

# **Carolina Breast Cancer Study 3**

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## **FOLLOW UP #2: Appendix A-2 – Mail-In Survey**

YOUR NAME: \_\_\_\_\_

Date completed: \_\_\_\_\_

Thank you for agreeing to complete this set of questions and mail it back to us in the enclosed pre-paid envelope. The goal of this study is to collect information that may help us to better understand the causes of breast cancer. There are no right or wrong answers to any of these questions. You should just report what you have experienced.

Your participation is voluntary, and all the information collected will be kept completely confidential. If you should come to any question that you do not want to answer, just skip it and go on to the next question.

If you would prefer to complete this set of questions by telephone, please call us and we will be happy to record your answers over the phone.

Our toll-free telephone number: 1-866-927-6920.

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Date completed: \_\_\_ / \_\_\_ / \_\_\_\_\_

**Let's begin. The first few questions are about a specific upper body concern known as lymphedema. Lymphedema is swelling of the arm, breast or trunk and can sometimes occur following treatment for breast cancer.**

**A1.** Since diagnosis of your breast cancer, have you been diagnosed with lymphedema?  
(Mark an "X" in front of **all that apply**)

- \_\_\_\_\_ a. **Right arm**  
 \_\_\_\_\_ b. **Left arm**  
 \_\_\_\_\_ c. **Right trunk**  
 \_\_\_\_\_ d. **Left trunk**  
 \_\_\_\_\_ e. **Right breast**  
 \_\_\_\_\_ f. **Left breast**  
 \_\_\_\_\_ g. **No (none of the above)**

(If you answered "NO", then --> **SKIP TO question A6**)

**A2.** What month and year were you first diagnosed with lymphedema?

\_\_\_\_\_ (Month)                      \_\_\_\_\_ (Year)

**A3.** Who diagnosed your lymphedema? (Mark an "X" in front of **all that apply**)

- \_\_\_\_\_ a. **Medical doctor**  
 \_\_\_\_\_ b. **Nurse**  
 \_\_\_\_\_ c. **Physical therapist**  
 \_\_\_\_\_ d. **Other (specify):** \_\_\_\_\_

**A4.** How would you characterize this lymphedema? (Select the closest option)

- \_\_\_\_\_ 1. **Single episode (had it but now resolved)**  
 \_\_\_\_\_ 2. **Recurrent (it comes and goes)**  
 \_\_\_\_\_ 3. **Persistent (almost always there)**

**A5.** Do you currently (that is, right now) have lymphedema?

- \_\_\_\_\_ 1. **YES**  
\_\_\_\_\_ 2. **NO**

**A6.** What hand do you normally write with?

- \_\_\_\_\_ 1. **Left**  
\_\_\_\_\_ 2. **Right**  
\_\_\_\_\_ 3. **Both**

**A7.** Since your diagnosis, have you talked with any of the following people about your breast cancer? (Mark an "X" in front of **all that apply**)

- \_\_\_\_\_ a. **Husband or partner**  
\_\_\_\_\_ b. **Children**  
\_\_\_\_\_ c. **Other relatives**  
\_\_\_\_\_ d. **Friends**  
\_\_\_\_\_ e. **Members of your church or other religious organization**  
\_\_\_\_\_ f. **Neighbors**  
\_\_\_\_\_ g. **Coworkers**  
\_\_\_\_\_ h. **Other (specify):** \_\_\_\_\_

**The next section includes questions about your physical well-being and your quality of life since your diagnosis of breast cancer. Some of the questions are of a personal nature.**

Below is a list of statements that other people with breast cancer have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<b><u>PHYSICAL WELL-BEING</u></b>		Not at all	A little bit	Some-what	Quite a bit	Very much
<b>A8</b>	I have a lack of energy.....	0	1	2	3	4
<b>A9</b>	I have nausea.....	0	1	2	3	4
<b>A10</b>	Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
<b>A11</b>	I have pain.....	0	1	2	3	4
<b>A12</b>	I am bothered by side effects of treatment.....	0	1	2	3	4
<b>A13</b>	I feel ill.....	0	1	2	3	4
<b>A14</b>	I am forced to spend time in bed.....	0	1	2	3	4
<b><u>SOCIAL/FAMILY WELL-BEING</u></b>		Not at all	A little bit	Some-what	Quite a bit	Very much
<b>A15</b>	I feel close to my friends.....	0	1	2	3	4
<b>A16</b>	I get emotional support from my family.....	0	1	2	3	4
<b>A17</b>	I get support from my friends.....	0	1	2	3	4
<b>A18</b>	My family has accepted my illness.....	0	1	2	3	4
<b>A19</b>	I am satisfied with family communication about my illness.....	0	1	2	3	4
<b>A20</b>	I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please skip to A22.</i>						
<b>A21</b>	I am satisfied with my sex life.....	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<b><u>EMOTIONAL WELL-BEING</u></b>		Not at all	A little bit	Some-what	Quite a bit	Very much
<b>A22</b>	I feel sad .....	0	1	2	3	4
<b>A23</b>	I am satisfied with how I am coping with my illness.....	0	1	2	3	4
<b>A24</b>	I am losing hope in the fight against my illness .....	0	1	2	3	4
<b>A25</b>	I feel nervous .....	0	1	2	3	4
<b>A26</b>	I worry about dying .....	0	1	2	3	4
<b>A27</b>	I worry that my condition will get worse .....	0	1	2	3	4

