Survivorship Guide for Virginians

Virginia Breast Cancer Foundation

vbcf.org
You are about to close the “breast cancer treatment” chapter of your life...so now what? How do you shift from being someone in active treatment to a survivor? How can you enjoy being healthy now without the fear of recurrence interfering with your new lease on life? While we can’t answer those questions for you, we can help you find resources that can help you find those answers for yourself. We hope you find the resources included in this packet to be helpful.
WHAT CAN I DO FOR MY HEALTH?

Physically

The most important thing you can do for your health after breast cancer treatment is to follow up with your doctor as recommended. If you haven’t discussed a post-treatment plan with your doctor, it is important to do that so you can both be on the same page about expectations you each have of each other during this new phase. Secondly, do what you can to take care of your physical health yourself. There is some research out there that indicates that excessive consumption of alcohol, trans fats, and sugar could influence the development of breast cancer, so you may choose to moderate or eliminate these foods from your diet. Obesity, particularly post-menopause, influences the development of breast cancer, so do what you can to be at a healthy weight. Physical activity has benefits to preventing the development of breast cancer outside of reducing obesity, so get moving! Before you embark on any new exercise routine or major dietary change, be sure to consult your doctor.

Mentally/Emotionally

The physical after effects of cancer treatment aren’t the only things that linger. One thing we have heard expressed often is that there is a pervasive fear among most survivors of a cancer recurrence. Issues with body image and the loss of the constant support from doctors, family, and friends once treatment ends are also serious emotional issues that breast cancer survivors must deal with. Everyone experiences the emotions that come with survivorship in different ways, but if you are struggling with some of these issues or others, VBCF would like to help you where we can.
HOW CAN I STAY CONNECTED TO OTHER SURVIVORS?

If you want to be connected to the survivor community after you are finished your treatment, there are a number of different options. VBCF has committees that you can join consisting of members from across the state which help VBCF to educate and advocate for people in Virginia. Sisters Network, a national survivor network for African American breast cancer survivors, has multiple chapters in Virginia. Your local hospital may also have a survivorship care program.

HOW CAN I CONTINUE TO FIGHT AGAINST BREAST CANCER?

Breast cancer is more than a pink ribbon. It is a life-changing experience that can leave some people with the desire to take action to improve the lives of patients and survivors, or even to fight for the eradication of breast cancer. VBCF is also passionate about advocacy, and we lead both a state and national advocacy day every year. VBCF was founded in 1991 by five women who wanted to make a difference in the lives of people with breast cancer in Virginia, so never underestimate what a few voices can accomplish. There are also national organizations that are committed to advocacy in the breast cancer world. Breast Cancer Action, which is behind the Think Before You Pink movement, is working to help consumers become more educated about buying “pink” products and aims to tackle breast cancer on a more systemic rather than individual level. Susan G. Komen has opportunities to either become a legislative advocate or a scientific advocate, and the National Breast Cancer Coalition has multiple avenues for advocacy as well, including their Project LEAD scientific education course.
SURVIVORSHIP CARE PLANS

WHAT IS A SURVIVORSHIP CARE PLAN?

Survivorship care plans are meant to help organize your treatment history as well as your follow up care. It may include information on your history with cancer as well as information such as future appointments, recommendations for health, and information on managing long-term effects. Often, your doctor will create and go over this plan with you. However, if they do not, you can find different care plan options online and bring them in to discuss with your doctor.

Studies have found that breast cancer survivors rate high satisfaction with the use of survivorship care packets and find them to make communication with their doctors easier. Survivors using these plans also report greater treatment knowledge and awareness of symptoms, demonstrating that there are several benefits to using such a plan. However, it is up to you to decide whether a care plan could be helpful to you. Talk to your doctor about how a survivorship plan may work for you.

