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13. ABSTRACT (Maximum 200 Words)
   Very little is known about the incidence, onset, time course, and symptomatology of premature menopause induced by breast cancer therapy. No prospective study has been reported. Accrual in the present study was begun on January 1, 1998 but has not reached target numbers, and therefore, accrual has continued. In order to continue following the current cohort, an application has been submitted for additional funding. Preliminary analyses of the 559 current participants have been done.

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INTRODUCTION

MENSTRUAL CYCLE MAINTENANCE AND QUALITY OF LIFE: A PROSPECTIVE STUDY

INTRODUCTION

The frequent morbidity associated with most cancers and their treatments make the measurement of health-related quality of life a critical mechanism for determining the toll of the entire disease. Young breast cancer patients additionally may face treatment-induced menopause and with it may experience hot flashes, mood changes, sleep disturbances, vaginal dryness, and the cascading effect of anxiety and depression. In the United States, Wake Forest University has particular expertise in quality of life with naturally occurring menopause. Wake Forest is the Coordinating Center in this issue for the Women’s Health Initiative, funded by the National Institute of Health, which has accrued more than 100,000 study subjects.

Very little is known about the incidence, onset, time course, and symptomatology of premature menopause induced by breast cancer therapy. No prospective study exists. The purpose of the present study is to identify determinants of treatment-related amenorrhea and its effect on quality of life in a cohort of young breast cancer patients.
BODY

STATEMENT OF WORK

Task 1. Months 1-2 - COMPLETED

a) Focus groups for final questionnaire wording

Focus groups were held at Wake Forest University under the direction of Dr. Sally Shumaker, the Principal Investigator of the clinical coordinating center. As well as the wording for the baseline data questionnaires, the proposed procedural sequences were decided with attention to the women’s preferences for baseline and follow-up procedures.

See work output in the revised annual report 1998 and 1999. This Manual of Procedures contains more than 200 pages and consists of chapters on organizational structure; protocol; recruitment prescreening and eligibility; consenting process; baseline data collection visits; collecting participant information; chart review forms; study data forms and questionnaires; instructions for menstrual diaries; follow up contacts; data management; and quality control. This assures that the research study procedure is conducted absolutely identically in accruing women throughout the country and over the duration of the study.

Done as first reported in the revised annual report 1998.

b) Pilot calendar and questionnaires in Texas and New York City population

The questionnaires and menstrual bleeding calendars were tested on non-protocol patients in Texas and New York City and were found to be satisfactory. This included follow up forms for baseline data and questionnaires, for six-month follow-up and for one-year follow-up attached in the revised annual report 1998.

Done as first reported in the revised annual report 1998.

c) Hire personnel.

Personnel were hired on schedule and within the budgeted salary amount.

Done as first reported in the revised annual report 1998.

d) Keep lists of potential patients.

Patients were identified from registrations of various services within each of the hospitals: Surgery, Radiation Therapy, Medical Oncology, Psychiatry, Nutrition and General Medicine.
Done as first reported in the revised annual report 1998.

Patients continue to be accrued through lists maintained in the various services within Memorial Sloan-Kettering Cancer Center.

**Task 2. Months 2-24**

a) Identify and Enroll patients – Time Line Amended

As noted, by September of 1998, 185 patients had been enrolled. This was considerably less than half of the targeted accrual by Month 9 after accrual began and steps were taken to increase the self-referral patients, as noted in the body of the revised annual report 1998.

Task 2: Time Extended

By September 1999, 456 patients had been enrolled in the study. This was less than the original targeted accrual numbers. Lt. Col. J. Pearson of the Office of Regulatory Affairs granted an extension for continued accrual. (attached in 1999 report)

In September 2000, 559 participants were enrolled in the study. To date, recruitment has gone smoothly, although we have encountered a higher than expected ineligibility rate across the participating centers. In our original proposal, we had anticipated 30% ineligibility in women aged 18-45 years due to a hysterectomy, irregular periods, or metastatic disease at diagnosis. In reality, however, our ineligibility rate has been approximately 45-48% across all centers. The primary exclusion criterion has been a prior hysterectomy, which has occurred in approximately 40% of the ineligible potential participants in this age group, particularly among the Southern population. As a result, although we have had a low overall refusal rate of 5-10% among all eligible women, our pool of eligible women has been lower than anticipated. Thus, we have fallen short of our original recruitment goal of 800 participants. Recruitment will continue through the remainder of the year. In order to continue to recruit and follow prospectively a cohort of 800 young women, an application has been submitted for additional funding. (Breast Cancer Center for Excellence Proposal: Quality of Life and Functional Status across the Life Course).

**Participant Accrual**

- Memorial Sloan-Kettering – 381 participants
- Wake Forest – 49 participants
- MD Anderson/Texas – 129 participants

Current recruitment ended at Wake Forest University and MD Anderson on December 31, 1999, which was the end of their contractual obligations for recruitment. Memorial Sloan-Kettering will continue to recruit through tumor registries, physician referrals, and self-referrals. Wake
Forest and MD Anderson will finish follow up for existing patients but will not recruit. In addition, further strategies have been implemented to recruit referral through physicians at Memorial Sloan-Kettering. One or more of the following strategies continues to be utilized in recruiting participants into the study:

1. **Patient Identification through Tumor and Surgical Registries.**
   Once women with stage 1-3 breast cancer have been identified, the patients' oncologists/surgeons are contacted by clinic staff to obtain approval to approach the patient. If the physician approves, the patient is approached at the clinic site, or the patient is sent a letter describing the purpose of the study, which will be followed by a telephone call. Approval was obtained from the IRB for permission to make follow up calls to these patients. The clinic staff person will screen the person to ensure she meets the eligibility criteria, and then will ask the patient to participate in the study is she is eligible.

2. **Referral through Physicians.**
   The clinical center’s participating investigators, oncologists, surgeons, and radiologists also identifies participants. In most instances, these physicians will have already explained the study to the participant, and the clinic staff contacts the patient to invite her to participate in the study. The patient is screened to ensure that she meets all eligibility criteria.

3. **Self-Referral**
   Women may hear about the study through the many strategies that have been implemented to recruit participants nationally. They are screened for study eligibility, and asked to join the study if the eligibility criteria are met. The patients will sign the informed consent, a medical record release, and will complete all baseline study questionnaires.

   The Clinical Coordinating Center at the Wake Forest School of Medicine continues to monitor recruitment and issues monthly recruitment reports to each participating institution.

**Task 3. Months 8-45**

a) Mail out and receive back study calendars and other data instruments.

Questionnaires and menstrual calendars have been received on schedule for 6, 12, 18, 24, and 30-month follow up. (See appendices A-F)

See the next section for current follow-up figures and retention rates.

b) Enter data in ongoing fashion.

**Data monitoring and tracking**
The Coordinating Center performs editing procedures to ensure the quality of the data collected
by the Clinical Centers. These are as follows: 1) initial screening of the data, using logic and range checks that are built into the data entry system and 2) edits which assess the serial integrity of the data.

Much of the data collected from study subjects comes from regularly scheduled mailings. Time windows have been defined for these scheduled mailings. A tracking system is in place to facilitate on-time collection of data.

c) Crosscheck data and clean.

**Adherence and retention rates**
Recruitment to this study began January 1, 1998. As of September 2000, 559 participants have been enrolled. To date, 53 participants have been dropped from the protocol (9.8%). This includes 7 participant deaths. Of the surviving 46 patients, reasons for dropping include: lost interest in the study (15 participants), could not be reached after repeated attempts (11), lack of time (7), overwhelmed by treatment and/or family responsibilities (3), and 10 asked to be dropped for miscellaneous reasons (eg. husband asked her to stop participating). Of the 506 active participants, adherence to completing study follow-up forms and bleeding calendars has averaged to 89% and 90% respectively, up through the 18 months assessment point. We attribute these high adherence rates to a detailed tracking system for the receipt of the study forms, and an incentive program to keep people interested in the program. Our tracking system alerts our study project managers when forms are not received by 21 days past their expected return date. This triggers a protocol where patients receive a postcard or telephone call, depending on their adherence history, to remind them of their overdue forms. Our data collector works with the patients to get the forms returned, and to address any concerns patients might have about the protocol and study requirements. Patients are also given the option of completing their calendars or forms on the telephone, if they prefer. Most patients complete follow-up forms by mail, however.

We have also instituted several adherence and retention and incentive strategies to keep women interested in the study. These have included sending all participants birthday cards, and holiday cards in December. A quarterly newsletter is also sent all to all participants, (the most recent spring 2000; Appendix G). This provides participants with the number and state of participants, information about literature related to breast cancer, information about the staff at the participating medical centers, recipes and information shared by our participants. We have also mailed all participants small tokens, such as books, key chains, kitchen magnets, and post-it boards.

In addition, to the above mechanisms, we also have a toll free 800 number for women to call and ask questions about their forms or the study. Participants are also provided with the e-mail addresses our program managers. Adherence rates have increases with the implementation of all these adherence strategies, and we will continue to find ways to retain the study cohort over the course of the follow-up period.
d) Write annual report.

October 1999 Annual Report complete.
October 2000 Annual Report complete.
KEY RESEARCH ACCOMPLISHMENTS

- The result of this research provides much needed longitudinal data on the quality of life of young patients following treatment from breast cancer.
- Analysis of the current data will assist in predicting which chemotherapy programs may be most likely to cause premature menopause following breast cancer treatment.
- Results enable critical questions regarding the risks of childbearing after breast cancer to be addressed.
- This study will provide a foundation for future research in the quality of life of young breast cancer survivors.

PRELIMINARY RESEARCH ACCOMPLISHMENTS

- Analyses have been initiated to examine amenorrhea at 12 months after enrollment. At 12 months post-baseline questionnaire at enrollment, 61% of the patients have had menstrual cycles in months 9-12.
- 45 – 50% of the patients are reporting menopause-related symptoms, primarily hot flashes and vaginal dryness, by the 12-month questionnaire assessment.
- Rates of self-reported arm and hand swelling are increasing over time (24% at 6 months and 30% at 12 months).
REPORTABLE OUTCOMES

Ongoing results of the study were reported at the Era of Hope; Department of Defense Breast Cancer Research Meeting in Atlanta, Georgia held in June 2000. The study was chosen as one of the platform presentations. In addition a poster was presented with statistics similar to those in the previous section. See the abstract for the meeting. (Appendix H).

The study was presented at the American Society of Clinical Oncology Annual meeting in New Orleans, Louisiana held in May 2000. See the abstract (Appendix I).

Additional funding has been applied for to continue to follow prospectively this cohort of 800 young women. (Breast Cancer Center for Excellence Proposal: Quality of Life and Functional Status across the Life Course).
CONCLUSIONS

As of September 2000, 559 have been recruited to the study. The average age of our current participants was 39 years at the time of enrollment. Approximately 86% are Caucasian, 6% are African–American, 4% are Hispanic, 3% are Asian-Pacific Islander, and 1% are Native American. Although only 14% are minorities, this is in line with other national studies. Targeted efforts have been made to recruit minority women, such as media attention in Spanish language and ethnic newspapers (See appendices of 1999 annual report). The women are well educated, with 64% having received at least a four-year college degree. The majority of our participants are married (70%), or living in a marriage-like relationship (5%). Approximately 9% are divorced or separated and 1% are widowed. Fifteen percent of the patients have never been married. Approximately 55% were working full-time at the time of diagnosis, and 13% were working part-time. Only 17% were full-time homemakers, disabled (6%), students (1%), or unemployed (3%). Approximately 70% have children under the age of 18.

Preliminary Data

Stage of cancer at diagnosis was Stage I: 42%, Stage II: 38%, and Stage III: 10%. Only 1% of patients had tumors located in both breasts. Approximately 94% had axillary node dissection. The type of surgery completed was 23% lumpectomy, 52% mastectomy, 23% both lumpectomy and mastectomy, and 2% no surgery. Twenty-eight percent of the patients had immediate reconstructive surgery concurrent with the mastectomy. Chemotherapy alone was administered to 31% of the cohort, (primarily IV Cytoxan and Adriamycin), radiation to 7.5%, and chemotherapy and radiation was received by 56% of the cohort.