<b><u>FUNCTIONAL WELL-BEING</u></b>		Not at all	A little bit	Some-what	Quite a bit	Very much
<b>A28</b>	I am able to work (include work at home) .....	0	1	2	3	4
<b>A29</b>	My work (include work at home) is fulfilling .....	0	1	2	3	4
<b>A30</b>	I am able to enjoy life.....	0	1	2	3	4
<b>A31</b>	I have accepted my illness.....	0	1	2	3	4
<b>A32</b>	I am sleeping well .....	0	1	2	3	4
<b>A33</b>	I am enjoying the things I usually do for fun .....	0	1	2	3	4
<b>A34</b>	I am content with the quality of my life right now .....	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<b><u>ADDITIONAL CONCERNS</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some- what</b>	<b>Quite a bit</b>	<b>Very much</b>
<b>A35</b>	I have been short of breath.....	0	1	2	3	4
<b>A36</b>	I am self-conscious about the way I dress.....	0	1	2	3	4
<b>A37</b>	One or both of my arms are swollen or tender .....	0	1	2	3	4
<b>A38</b>	I feel sexually attractive .....	0	1	2	3	4
<b>A39</b>	I am bothered by hair loss .....	0	1	2	3	4
<b>A40</b>	I worry that other members of my family might someday get the same illness I have.....	0	1	2	3	4
<b>A41</b>	I worry about the effect of stress on my illness.....	0	1	2	3	4
<b>A42</b>	I am bothered by a change in weight.....	0	1	2	3	4
<b>A43</b>	I am able to feel like a woman .....	0	1	2	3	4
<b>A44</b>	I have certain parts of my body where I experience significant pain .....	0	1	2	3	4

Please circle one number per line to indicate your response as it applies to the past 7 days.

<b><u>ADDITIONAL CONCERNS</u></b>		<b>Not at all</b>	<b>A little bit</b>	<b>Some-what</b>	<b>Quite a bit</b>	<b>Very much</b>
b _____	<b>E1a.</b> I have hot flashes .....	0	1	2	3	4
b _____	<b>E2a.</b> I have cold sweats .....	0	1	2	3	4
b _____	<b>E3a.</b> I have night sweats .....	0	1	2	3	4
b _____	<b>E4a.</b> I have vaginal discharge .....	0	1	2	3	4
b _____	<b>E5a.</b> I have vaginal itching/irritation .....	0	1	2	3	4
b _____	<b>E6a.</b> I have vaginal bleeding or spotting .....	0	1	2	3	4
b _____	<b>E7a.</b> I have vaginal dryness .....	0	1	2	3	4
b _____	<b>E8a.</b> I have pain or discomfort with intercourse .....	0	1	2	3	4
b _____	<b>E9a.</b> I have lost interest in sex .....	0	1	2	3	4
b _____	<b>E10a.</b> I have gained weight .....	0	1	2	3	4
b _____	<b>E11a.</b> I feel lightheaded (dizzy) .....	0	1	2	3	4
b _____	<b>E12a.</b> I have been vomiting .....	0	1	2	3	4
b _____	<b>E13a.</b> I have diarrhea (diarrhoea) .....	0	1	2	3	4
b _____	<b>E14a.</b> I get headaches .....	0	1	2	3	4
b _____	<b>E15a.</b> I feel bloated .....	0	1	2	3	4
b _____	<b>E16a.</b> I have breast sensitivity/tenderness .....	0	1	2	3	4
b _____	<b>E17a.</b> I have mood swings .....	0	1	2	3	4
b _____	<b>E18a.</b> I am irritable .....	0	1	2	3	4
b _____	<b>E19a.</b> I have pain in my joints .....	0	1	2	3	4



**Many women who have had breast cancer take endocrine therapy pills, also known as hormonal therapy or anti-estrogen therapy, to help keep breast cancer from coming back. Specific names of these drugs are Tamoxifen, Femara (or Letrozole), Aromasin (or Exemestane), and Arimidex (or Anastrozole).**

**E20.** Has your doctor ever prescribed hormonal therapy pills for you to help keep your breast cancer from coming back?