TALKING TO YOUR DOCTOR ABOUT A SURVIVORSHIP CARE PLAN

Once cancer treatment is finished it may be time to talk to your doctor about a plan. You can start by asking your doctor about his or her knowledge of and experience with survivorship care plans. It may also be a good idea to express what you hope to get from such a plan and to have questions or a care template prepared to use as a guide. Several templates are available for free online along with guides on what to include if you decide to create one yourself. We have provided a survivorship care plan on the next pages.
This Survivorship Care Plan is a cancer treatment summary and follow-up plan and is provided to you to keep with your health care records and to share with your primary care provider or any of your doctors and nurses. This summary is a brief record of major aspects of your cancer treatment not a detailed or comprehensive record of your care. You should review this with your cancer provider.

### General Information

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>Patient DOB:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient phone:</td>
<td>Email:</td>
</tr>
</tbody>
</table>

### Health Care Providers (Including Names, Institution)

- **Primary Care Provider:**
- **Surgeon:**
- **Radiation Oncologist:**
- **Medical Oncologist:**
- **Other Providers:**

### Treatment Summary

#### Diagnosis

- **Cancer Type/Histology Subtype:** Left/Right/Both Breast Cancer
- **Receptors:**
  - [ ] Estrogen positive;
  - [ ] Progesterone Positive;
  - [ ] HER2 positive
- **Stage:**
  - [ ] I
  - [ ] II
  - [ ] III
  - [ ] Not applicable

#### Treatment Completed

- **Surgery:**
  - [ ] Yes
  - [ ] No
- **Surgery Date(s) (year):**

- **Lymph node removal:**
  - [ ] Axillary Dissection
  - [ ] Sentinel Biopsy
- **Radiation:**
  - [ ] Yes
  - [ ] No
- **Body area treated:**
- **End Date (year):**

- **Systemic Therapy (chemotherapy, hormonal therapy, other):**
  - [ ] Yes
  - [ ] No
  - [ ] Before surgery
  - [ ] After surgery

#### Names of Agents Used

<table>
<thead>
<tr>
<th>Name of Agent</th>
<th>End Dates (year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 5-Fluorouracil</td>
<td></td>
</tr>
<tr>
<td>☐ Carboplatin</td>
<td></td>
</tr>
<tr>
<td>☐ Cyclophosphamide</td>
<td></td>
</tr>
<tr>
<td>☐ Docetaxel</td>
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<tr>
<td>☐ Doxorubicin</td>
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<tr>
<td>☐ Epirubicin</td>
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<tr>
<td>☐ Methotrexate</td>
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<tr>
<td>☐ Paclitaxel</td>
<td></td>
</tr>
<tr>
<td>☐ Pertuzumab</td>
<td></td>
</tr>
<tr>
<td>☐ Trastuzumab</td>
<td></td>
</tr>
<tr>
<td>☐ Other</td>
<td></td>
</tr>
</tbody>
</table>

#### Treatment Ongoing

<table>
<thead>
<tr>
<th>Additional treatment name</th>
<th>Planned duration</th>
<th>Possible Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Tamoxifen</td>
<td></td>
<td>Hot flashes and vaginal discharge (common); endometrial cancer, serious blood clots and eye problems (all very rare). Other rare side effects may occur.</td>
</tr>
</tbody>
</table>
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| □ Aromatase Inhibitors (anastrozole, exemestane and letrozole) | Hot flashes, joint/muscle aches, vaginal dryness and bone loss (common); hair thinning (rare) Other rare side effects may occur. |
| □ GnRH agonist (Zoladex, Lupron) for ovarian suppression | Hot flashes and vaginal dryness (common); other rare side effects may occur. |

Other:

Persistent symptoms or side effects at completion of treatment:

- Fatigue: □ No □ Yes
- Numbness: □ No □ Yes
- Psychosocial/Depression: □ No □ Yes
- Menopausal symptoms: □ No □ Yes
- Pain: □ No □ Yes
- Other rare side effects may occur.

Other (enter type(s)):

Familial Cancer Risk Assessment

Breast and or ovarian cancer in 1st or 2nd degree relatives: □ Yes □ No

Received Genetic counseling: □ Yes □ No
Genetic testing: □ Yes □ No
Genetic testing results:

Follow-up Care Plan

Your follow-up care plan is design to inform you and primary care providers regarding the recommended and required follow-up, cancer screening and routine health maintenance that is needed to maintain optimal health.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Weakening of the heart presenting as shortness of breath and swelling of legs (rare < 5%); and bones become weak and at risk for fracture (osteoporosis). It is important to remember that these symptoms can be due to other causes like diabetes or with normal aging. If these or any other new symptoms occur bring these to attention of your health care provider.