At 12 months post-baseline, (for the women who have reached that follow-up time point), 2.5% of the patients have indicated a recurrence in the treated breast or axilla, and an additional 25 have indicated breast cancer metastases in distant sites.

For the majority of patients, improvements in well being, particularly physical and functional well being are being observed between baseline, and 6 and 12 months. However, 45 – 50% of the patients are reporting menopause-related symptoms, primarily hot flashes and vaginal dryness, by the 12-month assessment. Rates of self-reported arm and hand swelling are also increasing over time (24% at 6 months and 30% at 12 months).

Analyses have been initiated to examine amenorrhea at 12 months after enrollment. At 12 months post-baseline questionnaire at enrollment, 61% of the patients have had menstrual cycles in months 9-12. Seven percent had no chemotherapy and received radiation only. In examining, continued menstrual cycling in relation to potential future pregnancy, approximately 31% of the patients had indicated they had wanted a first child, or additional children, 6 months prior to their diagnosis, and an additional 11% of the women were undecided. As of September 2000, 8 participants have reported pregnancies (ie. 3 ended in miscarriages, and 5 women are still pregnant), and 1 other patient gave birth to a healthy baby in May 2000. Based on the rate of
pregnancy that was desired among the cohort at baseline, we estimate, conservatively, that approximately 10 – 15% (n=100) of our sample will attempt to become pregnant as they progress further post-treatment.
References:

Menstrual Cycle Maintenance and Quality of Life After Breast Cancer Treatment: A Prospective Study

None
MENSTRUAL CYCLE MAINTENANCE
AND
QUALITY OF LIFE

6-Month Follow-up Survey

...........................................

Clinical Coordinating Center

Wake Forest University School of Medicine
Department of Public Health Sciences
Winston-Salem, North Carolina 27157-1063
(336) 716-2116

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Funded by
The U.S. Army Medical Research and Material Command:
Breast Cancer Research Program A
PART I

MEDICAL and REPRODUCTIVE HISTORY
FOLLOW-UP QUESTIONNAIRE

The following questions ask about health professionals you may have seen in the past 6 months. This information will help us describe in general terms the kinds of services being used.

1. In the past six months, which of the following doctors or other health professionals have you seen? (Please Check all that apply)

- [] None
- [] Acupuncturist
- [] Allergist
- [] Cardiologist
- [] Chiropractor
- [] Dentist
- [] Dermatologist
- [] Ear/Nose/Throat Doctor
- [] Eye Doctor
- [] Marital Counselor
- [] Gastroenterologist
- [] General Practitioner
- [] Gynecologist
- [] Infertility Specialist
- [] Internist
- [] Massage Therapist
- [] Neurologist
- [] Sexual Therapist
- [] Family Therapist
- [] Nutritionist
- [] Obstetrician
- [] Medical Oncologist/Chemotherapist
- [] Orthopedic Surgeon
- [] Homeopathic/Herbalist/Naturopathic
- [] Pain Control Professional
- [] Alternative Therapist (Homeopath, herbalist, naturopathologist, etc.)
- [] Physical Therapist
- [] Plastic Surgeon
- [] Psychiatrist
- [] Clinical Psychologist
- [] Radiologist
- [] Rheumatologist
- [] Social Worker
- [] Organized Support Group
- [] Surgeon
- [] Urologist
- [] Other: ____________________________
2. In the past 6 months, have you been seen at an emergency room?

☐ No
☐ Yes → For what reason: __________________________________________

3. In the past 6 months, have you been hospitalized or had surgery? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>If yes, for what reason?</th>
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<tbody>
<tr>
<td>(a) Hospitalized?</td>
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<tr>
<td>(b) Had surgery?</td>
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4. Has anything else changed regarding either your mental or physical health status? Please mark one box for each line item (a) and (b).

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<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>What has changed?</th>
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<tr>
<td>(a) Mental Health?</td>
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<tr>
<td>(b) Physical Health?</td>
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5. Have you had any biopsies in the past 6 months?
   □ No
   □ Yes → If yes, what was biopsied?

   Why was this biopsied?

6. In the past 6 months, have you had a recurrence of breast cancer?
   □ No
   □ Yes → If yes, how was this diagnosis made. (For example, biopsy, lab tests)?

7. Have you been diagnosed with any other cancer in the past 6 months?
   □ No
   □ Yes → If yes, what type?

   How was this diagnosis made? (For example, biopsy, lab tests)?

8. Today’s date is: □□□ / □□□ / □□□□
   Month    Day    Year
PART II  
REPRODUCTIVE HISTORY

The following questions ask about your menstrual cycles and reproductive history. We are very interested in this information so that we can understand more about women’s health during their childbearing years. Some of the questions ask you to give dates or the number of times when certain things happened. If you are not sure about the exact date or number of times, please give your best estimate.

1. What was the date of the first day of your last menstrual period (your best guess)?

   Month  Day  Year

2. In the past 6 months, have you been sexually active with a male partner:

   □ No  -> Go to question 6
   □ Yes  -> Go to question 3

3. Which method of birth control are you and your partner using currently? (Check all that apply.)

   □ No method  □ Safe periods (rhythm or counting days)
   □ Condoms (rubbers)  □ Norplant
   □ Birth control pills  □ Cervical cap
   □ Foams/jellies/suppositories  □ Tubal ligation (tubes tied)
   □ Sponge  □ Vasectomy
   □ Withdrawal (pulling out)  □ Other (Please describe:__________)
   □ Diaphragm  □ Don’t know
4. In the past month, how many times have you had sexual intercourse without using contraception?

☐ ☐ Times

5. In the past 6 months, have you become pregnant?

☐ No
☐ Yes → If yes, are you pregnant now?

☐ No
☐ Yes

6. In the past month, have you had any hot flashes or night sweats (hot flashes that occur during sleep)?

☐ No
☐ Yes --> If yes, how many have you had in the past week?

☐ ☐ ☐ hot flashes/night sweats
### PART III  CURRENT MEDICATIONS

1. Please list below all of the **prescription medications** you are taking currently. (Write “none” if you are not taking any prescription medications at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
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2. Please list below all of the **non-prescription medications or supplements** you are taking currently. (Write “none” if you are not taking any non-prescription medications or supplements at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
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SWELLING FORM

The following questions concern swelling in your arm and/or hand. Please mark the appropriate box(es) for each question.

1. In the past 6 months, has any swelling occurred in your arm or hand on the same side that you had your lumpectomy or mastectomy?

   □ No → (Go to question 8)
   □ Yes → (Continue to question 2)
   □ Don’t know → (Go to question 8)

2. Do you believe the start of your swelling was related to any of the following?

   Yes   No   Don’t Know
   □     □     □  Radiation treatment
   □     □     □  Breast reconstruction
   □     □     □  Infection or injury to arm / hand
   □     □     □  Weather changes
   □     □     □  General use of your arm
   □     □     □  Exercise
   □     □     □  Airplane travel
   □     □     □  Other: Please describe: ____________________________
2a. How soon after you had surgery and/or began treatment did this swelling occur?

☐ Less than 1 week
☐ 1 week to 4 weeks
☐ 1 month to 3 months
☐ 4 months to 6 months
☐ 7 months to 9 months
☐ 10 months to 12 months
☐ 13 months to 15 months

2b. Where does (did) the swelling occur? (Check all that apply)

☐ Hand
☐ Upper Arm
☐ Lower Arm

2c. Do (did) you consider the swelling to be mostly?

☐ Mild
☐ Moderate
☐ Severe

3. Does (did) the swelling interfere with any of the following?

Yes ☐ No ☐

☐ Clothing that you wear
☐ Your ability to do routine activities, such as household chores or grooming.
☐ Exercise
☐ Your appearance

Other, please describe: ____________________________
4. Does (did) swelling seem to get worse with any of the following?

Don’t

<table>
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<th>Yes</th>
<th>No</th>
<th>Know</th>
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<tr>
<td></td>
<td></td>
<td>Hot weather</td>
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<td>General use of your arm</td>
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<td>Exercise</td>
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<td>Sauna / Jacuzzi / Hot bath</td>
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<td>Airplane travel</td>
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<td>Specific foods</td>
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<td>Mental / emotional stress</td>
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<td>Other: Please describe: ____________________________</td>
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5. Prior to your breast cancer diagnosis, did you notice swelling in your hand and/or arm with any of the following? **(Check all that apply)**

Don’t

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<th>Yes</th>
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<td>Exercise</td>
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<td>Household Chores</td>
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<td>Eating salty foods</td>
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<td>Drinking alcoholic beverages</td>
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Swelling 18 mos. 5/99
6. Did you seek treatment for this swelling in the past 6 months?

☐ No → If no, why not?

☐ Yes → If yes, what type of treatment did you receive? (Check all that apply)

☐ Compression therapy by machine
☐ Glove / Sleeve Compression / Garment
☐ Physical therapy
☐ Manual lymphatic drainage
☐ Bandaging technique
☐ Other, please describe: ________________________________

7. Do you have swelling now?

☐ No → (Go to question 8)
☐ Yes → (Continue to question 7a)

7a. If yes, how long have you had swelling?

☐ Less than 1 week
☐ 2 - 4 weeks
☐ 1 - 3 months
☐ 4 - 6 months
☐ 7 - 9 months
☐ 10 - 12 months
8. In the past 6 months, do you remember any breaks in your skin, infected hang nails, or slight skin injuries in your arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 9)

☐ Yes → (Continue to question 8a)

☐ Don’t Know → (Continue to question 9)

8a. If yes, did you receive antibiotics?

☐ Yes

☐ No

☐ Don’t know

9. In the past 6 months, did you have any infection in the arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 10)

☐ Yes → (Continue to question 9a)

☐ Don’t Know → (Continue to question 10)

If yes, did you:

9a. receive antibiotics by mouth?

☐ No

☐ Yes

☐ Don’t know
If yes, did you:

9b. receive antibiotics by injection?

☐ No  ☐ Yes  ☐ Don’t know

10. Do you have pain in the affected arm and/or hand? (Check one box for each site)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>hand</td>
<td></td>
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<tr>
<td>arm</td>
<td></td>
<td></td>
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<tr>
<td>hand and arm</td>
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</tbody>
</table>
**SYMPTOMS QUESTIONNAIRE**

Below are statements about symptoms some people may experience. For each statement, check the appropriate box for the response that best describes how bothersome the symptom was for you during the past month. If you did not have the problem, check the box under the column titled “symptom did not occur”. Please do not skip any questions. Mark only one box on each line.

If you experienced the symptom, use the following key to indicate how bothersome it was:

- **Mild** = symptom did not interfere with usual activities.
- **Moderate** = symptom interfered somewhat with usual activities.
- **Severe** = symptom was so bothersome that usual activities could not be performed.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1. Fatigue or low energy level</td>
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<td>2. Mouth ulcers</td>
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<td>3. Restless sleep</td>
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<td>4. Sleeping too much</td>
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<tr>
<td>5. Nervousness or shakiness inside</td>
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<tr>
<td>6. Mood changes</td>
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<td>7. Feeling depressed</td>
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<tr>
<td>8. Lightheadedness when standing up</td>
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<tr>
<td>9. Faintness or dizziness at rest</td>
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<tr>
<td>10. Headaches</td>
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<td></td>
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<tr>
<td>11. Swelling of ankles or feet</td>
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<tr>
<td>12. Diarrhea</td>
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</tbody>
</table>

*Symptoms 18 mos. 5/99*
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>13. Constipation</td>
<td></td>
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<td>14. Abdominal pain/cramps</td>
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<td>15. Vaginal dryness</td>
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<td>16. Muscle pain/ache/or cramp</td>
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<td>17. Weight gain</td>
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<td>18. Weight loss</td>
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<td>19. General aches and pains</td>
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<td>20. Hot flashes</td>
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<td>21. Joint pains</td>
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<tr>
<td>22. Night sweats</td>
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<td></td>
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<td>23. Aches in back of neck and skull</td>
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<td>24. Forgetfulness</td>
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<td>25. Difficulty concentrating</td>
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<td>26. Increased appetite</td>
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<td>27. Short temper</td>
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<td>28. Decreased efficiency</td>
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<td>29. Loss of interest in work/activities</td>
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<td>30. Lowered work performance</td>
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<td>31. Blind spots, fuzzy vision</td>
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<td>32. Breast sensitivity/tenderness</td>
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<tr>
<td>33. Avoidance of social affairs</td>
<td></td>
<td></td>
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<tr>
<td>34. Cold sweats</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Decreased appetite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Feelings of suffocation</td>
<td></td>
<td></td>
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<tr>
<td>37. Difficulty healing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Bloating</td>
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<td></td>
</tr>
</tbody>
</table>

Symptoms 18 mos. 5/99
QUALITY OF LIFE FORM

1. In general, would you say your health is:  **(Check one)**
   
   Excellent   Very good   Good   Fair   Poor
   [ ]        [ ]      [ ]     [ ]      [ ]

   The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.
   
