed.

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

## Sample Tips and Strategies Cards for Patients

### FINDING GOOD INFORMATION

#### For Patients

##### Tips

- ✓ Ask your doctor for a list of recommended resources.
- ✓ Be sure to check with your doctor about the sources of information you have found.
- ✓ Look for resource publications by national cancer organizations such as the American Cancer Society, National Cancer Institute, and the National Coalition for Cancer Survivorship (most offer free publications and pamphlets). This card includes contact information.
- ✓ Web sites of national cancer organizations offer information online to read or download. Many provide additional resource lists.
- ✓ The National Cancer Institute has a “Question and Answer” fact sheet for evaluating health information sources on the Internet, available online at [www.cancer.gov](http://www.cancer.gov).

This card lists organizations, toll-free help lines, and Web sites that can help.

**National Alliance of Breast Cancer Organizations (NABCO): Link to Information Resources.**

(888) 806-2226

[www.nabco.org](http://www.nabco.org)

**National Cancer Institute (NCI): Cancer Information Service—This includes numerous publications, several available online.**

(800) 422-6237

[www.cancer.gov](http://www.cancer.gov)

**American Cancer Society (ACS): Numerous publications.**

(800) 227-2345

[www.cancer.org](http://www.cancer.org)

**NCI: How to Evaluate Health Information on the Internet: Questions and Answers**

[www.cancer.gov](http://www.cancer.gov)

Download from the NCI Web site by going to [www.cancer.gov](http://www.cancer.gov), clicking on “Cancer Information” and then “Support Services.”

**National Coalition for Cancer Survivorship: Publications and online resources.**

(877) 622-7937

[www.canceradvocacy.org](http://www.canceradvocacy.org)

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

**SUMMARY OF PUBLICATION RESOURCES**

This chart provides an overview of a sample list of credible publications and topic content. This list is provided as a starting point for information resources and is not intended as a comprehensive listing.

Publication	TOPIC									
	Cost	Medical Facts	Treatment Options	Second Opinions	Clinical Trials	Genetic Counseling	Coping with Emotional Aspects of Diagnosis	Support Groups	Insurance and Financial Issues	Practical Matters; Wigs, Equipment, Transport
<b>New York State Department of Health</b>										
<i>A Woman's Guide to Breast Cancer Diagnosis and Treatment</i>	Free of charge	*	*	*	*		*	*		*
Call (518) 474-5370 or write to: Publications, New York State Department of Health, Box 2000, Albany, NY 12220 Available online at <a href="http://www.health.state.ny.us/nysdoh/breast_cancer/home.html">www.health.state.ny.us/nysdoh/breast_cancer/home.html</a>										
<b>National Cancer Institute</b>										
<i>What You Need to Know About™ Breast Cancer</i>	10¢ ea. bulk; free online	*	*	*	*	*	*	*		*
Call (800) 422-6237; available online at <a href="http://www.cancer.gov/cancerinfo/wyntk">www.cancer.gov/cancerinfo/wyntk</a>										
<b>American Cancer Society</b>										
<i>After Diagnosis: A Guide for Patients and Families</i>	30¢ in bulk plus S/H	*	*	*	*	*	*	**		*
Call (800) 227-2345; available online at <a href="http://www.cancer.org">www.cancer.org</a> (Type the publication title into the search engine at this site.)										

**KEY**  
**[blank] = No information on the topic**    \* = Some information on the topic    \*\* = More information on the topic    \*\*\* = Most information on the topic

**SUMMARY OF PUBLICATION RESOURCES (cont.)**

Publication	TOPIC									
	Cost	Medical Facts	Treatment Options	Second Opinions	Clinical Trials	Genetic Counseling	Coping with Emotional Aspects of Diagnosis	Support Groups	Insurance and Financial Issues	Practical Matters; Wigs, Equipment, Transport
<b>National Cancer Institute</b>										
<i>Understanding Breast Cancer Treatment</i>	Free online	*	*	*	*	*	*	*		
Call (800) 422-6237; available online at <a href="http://oesi.nci.nih.gov/aboutbc/ubc_treatment.html">http://oesi.nci.nih.gov/aboutbc/ubc_treatment.html</a>										
<b>National Alliance of Breast Cancer Organizations</b>										
<i>Breast Cancer Resource List 2002/2003 Edition</i>	Available online; Call for information on bulk orders	*	*	*	*	*	*	***	*	**
Call (888) 806-2226; available online at <a href="http://www.nabco.org/index.php/7/40">www.nabco.org/index.php/7/40</a>										
<b>American Cancer Society</b>										
<i>For Women Facing Breast Cancer</i>	Free	*	*	*	*	*	*	*		
Call (800) 227-2345; available online at <a href="http://www.cancer.org">www.cancer.org</a> (Type "free brochures" into the search engine at this site.)										