These symptoms should be brought to the attention of your provider:

1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Please continue to see your primary care provider for all general health care recommended for a woman your age such as routine immunizations, and routine non-breast cancer screening like colonoscopy or bone density exams. Consult with your health care provider about prevention and screening for bone loss using bone density tests.

Schedule for Clinical Visits

<table>
<thead>
<tr>
<th>Coordinating Provider</th>
<th>When/How often</th>
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Cancer Surveillance Or Other Recommended Tests

<table>
<thead>
<tr>
<th>Coordinating Provider</th>
<th>TEST</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mammogram</td>
<td>Annually</td>
</tr>
<tr>
<td></td>
<td>MRI breast</td>
<td>As indicated by provider</td>
</tr>
<tr>
<td></td>
<td>Pap/pelvic exam</td>
<td>As indicated by provider</td>
</tr>
<tr>
<td></td>
<td>Colonoscopy</td>
<td>As indicated by provider</td>
</tr>
<tr>
<td></td>
<td>Bone Density</td>
<td>Every 2 years if on an aromatase inhibitor or as indicated by your provider</td>
</tr>
</tbody>
</table>

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Breast cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

- Anxiety or depression
- Emotional and mental health
- Fatigue
- Fertility
- Financial advice or assistance
- Insurance
- Memory or concentration loss
- Parenting
- Physical functioning
- School/work
- Sexual Functioning
- Stopping Smoking
- Weight changes
- Other

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

- Alcohol use
- Diet
- Management of my medications
- Management of my other illnesses
- Physical activity
- Sun screen use
- Tobacco use/cessation
- Weight management (loss/gain)

Resources you may be interested in:

- [www.cancer.net](http://www.cancer.net)
- Other:

Other comments:

Prepared by:                                                                                      Delivered on:

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FATIGUE

WHAT IS IT?

Fatigue is the feeling of having little to no energy, making it hard to do daily tasks and activities. It can be physical, emotional, and/or mental, and it can affect several areas of one’s life, including social relationships, job performance, mood and emotions, attitudes, etc. People experiencing fatigue often feel tired even after getting a good night’s sleep, often have trouble concentrating, and often struggle to find words when speaking.

HOW COMMON IS IT?

According to breastcancer.org, fatigue is the number one symptom associated with breast cancer treatment, and it is estimated that 9 out of 10 cancer patients experience fatigue during treatment. Furthermore, the prevalence of fatigue can still be as high as 30% in long-term cancer survivors.

TIPS FOR MANAGING IT

- Exercise and stay active to help you fight fatigue and sleep better
- Drink plenty of water
- Eat healthy, including plenty of fruits, vegetables, proteins, and whole grains
- Manage stress through relaxation practices such as meditation or deep breathing
- Take naps (no longer than 30 minutes)

HERE ARE LINKS TO MORE INFORMATION AND TIPS REGARDING FATIGUE:

www.breastcancer.org/treatment/side_effects/fatigue
www.cancernetwork.com/oncology-nursing/fatigue-long-term-cancer-survivors
WHAT IS IT?

“Chemo brain” is the term that has been given to include certain symptoms that cancer patients sometimes experience after or while going through cancer treatments. Common complaints include having trouble concentrating, remembering details, multi-tasking, and slower thinking and processing of information. Other symptoms include general confusion, fatigue, short term member problems, and a general fogginess.

HOW COMMON IS IT?

It is thought that about 30 percent of patients who undergo chemotherapy experience chemo brain symptoms, according to the American Cancer Society.