   Limited a lot   Limited a little   Not limited at all
   [ ]        [ ]      [ ]

3. Climbing several flights of stairs.
   
   Limited a lot   Limited a little   Not limited at all
   [ ]        [ ]      [ ]

During the past four weeks, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

4. Accomplished less than you would like.
   
   Yes          No
   [ ]        [ ]

5. Had difficulty performing the work or other activities, for example, it took extra effort.
   
   Yes          No
   [ ]        [ ]

   During the past four weeks, have you had any of the following problems with your work or other regular daily activities **as a result of emotional problems** (such as feeling depressed or anxious)?

6. Accomplished less than you would like.
   
   Yes          No
   [ ]        [ ]

7. Didn’t do work or other activities as carefully as usual.
   
   Yes          No
   [ ]        [ ]
8. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Check one)

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

9. During the past four weeks, how much did pain interfere with your normal activities (including both work outside the home, housework and family activities)? (Check one)

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks:

10. Have you felt calm and peaceful? (Check one)

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

11. Did you have a lot of energy? (Check one)

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time

12. Have you felt downhearted and blue? (Check one)

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little of the time
- None of the time
Below is a list of statements that other people with your illness have said are important. Please circle the number that best describes how true each statement has been for you _during the past 7 days._

<table>
<thead>
<tr>
<th>Physical Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. I had a lack of energy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I had nausea.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I had trouble meeting the needs of my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I had pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I was bothered by side effects of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. In general, I felt sick.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>19. I was forced to spend time in bed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tbody>
</table>

20. How much does your **Physical Well-Being** affect your quality of life? _Circle one number._

<table>
<thead>
<tr>
<th>0</th>
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<th>10</th>
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</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Very Much So</td>
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<table>
<thead>
<tr>
<th>Social/Family Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I felt distant from my friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. I got emotional support from my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. I got support from my friends and neighbors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. My family had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Family communication about my illness was poor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
</tr>
</tbody>
</table>

If you have a spouse/partner, or are sexually active, please answer questions 26-27. Otherwise, go to question 28.

26. I felt close to my partner (or main support).                                      | 1          | 2            | 3        | 4           | 5         |
| 27. I was satisfied with my sex life.                                                 | 1          | 2            | 3        | 4           | 5         |

28. How much does your **Social/Family Well-Being** affect your quality of life? _Circle one number._

<table>
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<tr>
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<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Very Much So</td>
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</tbody>
</table>

**Quality of Life 18 mos.5/99**
<table>
<thead>
<tr>
<th>Relationship With Doctor</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. I had confidence in my doctor(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. My doctor was available to answer my questions.</td>
<td>1</td>
<td>2</td>
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</tbody>
</table>

31. How much does your Relationship with your Doctor affect your quality of life? *(Circle one number.)*

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<tr>
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<th>7</th>
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<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
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<td>Very Much So</td>
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<table>
<thead>
<tr>
<th>Emotional Well-Being</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. I felt sad.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>33. I was proud of how I’m coping with my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>34. I was losing hope in the fight against my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
</tr>
<tr>
<td>35. I felt nervous.</td>
<td>1</td>
<td>2</td>
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</tr>
<tr>
<td>36. I worried about dying.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tbody>
</table>

37. How much does your Emotional Well-Being affect your quality of life? *(Circle one number.)*

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<table>
<thead>
<tr>
<th>Functional Well-Being</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
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</thead>
<tbody>
<tr>
<td>38. I was able to work (include work in home).</td>
<td>1</td>
<td>2</td>
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</tr>
<tr>
<td>39. My work (include work in home) was fulfilling.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>40. I was able to enjoy life “in the moment.”</td>
<td>1</td>
<td>2</td>
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<td>5</td>
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<tr>
<td>41. I had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>42. I was sleeping well.</td>
<td>1</td>
<td>2</td>
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<td>5</td>
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<tr>
<td>43. I enjoyed my usual leisure pursuits.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>44. I was content with the quality of my life right now.</td>
<td>1</td>
<td>2</td>
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</table>

45. How much does your Functional Well-Being affect your quality of life? *(Circle one number.)*

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<tbody>
<tr>
<td>Not at all</td>
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<tr>
<td>Very Much So</td>
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</table>
**Additional Concerns**

<table>
<thead>
<tr>
<th>Additional Concern</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. I was short of breath.</td>
<td>1</td>
<td>2</td>
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<td>5</td>
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<tr>
<td>47. I was self-conscious about the way I dressed.</td>
<td>1</td>
<td>2</td>
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<td>5</td>
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<tr>
<td>48. My arms were swollen or tender.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>49. I felt sexually attractive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>50. I was bothered by hair loss.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>51. I worried about the risk of cancer in other family members.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>52. I worried about the effect of stress on my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>53. I was bothered by a change in weight.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>54. I was able to feel like a woman.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

55. How much do these Additional Concerns affect your quality of life? (Circle one number.)

0 1 2 3 4 5 6 7 8 9 10

Not at all  Very Much So

**YOUR APPEARANCE**

This section asks you about your general perceptions regarding your body. Right now, how satisfied are you with these parts of your body? Please check the appropriate box for the response that best describes your satisfaction with each body part.

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Neutral</th>
<th>Somewhat satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>56</td>
<td>Hair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>57</td>
<td>Breasts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>58</td>
<td>Arms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>59</td>
<td>Face</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60</td>
<td>Waist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61</td>
<td>Hips</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>62</td>
<td>Thighs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>63</td>
<td>Overall body</td>
<td></td>
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</tbody>
</table>

*Quality of Life 18 mos.5/99*
How much do you agree or disagree with the following statement? (Check the appropriate box.)

64. The appearance of my breast area is important to me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

65. I view myself as a:

□ Very overweight person
□ Moderately overweight person
□ Normal weight person
□ Moderately thin person
□ Very thin person

PART III. SEXUALITY

These next questions are about the way health problems may interfere with your sex life. These questions are personal, but your answers are important in understanding how health problems may affect women’s sexuality.

66. Have you been sexually active with a partner during the last 6 months?

□ No ---> (If no, skip to Question 79).
□ Yes ---> (If yes, continue to Question 67).

67. How many times have you had sexual intercourse in the past month?

□ 0 times
□ 1 - 4 times
□ 5 - 10 times
□ 11 or more
For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH.**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>68. How often were you aware of wetness in your vagina as you became sexually excited?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>69. How often did it take a long time for your vagina to become wet or slippery as you became sexually excited?</td>
<td></td>
<td></td>
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<tr>
<td>70. During sexual relations, how frequently did you notice dryness of your vagina?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>71. How often did you feel pain or discomfort during vaginal penetration?</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>72. How often did you feel satisfied after sexual activity?</td>
<td></td>
<td></td>
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<tr>
<td>73. How often were you satisfied with the frequency of sexual activity?</td>
<td></td>
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</tr>
<tr>
<td>74. How frequently did you feel tense or nervous after a sexual experience?</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH.**

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>75. I avoided having my breast area fondled or kissed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>76. My partner avoided fondling or kissing my breast area.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>77. I notice I didn’t hug or kiss my partner much.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>78. I notice my partner didn’t hug and kiss me much.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
PART IV. SLEEP HABITS

The next group of questions ask about your sleep habits. Please check the appropriate box for the one response that best describes how often you experienced these situations in THE PAST 4 WEEKS.

79. Did you have trouble falling asleep?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week

80. Did you wake up several times a night?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week

81. Did you wake up earlier than you planned to?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week

82. Did you have trouble getting back to sleep after you woke up too early?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week
83. Overall, how was your typical night’s sleep during the past 4 weeks?

☐ Very sound or restful
☐ Sound or restful
☐ Average quality
☐ Restless
☐ Very restless

84. About how many hours of sleep did you get on a typical night during the past 4 weeks?

☐ 5 or less hours
☐ 6 hours
☐ 7 hours
☐ 8 hours
☐ 9 hours
☐ 10 or more hours

PART V. SPIRITUAL BELIEFS

The following questions are about spiritual beliefs. Please check the appropriate box indicating how true the statement has been for you during THE PAST WEEK.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>85. I felt peaceful.</td>
<td></td>
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<tr>
<td>86. I had a reason for living.</td>
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<tr>
<td>87. I felt a sense of purpose in my life.</td>
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<tr>
<td>88. I was able to reach down deep into myself for comfort.</td>
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<tr>
<td>89. I felt a sense of harmony within myself.</td>
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<tr>
<td>90. I found comfort in my faith.</td>
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</tr>
<tr>
<td>91. I found strength in my faith.</td>
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</tbody>
</table>
92. Where would you place yourself on the following scale, if “0” means that your life is just the way it was before your breast cancer, “+5” means that everything is totally different but better, and “-5” means that everything is totally different but worse. (Please circle ONE number).

-5  -4  -3  -2  -1  0  +1  +2  +3  +4  +5
Worse  Same as before  Better

PART VI. EMOTIONAL FEELINGS

The following questions consist of groups of statements. After reading each group of statements carefully, check the box next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally, check each one. Be sure to read all the statements in each group before making your choice.

93. ☐ I do not feel sad.
☐ I feel sad.
☐ I am sad all the time and I can’t snap out of it.
☐ I am so sad or unhappy that I can’t stand it.

94. ☐ I am not particularly discouraged about the future.
☐ I feel discouraged about the future.
☐ I feel I have nothing to look forward to.
☐ I feel that the future is hopeless and that things cannot improve.

95. ☐ I do not feel like a failure.
☐ I feel I have failed more than the average person.
☐ As I look back on my life, all I can see is a lot of failures.
☐ I feel I am a complete failure as a person.

96. ☐ I get as much satisfaction out of things as I used to.
☐ I don’t enjoy things the way I used to.
☐ I don’t get real satisfaction out of anything anymore.
☐ I am dissatisfied or bored with everything.
97. □ I don't feel particularly guilty.
   □ I feel guilty a good part of the time.
   □ I feel quite guilty most of the time.
   □ I feel guilty all of the time.

98. □ I don't feel I am being punished.
   □ I feel I may be punished.
   □ I expect to be punished.
   □ I feel I am being punished.

99. □ I don't feel disappointed in myself.
   □ I am disappointed in myself.
   □ I am disgusted with myself.
   □ I hate myself.

100. □ I don't feel I am any worse than anybody else.
     □ I am critical of myself for my weaknesses or mistakes.
     □ I blame myself all the time for my faults.
     □ I blame myself for everything bad that happens.

101. □ I don't have any thoughts of killing myself.
     □ I have thoughts of killing myself, but I would not carry them out.
     □ I would like to kill myself.
     □ I would kill myself if I had the chance.

102. □ I don't cry anymore than usual.
     □ I cry more now than I used to.
     □ I cry all the time now.
     □ I used to be able to cry, but now I can't cry even though I want to.
103.  □ I am no more irritated now than I ever am.
        □ I get annoyed or irritated more easily than I used to.
        □ I feel irritated all the time now.
        □ I don’t get irritated at all by the things that used to irritate me.

104.  □ I have not lost interest in other people.
        □ I am less interested in other people than I used to be.
        □ I have lost most of my interest in other people.
        □ I have lost all of my interest in other people.