**KEY**  
**[blank] = No information on the topic**    \* = Some information on the topic    \*\* = More information on the topic    \*\*\* = Most information on the topic



## Cancer Facts

(Text was downloaded directly from the National Cancer Institute Web site.)

### How To Evaluate Health Information on the Internet: Questions and Answers

The growing popularity of the Internet has made it easier and faster to find health information. However, the Internet also allows rapid and widespread distribution of false and misleading information. It is important for people to carefully consider the source of information and to discuss the information they find with their health care provider. This fact sheet can help people decide whether the health information they find on the Internet or receive via e-mail from a Web site is likely to be reliable.

#### 1. WHO RUNS THE WEB SITE?

Any Web site should make it easy for people to learn who is responsible for the site and its information. On the National Cancer Institute's (NCI) Cancer.gov Web site, for example, the NCI is clearly noted on every major page, along with a link to the site's homepage.

#### 2. WHO PAYS FOR THE WEB SITE?

It costs money to run a Web site. The source of a Web site's funding should be clearly stated or readily apparent. For example, Web addresses ending in ".gov" are Federal Government-sponsored sites, ".edu" indicates educational institutions, ".org" is often used by noncommercial organizations, and ".com" denotes commercial organizations. The source of funding can affect what content is presented, how the content is presented, and what the owners want to accomplish on the site.

#### 3. WHAT IS THE PURPOSE OF THE WEB SITE?

The purpose of the Web site is related to who runs and pays for it. Many Web sites have a link to information about the site. The link, which is often called "About This Site," should clearly state the purpose of the site and help users evaluate the trustworthiness of the information on the site.

#### KEY POINTS

- ✓ Any Web site should make it easy for people to learn who is responsible for the site and its information (see Question 1).
- ✓ If the person or organization in charge of the Web site did not write the material, the original source should be clearly identified (see Question 4).
- ✓ Health-related Web sites should give information about the medical credentials of the people who prepare or review the material on the site (see Question 6).
- ✓ Any Web site that asks users for personal information should explain exactly what the site will and will not do with that information (see Question 9).
- ✓ The Federal Trade Commission and the Food and Drug Administration are Government agencies that help protect consumers from false or misleading health claims on the Internet (see Question 12).

#### **4. WHAT IS THE ORIGINAL SOURCE OF THE INFORMATION ON THE WEB SITE?**

Many health and medical Web sites post information collected from other Web sites or sources. If the person or organization in charge of the site did not write the material, the original source should be clearly identified.

#### **5. HOW IS THE INFORMATION ON THE WEB SITE DOCUMENTED?**

In addition to identifying the original source of the material, the site should identify the evidence on which the material is based. Medical facts and figures should have references (such as citations of articles in medical journals). Also, opinions or advice should be clearly set apart from information that is “evidence-based” (that is, based on research results).

#### **6. HOW IS INFORMATION REVIEWED BEFORE IT IS POSTED ON THE WEB SITE?**

Health-related Web sites should give information about the medical credentials of the people who prepare or review the material on the Web site. For example, Cancer.gov contains cancer information summaries from the Institute’s PDQ® database. All PDQ cancer information summaries are peer-reviewed and updated regularly by six editorial boards of cancer specialists in adult treatment, pediatric (childhood) treatment, supportive care, screening and prevention, genetics, and complementary and alternative medicine. The editorial boards review current literature from more than 70 biomedical journals, evaluate its relevance, and synthesize it to write the PDQ summaries.

More information about PDQ is available in the NCI fact sheet *PDQ®: Questions and Answers*. This fact sheet can be accessed at [http://cis.nci.nih.gov/fact/2\\_2.htm](http://cis.nci.nih.gov/fact/2_2.htm) on the Internet, and can be requested by calling the Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

#### **7. HOW CURRENT IS THE INFORMATION ON THE WEB SITE?**

Web sites should be reviewed and updated on a regular basis. It is particularly important that medical information be current, and that the most recent update or review date be clearly posted. Even if the information has not changed, it is helpful to know that the site owners have reviewed it recently to ensure that the information is still valid.

#### **8. HOW DOES THE WEB SITE CHOOSE LINKS TO OTHER SITES?**

Reliable Web sites usually have a policy about how they establish links to other sites. Some medical Web sites take a conservative approach and do not link to any other sites; some link to any site that asks or pays for a link; others link only to sites that have met certain criteria.