TIPS FOR MANAGING IT

- Exercise regularly to combat fatigue and feel better mentally
- Play brain games (crossword puzzles, Sudoku, etc.)
- Create memory aids (reminders on your phone, daily to-do lists, etc.)
- Minimize distractions and focus on one task at a time
- Get plenty of rest
- Take time to de-stress (breathing exercises, taking a bath, meditating, etc.)
- Organize your environment
- Confide in family/friends/coworkers that you can trust

HERE ARE LINKS TO MORE INFORMATION AND TIPS REGARDING CHEMO BRAIN:

www.breastcancer.org/treatment/planning/ask_expert/2008_10
**NEUROPATHY**

**WHAT IS IT?**

Neuropathy is nerve damage that can come from chemotherapy treatments. It commonly causes pain in the hands and feet but can be found in other areas of the body as well and can get worse over time. Symptoms include general pain, tingling, burning, or sharpness in different areas of the body, as well as weakness, troubles walking or balancing, and picking things up with the hands. Some other symptoms can also include changes in vision and hearing and gastrointestinal problems.

**HOW COMMON IS IT?**

According to livestrong.org, about 1-2 % of Americans are affected by it. However, when looking directly at cancer populations treated with chemotherapy, the percentage of people experiencing neuropathy or neuropathy type symptoms goes up to 30-40% according to an article by the National Cancer Institute.

Certain pre-existing conditions can increase your risk, such as diabetes, thyroid dysfunction, infections, or autoimmune diseases.

**TIPS FOR MANAGING IT**

- Try low-impact exercises such as swimming or biking
- Stretching
- Relaxation techniques such as meditation
- Given that neuropathy can increase your risk of injury, remove possible tripping hazards and keep your home well lit
- Be cautious when moving and try to steady yourself when possible
- Consider using a cane or walker if you struggle with walking or balancing
- Consult with your doctor about pain management and the possibility of seeing a pain specialist or physical therapist
Making the decision to seek support from a therapist for the first time may be intimidating if you don't know what to expect. Here are some basics on what to expect so you can make an informed decision on whether therapy may be right for you.

**HOW DO I KNOW IF I SHOULD SEE A THERAPIST?**

Therapy sessions may differ on an individual basis, but there are some basics shared across all therapy practices. First, you can expect to be told about informed consent and confidentiality. This means that the information shared between you and your therapist will remain only between you and your therapist. Therapy providers are not allowed to share the information that you tell them with other family members, friends, etc. without your permission. The only exception being if you express an intention to do harm to either yourself or others. If you have any questions concerning their confidentiality policy, don't hesitate to ask them! Secondly, a lot of times the first session with your therapist may be a shorter “screening” or “assessment” session. This is so they can get the information they need to better understand your situation and what brings you to therapy. After that, sessions will follow individualized schedules based on what you want to accomplish in therapy.

**WHAT IF I DON’T LIKE IT?**

If at any time you decide that therapy isn’t right for you, you can let your therapist know and end the relationship. Similarly, if you do not feel that you are getting anything from your current therapist but want to continue trying therapy, it is absolutely okay to switch to someone else. Every practitioner has their own unique style, and it is important to find the style that works best for you and your goals. If you are worried about finding a good fit, before the first session it could be helpful to call up different therapists for a brief phone interview to determine from whom who you feel comfortable receiving services.
THERAPY RESOURCES

VBCF has taken the time to do some research into different therapy resources available throughout the different regions. We reached out to nurse navigators in the different regions for recommendations, and these recommendations make up the bulk of the list. The rest of the contacts come from Psychology Today's verified therapists found online. We also encourage you to take an active role in your search for support and do some research into therapists in your area. Visit locator.apa.org or www.findapsychologist.org to do a geographic search for practicing psychologists near you.