105.  □ I make decisions about as well as I ever could.
        □ I put off making decisions more than I used to.
        □ I have greater difficulty in making decisions than before.
        □ I can’t make decisions at all anymore.

106.  □ I don’t feel I look any worse than I used to.
        □ I am worried that I am looking old or unattractive.
        □ I feel that there are permanent changes in my appearance that make me look unattractive.
        □ I believe that I look ugly.

107.  □ I can work about as well as before.
        □ It takes an extra effort to get started at doing something.
        □ I have to push myself very hard to do anything.
        □ I can’t do any work at all.

108.  □ I can sleep as well as usual.
        □ I don’t sleep as well as I used to.
        □ I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
        □ I wake up several hours earlier than I used to and cannot get back to sleep.
109. □ I don’t get more tired than usual.
    □ I get tired more easily than I used to.
    □ I get tired from doing almost anything.
    □ I am too tired to do anything.

110. □ My appetite is no worse than usual.
    □ My appetite is not as good as it used to be.
    □ My appetite is much worse now.
    □ I have no appetite at all anymore.

111. □ I haven’t lost much weight, if any, lately.
    □ I have lost more than five (5) pounds.
    □ I have lost more than ten (10) pounds.
    □ I have lost more than fifteen (15) pounds.

112. □ I am no more worried about my health than usual.
    □ I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
    □ I am very worried about physical problems and it’s hard to think of much else.
    □ I am so worried about my physical problems that I cannot think about anything else.

113. □ I have not noticed any recent change in my interest in sex.
    □ I am less interested in sex than I used to be.
    □ I am much less interested in sex now.
    □ I have lost interest in sex completely.
SOCIAL SUPPORT FORM

The following are questions about the support that is available to you.

1. At the present time, about how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? (Please write the number in the boxes below.)

   [ ] Number of close friends and close relatives

People sometimes look to others for companionship, assistance, or other types of support. Currently, how often is each of the following kinds of support available to you if you need it? (Check one box for each statement.)

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Someone to help you if you were confined to bed.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>3. Someone you can count on to listen to you when you need to talk.</td>
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</tr>
<tr>
<td>4. Someone to give you good advice about a crisis.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Someone to take you to the doctor if you needed it.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. Someone who shows you love and affection.</td>
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<td></td>
<td></td>
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<tr>
<td>7. Someone to have a good time with.</td>
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<tr>
<td>8. Someone to give you information to help you understand a situation.</td>
<td></td>
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<tr>
<td>9. Someone to confide in or talk to about yourself or your problems.</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>None of the time</td>
<td>A little of the time</td>
<td>Some of the time</td>
<td>Most of the time</td>
<td>All of the time</td>
</tr>
<tr>
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<tr>
<td>10.</td>
<td>Someone who hugs you.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>11.</td>
<td>Someone to get together with for relaxation.</td>
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<td></td>
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<tr>
<td>12.</td>
<td>Someone to prepare your meals if you were unable to do it yourself.</td>
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<td></td>
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<tr>
<td>13.</td>
<td>Someone whose advice you really want.</td>
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<td></td>
<td></td>
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<tr>
<td>14.</td>
<td>Someone to do things with to help you get your mind off things.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>15.</td>
<td>Someone to help with daily chores if you were sick.</td>
<td></td>
<td></td>
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<tr>
<td>16.</td>
<td>Someone to share your most private worries and fears with.</td>
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<tr>
<td>17.</td>
<td>Someone to turn to for suggestions about how to deal with a personal problem.</td>
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<tr>
<td>18.</td>
<td>Someone to do something enjoyable with.</td>
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<tr>
<td>20.</td>
<td>Someone to love you and make you feel wanted.</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
For the following questions, please check the box that is the most true for you at the present time. (Check only one box for each statement.)

Of the people who are important to you, how many:

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>One</th>
<th>Some</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.</td>
<td>Don’t understand you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Get on your nerves.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>23.</td>
<td>Ask too much of you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Don’t include you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Show that they don’t like you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>Boss you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>Try to get you to do things you don’t want to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PERSONAL HABITS FORM

These questions are about habits that may affect your health (smoking, alcohol use, weight, and exercise). Please answer each question as accurately as possible.

1. Do you smoke currently?

   □ No
   □ Yes

   If yes, how many cigarettes do you smoke per day? (1 pack = 20 cigarettes)

   □ I smoke occasionally.
   □ 0 - 5 cigarettes a day
   □ 6 - 20 cigarettes a day
   □ 21 - 30 cigarettes a day
   □ 31 - 40 cigarettes a day
   □ more than 40 cigarettes a day

2. Do you currently drink alcoholic beverages?

   □ No
   □ Yes

   If yes, about how many alcoholic beverages (beer, wine, or mixed drinks) do you currently drink in an average month?

   □ Beverages per month
3. What is your current weight?

[ ] [ ] [ ] pounds

The following questions are about your usual physical activity and exercise. This includes walking and sports.

4. Think about the walking you do outside the home. In the past month, how often did you walk outside the home for more than 10 minutes without stopping? (Mark only one.)

[ ] Rarely or never ---> (Go to Question 5)
[ ] 1-3 times each month ---> (Go to Question 4a)
[ ] 1 time each week ---> (Go to Question 4a)
[ ] 2-3 times each week ---> (Go to Question 4a)
[ ] 4-6 times each week ---> (Go to Question 4a)
[ ] 7 or more times each week ---> (Go to Question 4a)

4a. When you walked outside the home for more than 10 minutes without stopping, how many minutes did you usually walk?

[ ] Less than 20 minutes
[ ] 20-39 minutes
[ ] 40-59 minutes
[ ] 1 hour or more

4b. What was your usual speed?

[ ] Casual strolling or walking (less than 2 miles an hour)
[ ] Average or normal (2-3 miles an hour)
[ ] Fairly fast (3-4 miles an hour)
[ ] Very fast (more than 4 miles an hour)
[ ] Don’t Know
Following are three categories of exercise, (strenuous, moderate, and mild). Not including walking outside the home, how often each week (7 days) do you usually do the following strenuous, moderate, and mild types of exercise?

5. **STRENUEOUS OR VERY HARD EXERCISE.** (You work up a sweat and your heart beats fast.) For example, aerobics, aerobic dancing, jogging, tennis, swimming laps.

- [ ] None ---> (Go to Question 6)
- [ ] 1 day per week ---> (Go to Question 5a)
- [ ] 2 days per week ---> (Go to Question 5a)
- [ ] 3 days per week ---> (Go to Question 5a)
- [ ] 4 days per week ---> (Go to Question 5a)
- [ ] 5 or more days per week ---> (Go to question 5a)

5a. How long do you usually exercise like this at one time?

- [ ] Less than 20 minutes
- [ ] 20-39 minutes
- [ ] 40-59 minutes
- [ ] 1 hour or more

6. **MODERATE EXERCISE** (Not exhausting). For example, biking outdoors, using an exercise machine (like a stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing.

- [ ] None ---> (Go to Question 7)
- [ ] 1 day per week ---> (Go to Question 6a)
- [ ] 2 days per week ---> (Go to Question 6a)
- [ ] 3 days per week ---> (Go to Question 6a)
- [ ] 4 days per week ---> (Go to Question 6a)
- [ ] 5 or more days per week ---> (Go to Question 6a)
6a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more

7. MILD EXERCISE. For example, slow dancing, bowling, golf.

☐ None
☐ 1 day per week ---> (Go to Question 7a)
☐ 2 days per week ---> (Go to Question 7a)
☐ 3 days per week ---> (Go to Question 7a)
☐ 4 days per week ---> (Go to Question 7a)
☐ 5 or more days per week ---> (Go to Question 7a)

7a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more
CONTACT INFORMATION FORM

We would like you to update your contact information so that we can keep in touch with you during the study. This information is very important, so please answer these questions completely. Please print the information in the space provided or mark the appropriate box.

1. Has your address changed since our last mailing to you?
   □ No  □ Yes → If yes, please provide current mailing address
   
   Your Current Mailing Address?

   __________________________________________
   __________________________________________
   __________________________________________

2. Telephone Numbers: Home: Area Code (___ ___) ___ ___ - ___ ___
   Work: Area Code (___ ___) ___ ___ - ___ ___
   Other: Area Code (___ ___) ___ ___ - ___ ___

3. When is the best time to contact you? Where is the best place to contact you?

   ____________________________  ____________________________
   Day of week                  time(s)

   ____________________________  ____________________________
   Day of week                  time(s)

   □ At home
   □ At work
   □ Other

   □ At home
   □ At work
   □ Other
4. In case we might ever need to contact you by telephone, may we leave a message for you on your answering machine, (if you have one), if we are unable to reach you directly?

☐ No
☐ Yes

5. What is your husband’s or partner’s legal name? (This information will help us keep in contact with you during the study. Please leave this blank if you are not currently married or with a long-term partner.)

__________________________________________  __________ _______________________________________
First MI Last

6. Please provide the names of two relatives or friends, not living in your household, who are likely to know how to contact you if we are unable to reach you.

Name: ____________________________________________________________
Address: __________________________________________________________

Phone Number:    Area Code (____) _______ - ______

Relationship to you: ________________________________________________

Name: ____________________________________________________________
Address: __________________________________________________________

Phone Number:    Area Code (____) _______ - ______

Relationship to you: ________________________________________________
MENSTRUAL CYCLE MAINTENANCE AND QUALITY OF LIFE

One-Year Follow-up Survey

Clinical Coordinating Center

Wake Forest University School of Medicine
Department of Public Health Sciences
Winston-Salem, North Carolina 27157-1063
(336) 713-4268

Funded by
The U.S. Army Medical Research and Material Command:
Breast Cancer Research Program A
DEMOGRAPHIC FOLLOW-UP FORM

YOUR BACKGROUND

The following questions are about your background. We would like to see if you have had any changes in your personal situation in the past year. Please mark the appropriate box for each question.

1. What is your marital status?
   - [ ] Never married
   - [ ] Presently married
   - [ ] Living in a marriage-like relationship
   - [ ] Divorced
   - [ ] Separated
   - [ ] Widowed

2. Which category below best describes the highest level of formal education you have completed? (Choose the one best answer).
   - [ ] No formal education
   - [ ] Grade school (1st through 8th grade)
   - [ ] Some high school (9th through 11th grade)
   - [ ] High school diploma or G.E.D.
   - [ ] Business or vocational training school after high school graduation
   - [ ] Some college (but a college degree was not obtained)
   - [ ] Associate Degree (A.D. or A.A.)
   - [ ] College graduate or Baccalaureate Degree (B.A. or B.S.)
   - [ ] Some college or professional school after college graduation
   - [ ] Master’s Degree
   - [ ] Doctoral Degree (Ph.D., M.D., J.D., D.D.S., etc.)
3. What was your total family income (before taxes) from all sources last year? (Check one box below. This information is important for describing the women in the study as a group and is kept strictly confidential).

☐ Less than $10,000
☐ $10,000 to $19,999
☐ $20,000 to $34,999
☐ $35,000 to $49,999
☐ $50,000 to $74,999
☐ $75,000 to $100,000
☐ More than $100,000

4. What type of health insurance do you have? (If you have more than one type of insurance, please mark the box for your primary source of insurance.)

☐ HMO
☐ Group Health Insurance
☐ V.A./Military Sponsored
☐ Individual Health Insurance (includes CHAMPUS)
☐ Medicaid
☐ Disability Insurance
☐ None
☐ Other (Please list: ______________________)

5. What is your current employment status? (Check the box that best describes you.)

☐ Unemployed/Looking for work → (Go to question 8)
☐ Retired → (Go to question 8)
☐ Full-time Homemaker → (Go to question 8)
☐ Employed - full-time → (Go to question 6)
☐ Employed - part-time → (Go to question 6)
☐ Disabled, unable to work → (Go to question 8)
☐ Student → (Go to question 8)
☐ Other (Please list: ______________________) → (Go to question 8)
6. If you are employed, which category best describes your occupation?