#### **9. WHAT INFORMATION ABOUT USERS DOES THE WEB SITE COLLECT, AND WHY?**

Web sites routinely track the path users take through their sites to determine what pages are being used. However, many health-related Web sites ask the user to “subscribe” or “become a member.” In some cases, this may be done so they can collect a user fee or select relevant information for the user. In all cases, the subscription or membership will allow personal information about the user to be collected by the Web site owners.

Any Web site asking users for personal information should explain exactly what the site will and will not do with the information. Many commercial sites sell “aggregate” data about their users to other companies—information such as what percent of their users are women with breast cancer. In some cases, they may collect and reuse information that is “personally identifiable,” such as the user’s ZIP Code, gender, and birth date. Users should be certain they read and understand any privacy policy or similar language on the site, and not sign up for anything they do not fully understand.

## 10. HOW DOES THE WEB SITE MANAGE INTERACTIONS WITH USERS?

There should always be a way for users to contact the Web site owners with problems, feedback, and questions. If the site hosts a chat room or other online discussion areas, it should tell users about the terms of using the service. Is the service moderated? If so, by whom, and why? It is always a good idea to spend time reading the discussion without joining in, to feel comfortable with the environment before becoming a participant.

## 11. HOW CAN PEOPLE VERIFY THE ACCURACY OF INFORMATION THEY RECEIVE VIA E-MAIL?

Any e-mail messages should be carefully evaluated. The origin of the message and its purpose should be considered. Some companies or organizations use e-mail to advertise products or attract people to their Web sites. The accuracy of health information may be influenced by the desire to promote a product or service.

## 12. HOW DOES THE FEDERAL GOVERNMENT PROTECT CONSUMERS FROM FALSE OR MISLEADING HEALTH CLAIMS POSTED ON THE INTERNET?

The **Federal Trade Commission (FTC)** enforces consumer protection laws. As part of its mission, the FTC investigates complaints about false or misleading health claims posted on the Internet. The FTC's *Operation Cure-All* page, located at <http://www.ftc.gov/bcp/online/edcams/cureall/> on the Internet, has information to help users evaluate health product claims.

**AGENCY:** Federal Trade Commission

**ADDRESS:** Consumer Response Center  
CRC-240  
Washington, DC 20580

**TELEPHONE:** 1-877-382-4357 (1-877-FTC-HELP) (toll free)  
TTY: 202-326-2502 (for deaf and hard of hearing callers)

**WEB SITE:** <http://www.ftc.gov/>

The **Food and Drug Administration (FDA)** regulates drugs and medical devices to ensure that they are safe and effective. The FDA's *Buying Medicines and Medical Products Online* Web page is located at <http://www.fda.gov/oc/buyonline/> on the Internet. *Buying Prescription Medicines Online: A Consumer Safety Guide* is available at <http://www.fda.gov/cder/drug/consumer/buyonline/guide.htm> on the Internet.

**AGENCY:** Food and Drug Administration

**ADDRESS:** 5600 Fishers Lane  
Rockville, MD 20857-0001

**TELEPHONE:** 1-888-463-6332 (1-888-INFO-FDA) (toll free)

**WEB SITE:** <http://www.fda.gov/>

## Sources of National Cancer Institute Information

### *Cancer Information Service*

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY (for deaf and hard of hearing callers): 1-800-332-8615

### *NCI Online*

**Internet:** Use <http://cancer.gov> to reach NCI's Web site.

**LiveHelp:** Cancer Information Specialists offer online assistance through the *LiveHelp* link on the NCI's Web site.



## **SECTION V: Overcoming Cultural Obstacles**

*Section V, Overcoming Cultural Obstacles*, provides resources and links to help health care providers overcome barriers that may be experienced by culturally diverse patients in accessing quality breast health care.

- **TIPS AND STRATEGIES CARD FOR PROVIDERS**

- Overcoming Cultural Obstacles/Multicultural Resources

*You may copy or download these materials.*

- **RESOURCES FOR PATIENTS**

- See Section II Pocket for National Alliance of Breast Cancer Organizations Resource Card: Spanish

- **TOOLS FOR PROVIDERS:**

- Links to Online Multicultural Resources
- Multicultural Resources: Locating Resource Materials for Patients

*The following materials are located in the pocket at the beginning of Section II.*

- National Alliance of Breast Cancer Organizations: *NABCO Resource Card*<sup>SM</sup> (also available in Spanish)
- National Coalition for Cancer Survivorship *Cancer Survival Toolbox*<sup>®</sup> and *Order Card* (also available in Spanish and Chinese)
- New York State Department of Health Booklet: *A Women's Guide to Breast Cancer Diagnosis and Treatment* (also available in Spanish)

*To order resources for patients: See Multicultural Resource List for contact information. See also Section II: Resources for Patients for contact information, or use order cards where provided.*



## Sample Tips and Strategies Card For Providers

### OVERCOMING CULTURAL OBSTACLES

#### *For Health Care Providers*

Consider your patient's responses within the context of her cultural norms.