\_\_\_\_ 1. **YES**

\_\_\_\_ 9. **I DON'T KNOW**

\_\_\_\_ 2. **NO** **If NO, GO TO PAGE 11, question A45**

**E21.** At this time, are you taking hormonal therapy pills?

\_\_\_\_ 1. **Yes, I'm taking them exactly as prescribed by my doctor**

\_\_\_\_ 2. **Yes, I'm taking them, but not every day**

\_\_\_\_ 3. **No, I stopped taking those pills**

**E22.** When your doctor first prescribed these pills to you, how was the decision to take them made? (Mark an "X" in front of **one** answer)

\_\_\_\_ 1. **My doctor and I talked about it, and I made the decision**

\_\_\_\_ 2. **My doctor and I talked about it, and s/he made the decision**

\_\_\_\_ 3. **My doctor and I talked about it, and we made the decision together**

\_\_\_\_ 4. **My doctor and I didn't really talk about it—they were just prescribed to me**

**E23.** On page 6, you circled a number for the problems or symptoms you may have experienced in the past 7 days. Without changing your original answers, please go back to page 6 and place an "X" in the **shaded box** to the **left** of the problems or symptoms that you have experienced that you think are caused by your hormonal therapy pills.

**E24.** Over the past **two** weeks, how many days did you miss your hormonal therapy pills?  
(Mark an “**X**” in front of **one** answer)

- 0. **0 days**
- 1. **1 day**
- 2. **2 days**
- 3. **3 days**
- 4. **4 days**
- 5. **5 or more days**

**E25.** Did you ever cut back or stop taking your hormonal therapy pills because these pills made you feel bad?

- 1. **YES**
- 2. **NO**

**E26.** Many people forget to take their pills when they are away from home. Have you forgotten to take your hormonal therapy pills when you were away from home?

- 1. **Yes, I’ve sometimes forgotten to take my pills when away from home**
- 2. **No, I always remember to take my pills, even when I’m away from home**

**E27.** Taking pills every day can be hard. For you, is sticking to your hormonal therapy treatment plan... (Mark an “**X**” in front of **one** answer)

- 1. **Very hard**
- 2. **Somewhat hard**
- 3. **Not hard at all**

**E28.** Would you say you have trouble remembering to take your hormonal therapy pills...

- 1. **Often**
- 2. **Sometimes**
- 3. **Practically never**

**For you, how often is it true that you miss your hormonal therapy pills because...**  
(Circle **one** number per line)

	Often true for you	Sometimes true for you	Practically never true for you
<b>E29</b> The pills are too expensive.....	1	2	3
<b>E30</b> You just forget to take them....	1	2	3
<b>E31</b> You don't get around to refilling the prescription.....	1	2	3
<b>E32</b> The side effects of these pills are too hard to deal with.....	1	2	3
<b>E33</b> Taking medication for a long time is not healthy.....	1	2	3

**E34.** Think about the whole process of taking these hormonal therapy pills—from filling the prescription to taking the pills every day and putting up with the side effects from them. Do you think... (Mark an “**X**” in front of **one** answer)

\_\_\_ 1. **The good outweighs the bad**

\_\_\_ 2. **The good and bad are equal**

\_\_\_ 3. **The bad outweighs the good**

**E35.** Suppose you took all your hormone therapy pills as prescribed. What do you think the chance would be that your cancer would ever come back?

(Mark an “**X**” in front of **one** answer)

\_\_\_ 1. **Very low chance**

\_\_\_ 2. **Low chance**

\_\_\_ 3. **Moderate chance**

\_\_\_ 4. **High chance**

\_\_\_ 5. **Very high chance**

**E36.** Suppose you stopped taking these pills as prescribed. What do you think would happen to your chances of your breast cancer coming back? (Mark an “**X**” in front of **one** answer)

\_\_\_\_ 1. **My chances would go up a lot**

\_\_\_\_ 2. **My chances would go up a little**

\_\_\_\_ 3. **My chances would not really change**

**Please continue on next page, question A45.**

The following questions refer to procedures you may have had as part of your breast cancer workup and treatment. These procedures include breast biopsy, breast surgery, lymph node biopsy and lymph node removal.