☐ Professional, Technical & Related Occupations (such as teachers/professors, nurses, lawyers, physicians & engineers)

☐ Managers, Administrators, or Proprietors (such as sales managers, real estate agents, or postmasters)

☐ Clerical & Related Occupations (such as secretaries, clerks or mail carriers)

☐ Sales Occupations (such as salespersons, demonstrators, agents and brokers)

☐ Service Occupations (such as police, cooks, or hairdressers)

☐ Skilled Crafts, Service Repair Persons, & Related Occupations (such as carpenters, appliance repair, or telephone line workers)

☐ Equipment or Vehicle Operators & Related Occupations (such as drivers, railroad brakemen or sewer workers)

☐ Laborers (such as helpers, longshoremen, or warehouse workers)

☐ Farmers (owners, managers, operators or tenants)

☐ Members of the military

☐ Other (please describe):  

7. This following is a list of employment issues that a person might have. For each statement, indicate whether this has happened to you since your diagnosis. If it did occur, indicate whether you believe this situation was related to your diagnosis. (Check the box by the answers that are most true for you in each statement.)

Since your diagnosis have you:

a. believed you could not change jobs for fear of losing your health insurance?

☐ No

☐ Yes (If yes, was it related to your diagnosis?)

☐ No

☐ Yes
b. lost your health insurance due to sick leave?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
     □ No
     □ Yes

c. been fired or laid off?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
     □ No
     □ Yes

d. been demoted?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
     □ No
     □ Yes

e. been denied a promotion?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
     □ No
     □ Yes

f. been denied a wage increase?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
     □ No
     □ Yes
g. had your work responsibilities limited unnecessarily?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

h. been promoted?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

8. This following is a list of insurance issues that a person might have. For each statement, indicate whether this has happened to you since your diagnosis. If it did occur, indicate whether you believe this situation was related to your diagnosis. (Check the box by the answers that are most true for you in each statement.)

Since your diagnosis have:

a. you been denied health insurance?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

b. you been denied life insurance?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes
c. your health insurance rates increased?
   ☐ No
   ☐ Yes (If yes, was it related to your diagnosis?)
      ☐ No
      ☐ Yes

d. your life insurance rates increased?
   ☐ No
   ☐ Yes (If yes, was it related to your diagnosis?)
      ☐ No
      ☐ Yes

e. you had a health benefit payment denied?
   ☐ No
   ☐ Yes (If yes, was it related to your diagnosis?)
      ☐ No
      ☐ Yes

f. you had trouble changing from group health
to individual health insurance?
   ☐ No
   ☐ Yes (If yes, was it related to your diagnosis?)
      ☐ No
      ☐ Yes

9. Please give the date you completed this form:     ☐ ☐ / ☐ ☐ / ☐ ☐ ☐ ☐

   Month  Day  Year
PART 1

MEDICAL & REPRODUCTIVE HISTORY
FOLLOW-UP QUESTIONNAIRE

The following questions ask about health professionals you may have seen in the past 6 months. This information will help us describe in general terms the kinds of services being used.

1. In the past six months, which of the following doctors or other health professionals have you seen? (Please Check all that apply)

- [ ] None
- [ ] Acupuncturist
- [ ] Allergist
- [ ] Cardiologist
- [ ] Chiropractor
- [ ] Dentist
- [ ] Dermatologist
- [ ] Ear/Nose/Throat Doctor
- [ ] Eye Doctor
- [ ] Marital Counselor
- [ ] Gastroenterologist
- [ ] General Practitioner
- [ ] Gynecologist
- [ ] Infertility Specialist
- [ ] Internist
- [ ] Massage Therapist
- [ ] Neurologist
- [ ] Sexual Therapist
- [ ] Family Therapist
- [ ] Nutritionist
- [ ] Obstetrician
- [ ] Medical Oncologist/Chemotherapist
- [ ] Orthopedic Surgeon
- [ ] Homeopathic/Herbalist/Naturopathic
- [ ] Pain Control Professional
- [ ] Alternative Therapist (Homeopath, herbalist, naturopathologist, etc.)
- [ ] Physical Therapist
- [ ] Plastic Surgeon
- [ ] Psychiatrist
- [ ] Clinical Psychologist
- [ ] Radiologist
- [ ] Rheumatologist
- [ ] Social Worker
- [ ] Organized Support Group
- [ ] Surgeon
- [ ] Urologist
- [ ] Other: _______________________
2. In the past 6 months, have you been seen at an emergency room?

☐ No

☐ Yes \(\rightarrow\) For what reason: ________________________________

3. In the past 6 months, have you been hospitalized or had surgery? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>If yes, for what reason?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalized?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

|        |    |     |                          |
| (b)    |    |     |                          |
| Had surgery? |    |     |                          |

4. Has anything else changed regarding either your mental or physical health status? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>What has changed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

|        |    |     |                  |
| (b)    |    |     |                  |
| Physical Health? |    |     |                  |
5. Have you had any biopsies in the past 6 months?

☐ No
☐ Yes → If yes, what was biopsied?

Why was this biopsied?

6. In the past 6 months, have you had a re-occurrence of breast cancer?

☐ No
☐ Yes → If yes, how was this diagnosis made. (For example, biopsy, lab tests)?

7. Have you been diagnosed with any other cancer in the past 6 months?

☐ No
☐ Yes → If yes, what type?

How was this diagnosis made? (For example, biopsy, lab tests)?
PART II

REPRODUCTIVE HISTORY

The following questions ask about your menstrual cycles and reproductive history. We are very interested in this information so that we can understand more about women’s health during their childbearing years. Some of the questions ask you to give dates or the number of times when certain things happened. If you are not sure about the exact date or number of times, please give your best estimate.

1. What was the date of the first day of your last menstrual period (your best guess)?

   Month - Day - Year

2. In the past 6 months, have you been sexually active with a male partner:

   - No  Go to question 6
   - Yes  Go to question 3

3. Which method of birth control are you and your partner using currently? (Check all that apply.)

   - No method
   - Condoms (rubbers)
   - Birth control pills
   - Foams/jellies/suppositories
   - Sponge
   - Withdrawal (pulling out)
   - Diaphragm
   - Safe periods (rhythm or counting days)
   - Norplant
   - Cervical cap
   - Tubal ligation (tubes tied)
   - Vasectomy
   - Other (Please describe:__________)
   - Don’t know

4. In the past month, how many times have you had sexual intercourse without using contraception?

   Times
5. **In the past 6 months,** have you become pregnant?
   
   □ No
   □ Yes → **If yes,** are you pregnant now?
      
   □ No
   □ Yes

6. **In the past month,** have you had any hot flashes or night sweats (hot flashes that occur during sleep)?
   
   □ No
   □ Yes → **If yes,** how many have you had in the **past week**?

   □□□□ hot flashes/night sweats
FAMILY HISTORY UPDATE

Please update the following grid about the **history of breast cancer** among your female relatives. If you do not have a full-blooded relative in one of the categories listed below, please leave that line blank. (MARK ONLY ONE BOX PER LINE.)

1. **Did this relative have breast cancer?**

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Don't know if she had breast cancer</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>How old was she when her first breast cancer occurred?</strong></td>
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<tr>
<td>Less than 45</td>
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<tr>
<td>45 or older</td>
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<td></td>
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<tr>
<td>Don't know age</td>
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</tbody>
</table>

| a. Mother      |    |    |                                   |                |
| b. Sister 1    |    |    |                                   |                |
| c. Sister 2    |    |    |                                   |                |
| d. Sister 3    |    |    |                                   |                |
| e. Sister 4    |    |    |                                   |                |
| f. Daughter 1  |    |    |                                   |                |
| g. Daughter 2  |    |    |                                   |                |
| h. Daughter 3  |    |    |                                   |                |
| i. Daughter 4  |    |    |                                   |                |
| j. Maternal grandmother (your mother’s mother) |    |    |                                   |                |
| k. Paternal grandmother (your father’s mother) |    |    |                                   |                |
Please update the following grid about the **history of ovarian cancer** among your female relatives. If you do not have a full-blooded relative in one of the categories listed below, please leave that line blank.
(MARK ONLY ONE BOX PER LINE.)

2. **Did this relative have ovarian cancer?**

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>Don't know if she had ovarian cancer</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>How old was she when her first ovarian cancer occurred?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than 45</td>
<td>45 or older</td>
</tr>
<tr>
<td>a.</td>
<td>Mother</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b.</td>
<td>Sister 1</td>
<td>☐</td>
<td>☐</td>
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<td>c.</td>
<td>Sister 2</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d.</td>
<td>Sister 3</td>
<td>☐</td>
<td>☐</td>
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<td>e.</td>
<td>Sister 4</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>f.</td>
<td>Daughter 1</td>
<td>☐</td>
<td>☐</td>
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<td>g.</td>
<td>Daughter 2</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h.</td>
<td>Daughter 3</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>i.</td>
<td>Daughter 4</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>j.</td>
<td>Maternal grandmother (your mother's mother)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>k.</td>
<td>Paternal grandmother (your father's mother)</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
CURRENT MEDICATIONS

1. Please list below all of the **prescription medications** you are taking currently. (Write "none" if you are not taking any prescription medications at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
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<tbody>
<tr>
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</table>

2. Please list below all of the **non-prescription medications or supplements** you are taking currently. (Write "none" if are not taking any non-prescription medications or supplements at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
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<tbody>
<tr>
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*Medications One-Year 1/11/99*
**TREATMENT EXPECTATIONS**

1. We are interested in your expectations regarding the treatments you received over the past year. For each of the treatments listed below, how did your expectations before treatment compare with the actual treatment you received? Better than expected, the same as you expected, or worse than you expected? (Mark one box for each line.)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Not Applicable. (Did not have this treatment.)</th>
<th>Worse Than Expected</th>
<th>Same As Expected</th>
<th>Better Than Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lumpectomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Reconstructive Surgery</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Radiation</td>
<td></td>
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<tr>
<td>Chemotherapy</td>
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<tr>
<td>Tamoxifen</td>
<td></td>
<td></td>
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<tr>
<td>Bone Marrow Transplant</td>
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</tbody>
</table>
SWELLING FORM

The following questions concern swelling in your arm and/or hand. Please mark the appropriate box(es) for each question.

1. In the past 6 months, has any swelling occurred in your arm or hand on the same side that you had your lumpectomy or mastectomy?
   □ No → (Go to question 8)
   □ Yes → (Continue to question 2)
   □ Don’t know → (Go to question 8)

2. Do you believe the start of your swelling was related to any of the following?

   □ Yes □ No □ Don’t Know
   □ Radiation treatment
   □ Breast reconstruction
   □ Infection or injury to arm / hand
   □ Weather changes
   □ General use of your arm
   □ Exercise
   □ Airplane travel
   □ Other: Please describe: __________________________________________

Swelling One-Year 1/11/99
2a. How soon after you had surgery and/or began treatment did this swelling occur?

☐ Less than 1 week
☐ 1 week to 4 weeks
☐ 1 month to 3 months
☐ 4 months to 6 months
☐ 7 months to 9 months
☐ 10 months to 12 months
☐ 13 months to 15 months

2b. Where does (did) the swelling occur? (Check all that apply)

☐ Hand
☐ Upper Arm
☐ Lower Arm

2c. Do (did) you consider the swelling to be mostly?

☐ Mild
☐ Moderate
☐ Severe

3. Does (did) the swelling interfere with any of the following?

   Yes    No
   ☐  ☐ Clothing that you wear
   ☐  ☐ Your ability to do routine activities, such as household chores or grooming.
   ☐  ☐ Exercise
   ☐  ☐ Your appearance
   ☐  ☐ Other, please describe: ________________________________

Swelling One-Year 1/11/99
4. Does (did) swelling seem to get worse with any of the following?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t</th>
<th>Know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Hot weather</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>General use of your arm</td>
<td></td>
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<td></td>
<td></td>
<td>Exercise</td>
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<td></td>
<td>Sauna / Jacuzzi / Hot bath</td>
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<td></td>
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<td></td>
<td>Airplane travel</td>
<td></td>
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<td></td>
<td>Specific foods</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Mental / emotional stress</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Other: Please describe:</td>
<td></td>
</tr>
</tbody>
</table>

5. Prior to your breast cancer diagnosis, did you notice swelling in your hand and/or arm with any of the following? (Check all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t</th>
<th>Know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Exercise</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Household Chores</td>
<td></td>
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<td></td>
<td></td>
<td>Heat/Humidity</td>
<td></td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>Eating salty foods</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Drinking alcoholic beverages</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Other: Please describe:</td>
<td></td>
</tr>
</tbody>
</table>

Swelling One-Year 1/11/99
6. Did you seek treatment for this swelling in the past 6 months?