#### **Culturally appropriate material:**

- ✓ Provide language-appropriate materials.
- ✓ Utilize appropriate interpreter services.

#### **Culturally sensitive support services:**

- ✓ Seek an understanding of the individual's beliefs, needs, and concerns.
- ✓ Access resources on cultural beliefs and concepts and seek information on preferences from the patient and family.

#### **Major Cultural Concepts to Consider:**

1. Perception of Illness
2. Patterns of Kinship and Decision-making
3. Comfort with Touch

*Used with permission from Culture Clues™: University of Washington Medical Center*

### MULTICULTURAL RESOURCES

#### *For Health Care Providers*

#### **Culture Clues™: University of Washington Medical Center Patient and Family Education Services:**

<http://depts.washington.edu/pfes/cultureclues.html>

#### **Diversity RX Online Resource:**

Interpreter sources, services, and information  
[www.diversityrx.org](http://www.diversityrx.org)

#### **Multicultural communication resources:**

Links to online resources for providers  
[www.patientcommunications.com/PtCmMCult.htm](http://www.patientcommunications.com/PtCmMCult.htm)

#### **U.S. Office of Minority Health: A Breast Cancer Resource Guide for Minority Women:**

(800) 444-6472  
[www.omhrc.gov](http://www.omhrc.gov)

#### **National Cancer Institute Cancer Information Service:**

Fact sheets and Spanish language tools available  
[www.cancer.gov](http://www.cancer.gov)

#### **Susan G. Komen Breast Cancer Foundation Web site:**

Lists programs and materials available by population  
[www.komen.org](http://www.komen.org)

(See inside front pocket for the full series of cards, plus an order form for additional sets.)

### LINKS TO ONLINE MULTICULTURAL RESOURCES

Online Resources for Providers	Features
<b>Multicultural Communication Resources</b> <b>Online Address:</b> <a href="http://www.patientcommunications.com/PtCmMCult.htm">www.patientcommunications.com/PtCmMCult.htm</a>	<i>Web site provides links to online provider resources and interpreter information.</i>
<b>Diversity RX</b> <b>Online Address:</b> <a href="http://www.diversityrx.org">www.diversityrx.org</a>	<i>Interpreter sources, services, and information.</i>
<b>Culture Clues™: University of Washington Medical Center: Patient and Family Education Services</b> <b>Online Address:</b> <a href="http://depts.washington.edu/pfes/cultureclues.html">http://depts.washington.edu/pfes/cultureclues.html</a>	<i>Culture Clues™: Tip sheets for clinicians addressing cultural beliefs and considerations relating to health care. Sheets available online for seven specific cultures; more in progress.</i>
<b>EthnoMed Ethnic Medicine Guide, Harborview Medical Center, University of Washington</b> <b>Online Address:</b> <a href="http://healthlinks.washington.edu/clinical/ethnomed">http://healthlinks.washington.edu/clinical/ethnomed</a>	<i>Communication guidelines working with diverse populations. Offers culture-specific language profiles.</i>
<b>Multicultural Services</b>	
<b>Office of Minority Health (OMH) Resource Center:</b> <i>A Breast Cancer Resource Guide for Minority Women</i> U.S. Department of Health and Human Services <b>Online Address:</b> Free download of the resource guide available at <a href="http://www.omhrc.gov/breastcancerguide.pdf">www.omhrc.gov/breastcancerguide.pdf</a> For more information, call (800) 444-6472.	<i>Resource guide offers listings of organizations, programs, and resource materials relevant for breast cancer patients and health care professionals.</i> <i>The OMH Resource Center provides free information resources on a variety of minority health topics.</i>
<b>Cancer Awareness Network for Immigrant Minority Populations (CANIMP) Cancer Services Catalogue</b> <b>Online Address:</b> <a href="http://www.med.nyu.edu/cih/cancer/healtheducation.html">www.med.nyu.edu/cih/cancer/healtheducation.html</a>	<i>Users can search for organizations specializing in cancer related services. Listings by program name, service, location, and language capability. Information on breast cancer also available.</i>
<b>National Asian Women's Health Organization (NAWHO)</b> <b>Online Address:</b> <a href="http://www.nawho.org">www.nawho.org</a> ; (415) 989-9747	<i>Information, publications, advocacy, and outreach.</i>