**A45.** On which side(s) of your body did you have these procedure(s)?

- \_\_\_\_\_ 1. **Left**  
 \_\_\_\_\_ 2. **Right**  
 \_\_\_\_\_ 3. **Both**

Please circle the number below the best response to the following questions.

<u>On the side (or sides) where you had your procedure(s):</u>		Not at all	A little bit	Some-what	Quite a bit	Very much
<b>A46</b>	Movement of my arm on this side is painful.....	0	1	2	3	4
<b>A47</b>	I have poor range of arm movements on this side.....	0	1	2	3	4
<b>A48</b>	My arm on this side feels numb .....	0	1	2	3	4
<b>A49</b>	I have stiffness of my arm on this side.....	0	1	2	3	4
<b>A50</b>	My arm on this side feels heavy .....	0	1	2	3	4
<b>A51</b>	My arm on this side aches .....	0	1	2	3	4
<b>A52</b>	I have tightness of my arm on this side .....	0	1	2	3	4

Please answer every question, based on your condition during the past week, by circling the appropriate number. If you did not have the opportunity to perform an activity in the past week, please make your best estimate on which response would be the most accurate. It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
<b>A53</b> Open a tight or new jar.....	1	2	3	4	5
<b>A54</b> Write.....	1	2	3	4	5
<b>A55</b> Turn a key .....	1	2	3	4	5
<b>A56</b> Prepare a meal.....	1	2	3	4	5
<b>A57</b> Push open a heavy door .....	1	2	3	4	5
<b>A58</b> Place an object on a shelf above your head .....	1	2	3	4	5
<b>A59</b> Do heavy household chores (e.g., wash walls, wash floors) .....	1	2	3	4	5
<b>A60</b> Garden or do yard work .....	1	2	3	4	5
<b>A61</b> Make a bed .....	1	2	3	4	5
<b>A62</b> Carry a shopping bag or briefcase .....	1	2	3	4	5
<b>A63</b> Carry a heavy object (over 10 lbs) .....	1	2	3	4	5
<b>A64</b> Change a light bulb overhead .....	1	2	3	4	5
<b>A65</b> Wash or blow-dry your hair .....	1	2	3	4	5

		NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
<b>A66</b>	Wash your back.....	1	2	3	4	5
<b>A67</b>	Put on a pullover sweater.....	1	2	3	4	5
<b>A68</b>	Use a knife to cut food.....	1	2	3	4	5
<b>A69</b>	Recreational activities which require little effort (e.g., card playing, knitting, etc.) .....	1	2	3	4	5
<b>A70</b>	Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).....	1	2	3	4	5
<b>A71</b>	Recreational activities in which you move your arm freely (e.g., playing frisbee, badminton, etc.).....	1	2	3	4	5
<b>A72</b>	Manage transportation needs (getting from one place to another) .....	1	2	3	4	5
<b>A73</b>	Sexual activities.....	1	2	3	4	5

Now we want to know more about any arm, shoulder or hand problems that you may have. Please circle the number below the best response to the following questions.

		NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	EXTREMELY
<b>A74</b>	During the past week, to what extent have arm, shoulder or hand problems interfered with your normal social activities with family, friends, neighbors or groups?	1	2	3	4	5

		NOT AT ALL LIMITED	SLIGHTLY LIMITED	MODERATELY LIMITED	VERY LIMITED	UNABLE
<b>A75</b>	During the past week, were you limited in your work or other regular daily activities as a result of arm, shoulder or hand problems?	1	2	3	4	5

Please rate the severity of the following symptoms in the last week by circling the number below the best response.

	NONE	MILD	MODERATE	SEVERE	EXTREME
<b>A76</b> Arm, shoulder or hand pain .....	1	2	3	4	5
<b>A77</b> Arm, shoulder or hand pain when you performed any specific activity.....	1	2	3	4	5
<b>A78</b> Tingling (pins and needles) in your arm, shoulder or hand.....	1	2	3	4	5
<b>A79</b> Weakness in your arm, shoulder or hand.....	1	2	3	4	5
<b>A80</b> Stiffness in your arm, shoulder or hand.....	1	2	3	4	5

Please circle the number below the best response to the following question.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	SO MUCH DIFFICULTY THAT I CAN'T SLEEP
<b>A81</b> During the past week, how much difficulty have you had sleeping because of pain in your arm, shoulder or hand?	1	2	3	4	5

Please circle the number below the best response to the following statement.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
<b>A82</b> I feel less capable, less confident or less useful because of arm, shoulder or hand problems.	1	2	3	4	5



The following questions ask about the impact of your arm, shoulder or hand problems on your ability to work. If you are not working outside of the home, then please tell us about any difficulties that you have with housework or other tasks around your home.