☐ No → If no, why not?

☐ Yes → If yes, what type of treatment did you receive? (Check all that apply)

☐ Compression therapy by machine
☐ Glove / Sleeve Compression / Garment
☐ Physical therapy
☐ Manual lymphatic drainage
☐ Bandaging technique
☐ Other, please describe: ________________________________

7. Do you have swelling now?

☐ No → (Go to question 8)
☐ Yes → (Continue to question 7a)

7a. If yes, how long have you had swelling?

☐ Less than 1 week
☐ 2 - 4 weeks
☐ 1 - 3 months
☐ 4 - 6 months
☐ 7 - 9 months
☐ 10 - 12 months
8. In the past 6 months, do you remember any breaks in your skin, infected hang nails, or slight skin injuries in your arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 9)
☐ Yes → (Continue to question 8a)
☐ Don’t Know → (Continue to question 9)

8a. If yes, did you receive antibiotics?

☐ Yes
☐ No
☐ Don’t know

9. In the past 6 months, did you have any infection in the arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 10)
☐ Yes → (Continue to question 9a)
☐ Don’t Know → (Continue to question 10)

If yes, did you:

9a. receive antibiotics by mouth?

☐ No
☐ Yes → (Continue to question 9b)
☐ Don’t know
If yes, did you:

9b. receive antibiotics by injection?

☐ No
☐ Yes
☐ Don't know

10. Do you have pain in the affected arm and/or hand? (Check one box for each site)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>arm</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SYMPTOMS QUESTIONNAIRE

Below are statements about symptoms some people may experience. For each statement, check the appropriate box for the response that best describes how bothersome the symptom was for you during the past month. If you did not have the problem, check the box under the column titled “symptom did not occur”. Please do not skip any questions. Mark only one box on each line.

If you experienced the symptom, use the following key to indicate how bothersome it was:

- **Mild** = symptom did not interfere with usual activities.
- **Moderate** = symptom interfered somewhat with usual activities.
- **Severe** = symptom was so bothersome that usual activities could not be performed.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1. Fatigue or low energy level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Mouth ulcers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Restless sleep</td>
<td></td>
<td></td>
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<tr>
<td>4. Sleeping too much</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Nervousness or shakiness inside</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Mood changes</td>
<td></td>
<td></td>
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<tr>
<td>7. Feeling depressed</td>
<td></td>
<td></td>
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<tr>
<td>8. Lightheadedness when standing up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Faintness or dizziness at rest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Headaches</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Swelling of ankles or feet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Diarrhea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom</td>
<td>Symptom did not occur</td>
<td>Symptom Occurred and Was:</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>13. Constipation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Abdominal pain/cramps</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Vaginal dryness</td>
<td></td>
<td></td>
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<tr>
<td>16. Muscle pain/ache/or cramp</td>
<td></td>
<td></td>
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<tr>
<td>17. Weight gain</td>
<td></td>
<td></td>
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<tr>
<td>18. Weight loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. General aches and pains</td>
<td></td>
<td></td>
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<tr>
<td>20. Hot flashes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Joint pains</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Night sweats</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Aches in back of neck and skull</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Forgetfulness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Difficulty concentrating</td>
<td></td>
<td></td>
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<tr>
<td>26. Increased appetite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Short temper</td>
<td></td>
<td></td>
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<tr>
<td>28. Decreased efficiency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Loss of interest in work/activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Lowered work performance</td>
<td></td>
<td></td>
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<tr>
<td>31. Blind spots, fuzzy vision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Breast sensitivity/tenderness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Avoidance of social affairs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. Cold sweats</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Decreased appetite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Feelings of suffocation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Difficulty healing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Bloating</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
QUALITY OF LIFE FORM

1. In general, would you say your health is: *(Check one)*
   
   [ ] Excellent  [ ] Very good  [ ] Good  [ ] Fair  [ ] Poor

   The following questions are about activities you might do during a typical day. *Does your health now limit you in these activities? If so, how much?*

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.
   
   [ ] Limited a lot  [ ] Limited a little  [ ] Not limited at all

3. Climbing several flights of stairs.
   
   [ ] Limited a lot  [ ] Limited a little  [ ] Not limited at all

   During the *past four weeks*, have you had any of the following problems with your work or other regular daily activities *as a result of your physical health?*

   Yes  No

4. Accomplished less than you would like.
   
   [ ]

5. Had difficulty performing the work or other activities, for example, it took extra effort.
   
   [ ]

   During the *past four weeks*, have you had any of the following problems with your work or other regular daily activities *as a result of emotional problems* (such as feeling depressed or anxious)?

   Yes  No

6. Accomplished less than you would like.
   
   [ ]

7. Didn’t do work or other activities as carefully as usual.
   
   [ ]
8. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Check one)

Not at all  Slightly  Moderately  Quite a bit  Extremely
☐  ☐  ☐  ☐  ☐

9. During the past four weeks, how much did pain interfere with your normal activities (including both work outside the home, housework and family activities)? (Check one)

Not at all  Slightly  Moderately  Quite a bit  Extremely
☐  ☐  ☐  ☐  ☐

These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks:

10. Have you felt calm and peaceful? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
☐  ☐  ☐  ☐  ☐  ☐

11. Did you have a lot of energy? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
☐  ☐  ☐  ☐  ☐  ☐

12. Have you felt downhearted and blue? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
☐  ☐  ☐  ☐  ☐  ☐
Below is a list of statements that other people with your illness have said are important. Please circle the number that best describes how true each statement has been for you during the past 7 days.

<table>
<thead>
<tr>
<th>Physical Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. I had a lack of energy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I had nausea.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I had trouble meeting the needs of my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I had pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I was bothered by side effects of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. In general, I felt sick.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I was forced to spend time in bed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

20. How much does your Physical Well-Being affect your quality of life? (Circle one number.)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
| Not at all | Very Much So

<table>
<thead>
<tr>
<th>Social/Family Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I felt distant from my friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. I got emotional support from my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. I got support from my friends and neighbors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. My family had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Family communication about my illness was poor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

If you have a spouse/partner, or are sexually active, please answer questions 26-27. Otherwise, go to question 28.

26. I felt close to my partner (or main support). | 1 | 2 | 3 | 4 | 5 |
27. I was satisfied with my sex life. | 1 | 2 | 3 | 4 | 5 |

28. How much does your Social/Family Well-Being affect your quality of life? (Circle one number.)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
| Not at all | Very Much So

Quality of Life One-Year 1/11/99
### Relationship With Doctor

<table>
<thead>
<tr>
<th>Question</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. I had confidence in my doctor(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. My doctor was available to answer my questions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Emotional Well-Being

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. I felt sad.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>33. I was proud of how I'm coping with my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>34. I was losing hope in the fight against my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>35. I felt nervous.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>36. I worried about dying.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Functional Well-Being

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>38. I was able to work (include work in home).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>39. My work (include work in home) was fulfilling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>40. I was able to enjoy life “in the moment.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>41. I had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>42. I was sleeping well.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>43. I enjoyed my usual leisure pursuits.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>44. I was content with the quality of my life right now.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Quality of Life One-Year 1/11/99

4 of 13
Additional Concerns

46. I was short of breath.
47. I was self-conscious about the way I dressed.
48. My arms were swollen or tender.
49. I felt sexually attractive.
50. I was bothered by hair loss.
51. I worried about the risk of cancer in other family members.
52. I worried about the effect of stress on my illness.
53. I was bothered by a change in weight.
54. I was able to feel like a woman.

55. How much do these Additional Concerns affect your quality of life? (Circle one number.)

0 1 2 3 4 5 6 7 8 9 10
Not at all Very Much So

YOUR APPEARANCE

This section asks you about your general perceptions regarding your body. Right now, how satisfied are you with these parts of your body? Please check the appropriate box for the response that best describes your satisfaction with each body part.

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Neutral</th>
<th>Somewhat satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>56. Hair</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>57. Breasts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>58. Arms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>59. Face</td>
<td></td>
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</tr>
<tr>
<td>60. Waist</td>
<td></td>
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<tr>
<td>61. Hips</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>62. Thighs</td>
<td></td>
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<td></td>
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<tr>
<td>63. Overall body</td>
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</tbody>
</table>
How much do you agree or disagree with the following statement? (Check the appropriate box.)

64. The appearance of my breast area is important to me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

65. I view myself as a:

☐ Very overweight person
☐ Moderately overweight person
☐ Normal weight person
☐ Moderately thin person
☐ Very thin person

PART III. SEXUALITY

These next questions are about the way health problems may interfere with your sex life. These questions are personal, but your answers are important in understanding how health problems may affect women’s sexuality.

66. Have you been sexually active with a partner during the last 6 months?

☐ No ——> (If no, skip to Question 79).
☐ Yes ——> (If yes, continue to Question 67).

67. How many times have you had sexual intercourse in the past month?

☐ 0 times
☐ 1 - 4 times
☐ 5 - 10 times
☐ 11 or more
For the following questions, please check the box for the response that best describes your sexual feelings and experiences DURING THE PAST MONTH.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>68. How often were you aware of wetness in your vagina as you became sexually excited?</td>
<td></td>
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<tr>
<td>69. How often did it take a long time for your vagina to become wet or slippery as you became sexually excited?</td>
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<tr>
<td>70. During sexual relations, how frequently did you notice dryness of your vagina?</td>
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<tr>
<td>71. How often did you feel pain or discomfort during vaginal penetration?</td>
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<tr>
<td>72. How often did you feel satisfied after sexual activity?</td>
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<tr>
<td>73. How often were you satisfied with the frequency of sexual activity?</td>
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</tr>
<tr>
<td>74. How frequently did you feel tense or nervous after a sexual experience?</td>
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<td></td>
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</tr>
</tbody>
</table>

For the following questions, please check the box for the response that best describes your sexual feelings and experiences DURING THE PAST MONTH.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>75. I avoided having my breast area fondled or kissed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>76. My partner avoided fondling or kissing my breast area.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>77. I notice I didn’t hug or kiss my partner much.</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>78. I notice my partner didn’t hug and kiss me much.</td>
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</tr>
</tbody>
</table>
PART IV. SLEEP HABITS

The next group of questions ask about your sleep habits. Please check the appropriate box for the one response that best describes how often you experienced these situations in THE PAST 4 WEEKS.

79. Did you have trouble falling asleep?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week

80. Did you wake up several times a night?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week

81. Did you wake up earlier than you planned to?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week

82. Did you have trouble getting back to sleep after you woke up too early?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week
83. Overall, how was your typical night's sleep during the past 4 weeks?

- [ ] Very sound or restful
- [ ] Sound or restful
- [ ] Average quality
- [ ] Restless
- [ ] Very restless

84. About how many hours of sleep did you get on a typical night during the past 4 weeks?

- [ ] 5 or less hours
- [ ] 6 hours
- [ ] 7 hours
- [ ] 8 hours
- [ ] 9 hours
- [ ] 10 or more hours

PART V. SPIRITUAL BELIEFS

The following questions are about spiritual beliefs. Please check the appropriate box indicating how true the statement has been for you during THE PAST WEEK.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>85. I felt peaceful.</td>
<td></td>
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<tr>
<td>86. I had a reason for living.</td>
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<tr>
<td>87. I felt a sense of purpose in my life.</td>
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<tr>
<td>88. I was able to reach down deep into myself for comfort.</td>
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<tr>
<td>89. I felt a sense of harmony within myself.</td>
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<tr>
<td>90. I found comfort in my faith.</td>
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<tr>
<td>91. I found strength in my faith.</td>
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</tbody>
</table>
92. Where would you place yourself on the following scale, if “0” means that your life is just the way it was before your breast cancer, “+5” means that everything is totally different but better, and “-5” means that everything is totally different but worse. (Please circle ONE number).