Region 1 – Central Virginia

Drive Norma Murdoch-Kitt, PhD
Location: 3217 Chamberlayne Avenue, Richmond, VA 23227
Phone: (804) 684-1958
Insurance: Call for more information

Lee Carter, LCSW
Location: 2200 Pump Road Suite 220 Henrico, VA 23233
Phone: (804) 252-7953
Insurance: Most commercial insurances are accepted, including: Anthem Blue Cross/Blue Shield, Aetna, Cigna, United Healthcare, United Behavioral Health, Southern Health, Medicare, MH Net, Several Employee Assistance Programs

Region 2 – Tidewater

Elizabeth (Betsy) Koivisto, Pre-Licensed Professional, MS – Stillwaters Counseling and Psychotherapy
Location: Virginia Beach, Virginia 23462
Phone: (757) 320-4398
Insurance: Call for more information

Drive Claudia Capizzi-Gay, PsyD – Cognitive Behavioral Therapy Center
Location: 1403 Greenbrier Parkway #215 Chesapeake, Virginia 23320
Phone: (757) 410-0700
Insurance: Aetna, Anthem BC/BS, Cigna, CompPsych, CompCare, Humana, Medicare, MHN, Optima Behavioral Health, OptimaHealth, Private Health Care SySuiitems, Tricare (Standard, Prime, and Tricare for Life), Value Options, Virginia Health Network, Wellpoint Unicare & Healthlink. Call to verify

Region 3 – Northern Neck

Rock Landing Psychological Group
Location: 11825 Rock Landing Drive, Newport News, VA
Counselors/Phone:
Pam Pare, LPC (757) 873-1736
Anne Aja, Ed.D (757) 873-1736
Harriette Barnes-Parker, PhD (757)- 873-1736
Insurance: Call for more information

Joanna Price – Peninsula Pastoral Counseling
Location: 707 Gum Rock Ct, Newport News, VA
Phone: (757) 873-2273
Insurance: Aetna, Anthem, Cigna, CompPsych, First Health, Holman Group, Kinnamon, Magellan, Mid-Atlantic, Mutual Prefer, Sentara/Optima, TriCare, United Behavioral Health, Value Options, and/or Virginia HealthNet

Colonial Psychiatric Associates
Location: 708 Mobjack Pl, Newport News, VA
Phone: (757) 873-1958
Counselors:
Bonnie J Kelly
Newton G Deschazo
Nayda M Flores
Insurance: Aetna, Anthem, Cigna, Medicaid, Medicare, Optima, Tricare, United Healthcare, Value Options, Many EAPs (Employee Assistance Program)

Frederick A Levy
Location: 732 Thimble Shoals Boulevard Suite 702, Newport News, VA
Phone: (757) 873-1240
Insurance: Champus (including FHC, CHOICE, and TRICARE PRIME), Value Behavioral Health, FHC Options, Mamsi, Met Life, The Virginia Health Network, Trigon Blue Cross Blue Shield, U.S.
Behavioral Healthcare, as well as a variety of commercial carriers

Frances Reinker, PhD.
**Location:** 1317 Jamestown Road #102, **Williamsburg, VA**
**Phone:** (757) 220-2700
**Insurance:** Anthem (BC/BS plans), Aetna, Cigna, Healthnet/Tricare, Humana, Magellan, Medicare, MHN, Optima, Student Resources, United Behavioral Health, United HealthCare, WPS/Tricare for Life

Marcia Grubbs-Weis, LPC
**Location:** 1318 Jamestown Road #101, **Williamsburg, VA**
**Phone:** (757) 561-2066
**Insurance:** Aetna, Anthem, Cigna, Medicaid, Medicare, Optima, Tricare, United Healthcare, Value Options, Many EAPs (Employee Assistance Program)

Joan Milkavich, LPC
**Location:** 325 McLaws Circle Suite 3, **Williamsburg, VA**
**Phone:** (757) 564-4590
**Insurance:** Call for more information

Corey Thayer, LPC
**Location:** 352 McLaws Circle, **Williamsburg, VA**
**Phone:** (757) 220-0118
**Insurance:** Call for more information

Barbara Kaplan – Richmond Road Counseling Center
**Location:** 1001 A Richmond Road, **Williamsburg, VA**
**Phone:** (757) 220-2669
**Insurance:** Call for more information

Sadie F Sheafe, Ph.D., LCSW
**Location:** 2021 Cunningham Drive Suite 101, **Hampton, VA**
**Phone:** (757) 864-0673
**Insurance:** Call for more information

Genesis Counseling (Christian)
**Location:** 2202 Executive Drive Suite C, **Hampton, VA**
**Phone:** (757) 827-7707
**Insurance:** Call for more information