Please circle the number that best describes your physical ability in the past 7 days.

Did you have any difficulty:		NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
<b>A83</b>	Using your usual technique for your work?	1	2	3	4	5
<b>A84</b>	Doing your usual work because of arm, shoulder or hand pain?	1	2	3	4	5
<b>A85</b>	Doing your work as well as you would like?	1	2	3	4	5
<b>A86</b>	Spending your usual amount of time doing your work?	1	2	3	4	5

The following section includes a list of statements that other people with your illness have said are important.

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

		Not at all	A little bit	Some-what	Quite a bit	Very much
<b>A87</b>	I feel peaceful .....	0	1	2	3	4
<b>A88</b>	I have a reason for living.....	0	1	2	3	4
<b>A89</b>	My life has been productive .....	0	1	2	3	4
<b>A90</b>	I have trouble feeling peace of mind.....	0	1	2	3	4
<b>A91</b>	I feel a sense of purpose in my life .....	0	1	2	3	4
<b>A92</b>	I am able to reach down deep into myself for comfort.....	0	1	2	3	4
<b>A93</b>	I feel a sense of harmony within myself.....	0	1	2	3	4
<b>A94</b>	My life lacks meaning and purpose .....	0	1	2	3	4
<b>A95</b>	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
<b>A96</b>	I find strength in my faith or spiritual beliefs.....	0	1	2	3	4
<b>A97</b>	My illness has strengthened my faith or spiritual beliefs .....	0	1	2	3	4
<b>A98</b>	I know that whatever happens with my illness, things will be okay.....	0	1	2	3	4

**The following questions ask for information about your work history since your breast cancer diagnosis, and about your household.**

**A99.** Have you been working since your diagnosis of breast cancer? This includes full-time or part-time, paid or unpaid work, as well as self-employment. (Mark an “X” in front of your answer)

\_\_\_\_\_ 1. **YES**

\_\_\_\_\_ 2. **NO** → If **NO**, Skip to Question **A102**.

**A100.** How many days of work have you missed due to your diagnosis of breast cancer?

\_\_\_\_\_ **days**

**A101.** Since your diagnosis of breast cancer, which of the following best describes what you do most (at least half the time) at work? (Mark an “X” in front of **all that apply**)

\_\_\_\_\_ a. **Sitting**

\_\_\_\_\_ b. **Standing**

\_\_\_\_\_ c. **Walking**

\_\_\_\_\_ d. **Heavy labor or other physically demanding work**

\_\_\_\_\_ e. **Other. Please describe:** \_\_\_\_\_

\_\_\_\_\_ f. **I prefer not to answer.**

**A102.** Did you lose your job due to your diagnosis of breast cancer? (Mark an “X” in front of your answer)

\_\_\_\_\_ 1. **YES**

\_\_\_\_\_ 2. **NO**

**A103.** What is your present marital status? (Mark an "X" in front of your answer)

- \_\_\_\_\_ 1. **I have never married or lived as married**
- \_\_\_\_\_ 2. **I am married, or living as married**
- \_\_\_\_\_ 3. **I am widowed**
- \_\_\_\_\_ 4. **I am separated, divorced, or no longer living as married**
- \_\_\_\_\_ 9. **I prefer not to answer**

**A104.** Has there been a decrease in your family income since you were diagnosed with breast cancer? (Mark an "X" in front of your answer)

- \_\_\_\_\_ 1. **YES**
- \_\_\_\_\_ 2. **NO**

**This completes your participation in Follow Up #2 of the Carolina Breast Cancer Study. Thank you for your help with this important research study.**

**Please return this document in the postage-prepaid envelope provided to:**

**UNC-Chapel Hill  
Carolina Breast Cancer Study  
Attn: Judy Bryan, Rm. 333  
1700 Martin Luther King Jr. Blvd.  
Chapel Hill, NC 27599-7294**

**Reminder: You will receive a check in the amount of \$12.00 for returning this document (or providing these answers by telephone).**

**Questions? Call:**

**Mary Beth Bell, Project Manager**

**Tel. 919-966-9439**

**or toll-free: 1-866-927-6920**

**THANK YOU!**