-5  -4  -3  -2  -1  0   +1  +2  +3  +4  +5  
Worse  Same as before  Better

PART VI.  EMOTIONAL FEELINGS

The following questions consist of groups of statements. After reading each group of statements carefully, check the box next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally, check each one. Be sure to read all the statements in each group before making your choice.

93. □ I do not feel sad.
   □ I feel sad.
   □ I am sad all the time and I can’t snap out of it.
   □ I am so sad or unhappy that I can’t stand it.

94. □ I am not particularly discouraged about the future.
   □ I feel discouraged about the future.
   □ I feel I have nothing to look forward to.
   □ I feel that the future is hopeless and that things cannot improve.

95. □ I do not feel like a failure.
   □ I feel I have failed more than the average person.
   □ As I look back on my life, all I can see is a lot of failures.
   □ I feel I am a complete failure as a person.

96. □ I get as much satisfaction out of things as I used to.
   □ I don’t enjoy things the way I used to.
   □ I don’t get real satisfaction out of anything anymore.
   □ I am dissatisfied or bored with everything.
97. □ I don't feel particularly guilty.
□ I feel guilty a good part of the time.
□ I feel quite guilty most of the time.
□ I feel guilty all of the time.

98. □ I don't feel I am being punished.
□ I feel I may be punished.
□ I expect to be punished.
□ I feel I am being punished.

99. □ I don't feel disappointed in myself.
□ I am disappointed in myself.
□ I am disgusted with myself.
□ I hate myself.

100. □ I don't feel I am any worse than anybody else.
□ I am critical of myself for my weaknesses or mistakes.
□ I blame myself all the time for my faults.
□ I blame myself for everything bad that happens.

101. □ I don't have any thoughts of killing myself.
□ I have thoughts of killing myself, but I would not carry them out.
□ I would like to kill myself.
□ I would kill myself if I had the chance.

102. □ I don't cry anymore than usual.
□ I cry more now than I used to.
□ I cry all the time now.
□ I used to be able to cry, but now I can't cry even though I want to.
103. □ I am no more irritated now than I ever am.
    □ I get annoyed or irritated more easily than I used to.
    □ I feel irritated all the time now.
    □ I don’t get irritated at all by the things that used to irritate me.

104. □ I have not lost interest in other people.
    □ I am less interested in other people than I used to be.
    □ I have lost most of my interest in other people.
    □ I have lost all of my interest in other people.

105. □ I make decisions about as well as I ever could.
    □ I put off making decisions more than I used to.
    □ I have greater difficulty in making decisions than before.
    □ I can’t make decisions at all anymore.

106. □ I don’t feel I look any worse than I used to.
    □ I am worried that I am looking old or unattractive.
    □ I feel that there are permanent changes in my appearance that make me look unattractive.
    □ I believe that I look ugly.

107. □ I can work about as well as before.
    □ It takes an extra effort to get started at doing something.
    □ I have to push myself very hard to do anything.
    □ I can’t do any work at all.

108. □ I can sleep as well as usual.
    □ I don’t sleep as well as I used to.
    □ I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
    □ I wake up several hours earlier than I used to and cannot get back to sleep.
109. □ I don’t get more tired than usual.
□ I get tired more easily than I used to.
□ I get tired from doing almost anything.
□ I am too tired to do anything.

110. □ My appetite is no worse than usual.
□ My appetite is not as good as it used to be.
□ My appetite is much worse now.
□ I have no appetite at all anymore.

111. □ I haven’t lost much weight, if any, lately.
□ I have lost more than five (5) pounds.
□ I have lost more than ten (10) pounds.
□ I have lost more than fifteen (15) pounds.

112. □ I am no more worried about my health than usual.
□ I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
□ I am very worried about physical problems and it’s hard to think of much else.
□ I am so worried about my physical problems that I cannot think about anything else.

113. □ I have not noticed any recent change in my interest in sex.
□ I am less interested in sex than I used to be.
□ I am much less interested in sex now.
□ I have lost interest in sex completely.
SOCIAL SUPPORT FORM

The following are questions about the support that is available to you.

1. At the present time, about how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? (Please write the number in the boxes below.)

   [ ] Number of close friends and close relatives

People sometimes look to others for companionship, assistance, or other types of support. Currently, how often is each of the following kinds of support available to you if you need it? (Check one box for each statement.)

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Someone to help you if you were confined to bed.</td>
<td></td>
<td></td>
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<tr>
<td>3. Someone you can count on to listen to you when you need to talk.</td>
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<tr>
<td>4. Someone to give you good advice about a crisis.</td>
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<tr>
<td>5. Someone to take you to the doctor if you needed it.</td>
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<tr>
<td>6. Someone who shows you love and affection.</td>
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<td>7. Someone to have a good time with.</td>
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<tr>
<td>8. Someone to give you information to help you understand a situation.</td>
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<tr>
<td>9. Someone to confide in or talk to about yourself or your problems.</td>
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<tr>
<td></td>
<td>None of the time</td>
<td>A little of the time</td>
<td>Some of the time</td>
<td>Most of the time</td>
<td>All of the time</td>
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<tr>
<td>10.</td>
<td>Someone who hugs you.</td>
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<td>11.</td>
<td>Someone to get together with for relaxation.</td>
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<td>12.</td>
<td>Someone to prepare your meals if you were unable to do it yourself.</td>
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<tr>
<td>13.</td>
<td>Someone whose advice you really want.</td>
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<td>14.</td>
<td>Someone to do things with to help you get your mind off things.</td>
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<td>15.</td>
<td>Someone to help with daily chores if you were sick.</td>
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<td>16.</td>
<td>Someone to share your most private worries and fears with.</td>
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<td>17.</td>
<td>Someone to turn to for suggestions about how to deal with a personal problem.</td>
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<td>18.</td>
<td>Someone to do something enjoyable with.</td>
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<tr>
<td>20.</td>
<td>Someone to love you and make you feel wanted.</td>
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</tbody>
</table>
For the following questions, please check the box that is the most true for you at the present time. (Check only one box for each statement.)

Of the people who are important to you, how many:

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>One</th>
<th>Some</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Don't understand you.</td>
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<td>22. Get on your nerves.</td>
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<td>23. Ask too much of you.</td>
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<td>25. Don't include you.</td>
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<td>26. Show that they don't like you.</td>
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<td>27. Boss you.</td>
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<tr>
<td>28. Try to get you to do things you don't want to do.</td>
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</tbody>
</table>
PERSONAL HABITS FORM

These questions are about habits that may affect your health (smoking, alcohol use, weight, and exercise). Please answer each question as accurately as possible.

1. Do you smoke currently?

☐ No
☐ Yes

If yes, how many cigarettes do you smoke per day? (1 pack = 20 cigarettes)

☐ I smoke occasionally.
☐ 0 - 5 cigarettes a day
☐ 6 - 20 cigarettes a day
☐ 21 - 30 cigarettes a day
☐ 31 - 40 cigarettes a day
☐ more than 40 cigarettes a day

2. Do you currently drink alcoholic beverages?

☐ No
☐ Yes

If yes, about how many alcoholic beverages (beer, wine, or mixed drinks) do you currently drink in an average month?

☐☐☐ Beverages per month
3. What is your current weight? 

[ ] [ ] [ ] pounds

The following questions are about your usual physical activity and exercise. This includes walking and sports.

4. Think about the walking you do outside the home. In the past month, how often did you walk outside the home for more than 10 minutes without stopping? (Mark only one.)

[ ] Rarely or never   ---> (Go to Question 5)
[ ] 1-3 times each month   ---> (Go to Question 4a)
[ ] 1 time each week   ---> (Go to Question 4a)
[ ] 2-3 times each week   ---> (Go to Question 4a)
[ ] 4-6 times each week   ---> (Go to Question 4a)
[ ] 7 or more times each week   ---> (Go to Question 4a)

4a. When you walked outside the home for more than 10 minutes without stopping, how many minutes did you usually walk?

[ ] Less than 20 minutes
[ ] 20-39 minutes
[ ] 40-59 minutes
[ ] 1 hour or more

4b. What was your usual speed?

[ ] Casual strolling or walking (less than 2 miles an hour)
[ ] Average or normal (2-3 miles an hour)
[ ] Fairly fast (3-4 miles an hour)
[ ] Very fast (more than 4 miles an hour)
[ ] Don’t Know
Following are three categories of exercise, (strenuous, moderate, and mild). Not including walking outside the home, how often each week (7 days) do you usually do the following strenuous, moderate, and mild types of exercise?

5. STRENUOUS OR VERY HARD EXERCISE. (You work up a sweat and your heart beats fast.) For example, aerobics, aerobic dancing, jogging, tennis, swimming laps.

☐ None ---> (Go to Question 6)
☐ 1 day per week ---> (Go to Question 5a)
☐ 2 days per week ---> (Go to Question 5a)
☐ 3 days per week ---> (Go to Question 5a)
☐ 4 days per week ---> (Go to Question 5a)
☐ 5 or more days per week ---> (Go to Question 5a)

5a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more

6. MODERATE EXERCISE (Not exhausting). For example, biking outdoors, using an exercise machine (like a stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing.

☐ None ---> (Go to Question 7)
☐ 1 day per week ---> (Go to Question 6a)
☐ 2 days per week ---> (Go to Question 6a)
☐ 3 days per week ---> (Go to Question 6a)
☐ 4 days per week ---> (Go to Question 6a)
☐ 5 or more days per week ---> (Go to Question 6a)
6a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more

7. MILD EXERCISE. For example, slow dancing, bowling, golf.

☐ None
☐ 1 day per week ---> (Go to Question 7a)
☐ 2 days per week ---> (Go to Question 7a)
☐ 3 days per week ---> (Go to Question 7a)
☐ 4 days per week ---> (Go to Question 7a)
☐ 5 or more days per week ---> (Go to Question 7a)

7a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more
We are interested in how your life, in general, has been since your diagnosis.

1. What major challenges have you faced since your diagnosis?

2. What positive experiences have you had? (For example, things you learned about yourself, how you interact with your family, etc.)
LIFE EVENTS

Below are things that sometimes happen to people. Please try to think back over the past year to remember if any of these things happened. (Mark only one box on each line.)

<table>
<thead>
<tr>
<th>Over the past year:</th>
<th>YES, and it upset me:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NO</td>
</tr>
<tr>
<td>1. Did you have any major problems with money.</td>
<td></td>
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<tr>
<td>2. Did you or a family member or close friend lose their jobs or retire?</td>
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<tr>
<td>3. Did you have a major conflict with children?</td>
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<tr>
<td>4. Did you have a divorce or break-up with a spouse or partner?</td>
<td></td>
</tr>
<tr>
<td>5. Did a family member or close friend have a divorce or breakup?</td>
<td></td>
</tr>
<tr>
<td>6. Did a close friend or family member die or have a serious illness (other than your spouse or partner.)</td>
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<tr>
<td>7. Did you have any major accidents, disasters, muggings, unwanted sexual experiences, robberies, or similar events?</td>
<td></td>
</tr>
<tr>
<td>8. Did your spouse or partner die or have a serious illness?</td>
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<tr>
<td>9. Were you physically abused by a family member or close friend?</td>
<td></td>
</tr>
<tr>
<td>10. Were you verbally abused by a family member or close friend?</td>
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<tr>
<td>11. Did a pet die?</td>
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</tbody>
</table>
CONTACT INFORMATION FORM

We would like you to update your contact information so that we can keep in touch with you during the study. This information is very important, so please answer these questions completely. Please print the information in the space provided or mark the appropriate box.

1. Has your address changed since our last mailing to you?
   □ No          □ Yes → If yes, please provide current mailing address

   Your Current Mailing Address?