Riverside Behavioral Health
**Location:** 2244 Executive Drive, **Hampton, VA**
**Phone:** (757) 827-1001
**Insurance:** Call for more information

Suiteider & Assoc.
**Location:** 6810 Teagle Lane, **Gloucester, VA**
**Phone:** (804) 210-1104
**Insurance:** Call for more information

Chesapeake Counseling Associates, PC
**Location:** 7296 York Avenue, **Gloucester, VA**
**Phone:** (804) 693-5057
**Insurance:** Call for more information

MPNN Counseling Center (CBS)
**Phone:** (804) 693-5057
**Insurance:** Call for more information

Cancer Care Counseling (offer oncology social workers to speak with)
**Phone:** 1-800-813-4673

**Region 4 – Northern Virginia**

Linda Oberleitner, LPC
**Location:** Chantilly, Virginia 20152
**Phone:** (703) 596-4616
**Insurance:** Call for more information

Helen LowenSuitein, LCSW – All About Wellness
**Location:** 7643 Leesburg Pike, **Falls Church, VA**
**Phone:** (703) 854-9909
**Insurance:** Call for more information

**Region 5 – Valley**

Ann Laura Atwell, Oncology Social Worker
**Phone:** (434) 654-8837
**Email:** alatwell@sentara.com
**Insurance:** Call your provider to find out what is covered. Visit the website for information on financial assistance.

Dessie Elwell, LPC – Eros & Agape Counseling
**Location:** 2015 Reservoir Street, Suite 205, **Harrisonburg, VA**
**Phone:** (540) 217-4268
Insurance: Eros & Agape Counseling, PLLC is a self-pay out of network provider. Call your provider to find out if you will be reimbursed.

**Region 6 – WeSuitern Virginia**

Tracy Wills, LPC, LMHC – Life in Balance  
**Location:** 125 Akers Farm Road, Suite D, Christiansburg, VA 24073  
**Phone:** (540) 381-6215  
**Insurance:** Aetna, Anthem, Anthem EAP, Beacon Hill, Compsych, Humana, Magellan, MHNET, Optima, VA Premier and Value Options

Gail Evans, LPC – Compassion by the Hour  
**Location:** 541 Luck Avenue, SW, Suite 209, Roanoke, VA 24016  
**Insurance:** Call for more information

Lisa C Westmoreland, LPC – Westmoreland Counseling, LCC  
**Location:** 3524 Brambleton Avenue 1, Roanoke, VA 24018  
**Phone:** (540) 709-7530  
**Insurance:** Call for more information

**Region 7 – Southwest Virginia**

Kim Carter – Commonwealth Catholic Charities  
**Location:** 507 Park Avenue SW, Norton, VA 24273  
**Phone:** (276) 200-2805 OR (276) 679-1195  
**Insurance:** Call for more information

Lee County Behavioral Health Services  
**Location:** 34084 Wilderness Road, Jonesville, VA 24263  
**Counselors:**  
Karen Baker  
Karen Eldridge  
**Phone:** (276) 346-3590  
**Insurance:** Call for more information

Scott County Behavioral Health Services  
**Location:** 1006 U.S. Highway 23 N Weber City, VA 24290  
**Counselors:**  
Jane Fanslow  
Mary Alice Fields  
Farah Williams  
**Phone:** (276) 225-0976  
**Insurance:** Call for more information

**Region 8 – Southside Virginia**

Susan Sisler, LPC - Sisler Counseling Services  
**Location:** 222 King Street, PO Box 85, Keysville, VA 23947  
**Phone:** (434) 480-3861  
**Insurance:** Call for more information

Erin R Jurich-Finney, PsyD – Counseling Associates of Abingdon  
**Location:** 335 East Main St. Abingdon, VA 24210  
**Phone:** (276) 663-4716  
**Insurance:** Call for more information
VBCF is a statewide, Richmond-based nonprofit committed to the eradication of breast cancer through education and advocacy.

2821 Emerywood Parkway, Suite 203
Richmond, VA 23294

800-345-8223  |  804-285-1200

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