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## **LINKS TO ONLINE MULTICULTURAL RESOURCES (CONT.)**

<b>Online Resources for Providers</b>	<b>Features</b>
<b>Susan G. Komen Breast Cancer Foundation The Komen Connection</b>	<i>The BreastCancerInfo.com site features information on programs, materials, and breast health resources, as well as questions and answers on breast cancer for special populations.</i>
<b>Online Address:</b> <a href="http://www.komen.org/bci/komenconnection">www.komen.org/bci/komenconnection</a>	
<b>National Cancer Institute Cancer Information Service</b>	<i>Information on Web site is available in Spanish.</i>
<b>Online Address:</b> <a href="http://www.cancer.gov">www.cancer.gov</a>	

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*This sample list of links to cultural resources is provided to assist health care providers in reducing barriers to quality care for diverse populations. It is not intended as a comprehensive listing.*

## Tools for Providers

### MULTICULTURAL RESOURCES

#### Locating Resource Materials for Patients

#### Features

**Office of Minority Health:**  
*A Breast Cancer Resource Guide for  
Minority Women*

*Lists organizations, programs, and resource materials relevant for breast cancer patients.*

**How to Obtain:** Call (800) 444-6472  
Free download available: [www.omhrc.gov/breastcancerguide.pdf](http://www.omhrc.gov/breastcancerguide.pdf)

**National Cancer Institute  
Cancer Information Service**

*Information on Web site is available in Spanish. Lists fact sheets and language tools available in Spanish.*

**How to Obtain:** Call (800) 422-6237  
Available online: [www.cancer.gov](http://www.cancer.gov)

**Susan G. Komen Breast Cancer  
Foundation  
Komen Connection**

*Can search for listings of support groups, programs, and resource materials for several population groups.*

**How to Obtain:** [www.komen.org](http://www.komen.org)

**HANYS Breast Cancer  
Demonstration Project™ Web Site**  
*Breast Cancer: Foreign Language/  
Minority Resources*

*Provides links to multiple Web sites featuring foreign language materials relevant to breast cancer.*

**How to Obtain:** Go to [www.hanys.org](http://www.hanys.org), click on “Breast Cancer Project” and select “Virtual Library” and “Resources for Health Care Professionals.”

#### RESOURCE MATERIALS

**National Coalition for Cancer  
Survivorship**  
*Cancer Survival Toolbox®*

*Self-learning audio program designed to help newly diagnosed patients develop skills to help cope with the challenges of cancer diagnosis. Available in Spanish language on audio cassettes. Chinese language available in book form only.*

**How to Obtain:** Call: (877) 866-5748  
Can listen or read online in Spanish or Chinese at [www.cancersurvivaltoolbox.org](http://www.cancersurvivaltoolbox.org)

CONTINUED...

### MULTICULTURAL RESOURCES (CONT.)

#### Locating Resource Materials for Patients

#### Features

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##### **NCI Office of Education and Special Initiatives and Office of Cancer Survivorship**

*New publication: Resource book for Latino survivors, families, and health care professionals: an adaptation of Life After Cancer Treatment. Offers scientific information from health professionals, communication strategies, and coping tips from cancer survivors.*

**How to Obtain:** Book is available on the Web at [www.cancer.gov/espanol/vida-despues-del-tratamiento](http://www.cancer.gov/espanol/vida-despues-del-tratamiento)  
To order free copies of *Siga adelante: la vida después del tratamiento del cáncer*, call (800) 422-6237.

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##### **Chinese Vocabulary List**

*English/Chinese Breast Cancer Vocabulary List*

**How to Obtain:** Available online at [www2.wgbh.org/MBCWEIS/LTC/QSCC/chinlist.htm](http://www2.wgbh.org/MBCWEIS/LTC/QSCC/chinlist.htm)

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#### HELPLINES OR WEB SITES

##### **Susan G. Komen Breast Cancer Foundation National Breast Care Helpline**

*Toll-free Spanish*

**How to Obtain:** Call (800) 462-9273

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##### **Y-Me National Breast Cancer Organization Hotline**

*Toll-free Spanish*

**How to Obtain:** Call (800) 986-9505; Web site also in Spanish at [www.y-me.org/espanol](http://www.y-me.org/espanol)

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##### **Share Self-Help for Women with Breast Cancer**

*Spanish*

**How to Obtain:** Call (212) 719-4454

“LatinaSHARE” section on Web site available at [www.sharecancersupport.org](http://www.sharecancersupport.org)

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*This sample list of links to cultural resources is provided to assist health care providers in reducing barriers to quality care for diverse populations. It is not intended as a comprehensive listing.*

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