2. Telephone Numbers:  Home:              Area Code (______)______-______

                        Work:              Area Code (______)______-______

                        Other:             Area Code (______)______-______

3. When is the best time to contact you?                                  Where is the best place to contact you?

   Day of week  time(s)    □ At home

   Day of week  time(s)    □ At work

   Day of week  time(s)    □ Other

   Day of week  time(s)    □ At home

   Day of week  time(s)    □ At work

   Day of week  time(s)    □ Other
4. In case we might ever need to contact you by telephone, may we leave a message for you on your answering machine, (if you have one), if we are unable to reach you directly?

☐ No
☐ Yes

5. What is your husband's or partner's legal name? (This information will help us keep in contact with you during the study. Please leave this blank if you are not currently married or with a long-term partner.)

_____________________________  __________  ________________
First              MI           Last

6. Please provide the names of two relatives or friends, not living in your household, who are likely to know how to contact you if we are unable to reach you.

Name: ________________________________
Address: ________________________________

Phone Number: Area Code (___ ___) ___ ___ - ___ ___ ___
Relationship to you: ________________________________

Name: ________________________________
Address: ________________________________

Phone Number: Area Code (___ ___) ___ ___ - ___ ___ ___
Relationship to you: ________________________________
MENSTRUAL CYCLE MAINTENANCE AND QUALITY OF LIFE

18-Month Follow-up Survey

Clinical Coordinating Center

Wake Forest University School of Medicine
Department of Public Health Sciences
Winston-Salem, North Carolina 27157-1063
(336) 716-2116

Funded by
The U.S. Army Medical Research and Material Command:
Breast Cancer Research Program A
PART I  MEDICAL and REPRODUCTIVE HISTORY  FOLLOW-UP QUESTIONNAIRE

The following questions ask about health professionals you may have seen in the past 6 months. This information will help us describe in general terms the kinds of services being used.

1. In the past six months, which of the following doctors or other health professionals have you seen?  (Please Check all that apply)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>None</td>
</tr>
<tr>
<td>☐</td>
<td>Acupuncturist</td>
</tr>
<tr>
<td>☐</td>
<td>Allergist</td>
</tr>
<tr>
<td>☐</td>
<td>Cardiologist</td>
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<tr>
<td>☐</td>
<td>Chiropractor</td>
</tr>
<tr>
<td>☐</td>
<td>Dentist</td>
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<tr>
<td>☐</td>
<td>Dermatologist</td>
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<tr>
<td>☐</td>
<td>Ear/Nose/Throat Doctor</td>
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<td>☐</td>
<td>Eye Doctor</td>
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<td>☐</td>
<td>Marital Counselor</td>
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<td>☐</td>
<td>Gastroenterologist</td>
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<td>☐</td>
<td>General Practitioner</td>
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<td>☐</td>
<td>Gynecologist</td>
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<tr>
<td>☐</td>
<td>Infertility Specialist</td>
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<td>☐</td>
<td>Internist</td>
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<tr>
<td>☐</td>
<td>Massage Therapist</td>
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<tr>
<td>☐</td>
<td>Neurologist</td>
</tr>
<tr>
<td>☐</td>
<td>Sexual Therapist</td>
</tr>
<tr>
<td>☐</td>
<td>Other: ____________________________</td>
</tr>
</tbody>
</table>
2. In the past 6 months, have you been seen at an emergency room?
   
   □ No
   □ Yes → For what reason: ________________________________

3. In the past 6 months, have you been hospitalized or had surgery? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>If yes, for what reason?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Hospitalized?</td>
<td></td>
<td></td>
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<tr>
<td>(b) Had surgery?</td>
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</tr>
</tbody>
</table>

4. Has anything else changed regarding either your mental or physical health status? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>What has changed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Mental Health?</td>
<td></td>
<td></td>
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<tr>
<td>(b) Physical Health?</td>
<td></td>
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</tr>
</tbody>
</table>
5. Have you had any biopsies in the past 6 months?

☐ No
☐ Yes → If yes, what was biopsied? ________________________________

Why was this biopsied? ________________________________________

6. In the past 6 months, have you had a recurrence of breast cancer?

☐ No
☐ Yes → If yes, how was this diagnosis made. (For example, biopsy, lab tests)?

____________________________________________________________________

7. Have you been diagnosed with any other cancer in the past 6 months?

☐ No
☐ Yes → If yes, what type? ________________________________________

How was this diagnosis made? (For example, biopsy, lab tests)?

____________________________________________________________________

8. Today’s date is:   [ ] / [ ] / [ ]
       Month       Day       Year

Medhist 18 mos. 5/99
PART II  REPRODUCTIVE HISTORY

The following questions ask about your menstrual cycles and reproductive history. We are very interested in this information so that we can understand more about women’s health during their childbearing years. Some of the questions ask you to give dates or the number of times when certain things happened. If you are not sure about the exact date or number of times, please give your best estimate.

1. What was the date of the first day of your last menstrual period (your best guess)?

   - Month - Day - Year

2. In the past 6 months, have you been sexually active with a male partner:

   - No  → Go to question 6
   - Yes  → Go to question 3

3. Which method of birth control are you and your partner using currently? (Check all that apply.)

   - No method
   - Condoms (rubbers)
   - Birth control pills
   - Foams/jellies/suppositories
   - Sponge
   - Withdrawal (pulling out)
   - Diaphragm
   - Safe periods (rhythm or counting days)
   - Norplant
   - Cervical cap
   - Tubal ligation (tubes tied)
   - Vasectomy
   - Other (Please describe: )
   - Don’t know
4. **In the past month**, how many times have you had sexual intercourse without using contraception?

   □□□ Times

5. **In the past 6 months**, have you become pregnant?

   □ No
   □ Yes → If yes, are you pregnant now?
   □ No
   □ Yes

6. **In the past month**, have you had any hot flashes or night sweats (hot flashes that occur during sleep)?

   □ No
   □ Yes ----> If yes, how many have you had in the **past week**?
   □□□□ hot flashes/night sweats
PART III  CURRENT MEDICATIONS

1. Please list below all of the *prescription medications* you are taking currently. (Write “none” if you are not taking any prescription medications at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

2. Please list below all of the *non-prescription medications or supplements* you are taking currently. (Write “none” if you are not taking any non-prescription medications or supplements at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>
SWELLING FORM

The following questions concern swelling in your arm and/or hand. Please mark the appropriate box(es) for each question.

1. In the past 6 months, has any swelling occurred in your arm or hand on the same side that you had your lumpectomy or mastectomy?

   □ No → (Go to question 8)
   □ Yes → (Continue to question 2)
   □ Don’t know → (Go to question 8)

2. Do you believe the start of your swelling was related to any of the following?

   Yes  No  Don’t Know
   □  □  □  Radiation treatment
   □  □  □  Breast reconstruction
   □  □  □  Infection or injury to arm / hand
   □  □  □  Weather changes
   □  □  □  General use of your arm
   □  □  □  Exercise
   □  □  □  Airplane travel

   Other: Please describe: ________________________________

   ________________________________
2a. How soon after you had surgery and/or began treatment did this swelling occur?

☐ Less than 1 week
☐ 1 week to 4 weeks
☐ 1 month to 3 months
☐ 4 months to 6 months
☐ 7 months to 9 months
☐ 10 months to 12 months
☐ 13 months to 15 months

2b. Where does (did) the swelling occur? (Check all that apply)

☐ Hand
☐ Upper Arm
☐ Lower Arm

2c. Do (did) you consider the swelling to be mostly?

☐ Mild
☐ Moderate
☐ Severe

3. Does (did) the swelling interfere with any of the following?

Yes ☐ No ☐

☐ Clothing that you wear
☐ Your ability to do routine activities, such as household chores or grooming.
☐ Exercise
☐ Your appearance

Other, please describe: __________________________________________
4. Does (did) swelling seem to get worse with any of the following?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don't</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Know</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hot weather</td>
</tr>
<tr>
<td></td>
<td></td>
<td>General use of your arm</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sauna / Jacuzzi / Hot bath</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Airplane travel</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specific foods</td>
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<tr>
<td></td>
<td></td>
<td>Mental / emotional stress</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other: Please describe: __________________________________________</td>
</tr>
</tbody>
</table>

5. Prior to your breast cancer diagnosis, did you notice swelling in your hand and/or arm with any of the following? (Check all that apply)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don't</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Know</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Household Chores</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Heat/Humidity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eating salty foods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Drinking alcoholic beverages</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other: Please describe: __________________________________________</td>
</tr>
</tbody>
</table>

Swelling 18 mos. 5/99
6. Did you seek treatment for this swelling in the past 6 months?

☐ No → If no, why not?

☐ Yes → If yes, what type of treatment did you receive? (Check all that apply)

☐ Compression therapy by machine
☐ Glove / Sleeve Compression / Garment
☐ Physical therapy
☐ Manual lymphatic drainage
☐ Bandaging technique
☐ Other, please describe: ____________________________________________

7. Do you have swelling now?

☐ No → (Go to question 8)
☐ Yes → (Continue to question 7a)

7a. If yes, how long have you had swelling?

☐ Less than 1 week
☐ 2 - 4 weeks
☐ 1 - 3 months
☐ 4 - 6 months
☐ 7 - 9 months
☐ 10 - 12 months
8. In the past 6 months, do you remember any breaks in your skin, infected hang nails, or slight skin injuries in your arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 9)
☐ Yes → (Continue to question 8a)
☐ Don’t Know → (Continue to question 9)

8a. If yes, did you receive antibiotics?

☐ Yes
☐ No
☐ Don’t know

9. In the past 6 months, did you have any infection in the arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 10)
☐ Yes → (Continue to question 9a)
☐ Don’t Know → (Continue to question 10)

If yes, did you:

9a. receive antibiotics by mouth?

☐ No
☐ Yes
☐ Don’t know
If yes, did you:

9b. receive antibiotics by injection?

[ ] No
[ ] Yes
[ ] Don’t know

10. Do you have pain in the affected arm and/or hand? (Check one box for each site)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hand and arm</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SYMPTOMS QUESTIONNAIRE

Below are statements about symptoms some people may experience. For each statement, check the appropriate box for the response that best describes how bothersome the symptom was for you during the past month. If you did not have the problem, check the box under the column titled “symptom did not occur”. Please do not skip any questions. **Mark only one box on each line.**

If you experienced the symptom, use the following key to indicate how bothersome it was:

- **Mild** = symptom did not interfere with usual activities.
- **Moderate** = symptom interfered somewhat with usual activities.
- **Severe** = symptom was so bothersome that usual activities could not be performed.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fatigue or low energy level</td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>2. Mouth ulcers</td>
<td></td>
<td></td>
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<tr>
<td>3. Restless sleep</td>
<td></td>
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<tr>
<td>4. Sleeping too much</td>
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<td></td>
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<tr>
<td>5. Nervousness or shakiness inside</td>
<td></td>
<td></td>
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<tr>
<td>6. Mood changes</td>
<td></td>
<td></td>
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<tr>
<td>7. Feeling depressed</td>
<td></td>
<td></td>
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<tr>
<td>8. Lightheadedness when standing up</td>
<td></td>
<td></td>
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<tr>
<td>9. Faintness or dizziness at rest</td>
<td></td>
<td></td>
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<tr>
<td>10. Headaches</td>
<td></td>
<td></td>
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<tr>
<td>11. Swelling of ankles or feet</td>
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<td></td>
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<tr>
<td>12. Diarrhea</td>
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</tr>
</tbody>
</table>

*Symptoms 18 mos. 5/99*
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Constipation</td>
<td></td>
<td></td>
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<tr>
<td>14. Abdominal pain/cramps</td>
<td></td>
<td></td>
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<tr>
<td>15. Vaginal dryness</td>
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<tr>
<td>16. Muscle pain/ache/or cramp</td>
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<td></td>
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<tr>
<td>17. Weight gain</td>
<td></td>
<td></td>
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<tr>
<td>18. Weight loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. General aches and pains</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Hot flashes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Joint pains</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Night sweats</td>
<td></td>
<td></td>
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<tr>
<td>23. Aches in back of neck and skull</td>
<td></td>
<td></td>
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<tr>
<td>24. Forgetfulness</td>
<td></td>
<td></td>
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<tr>
<td>25. Difficulty concentrating</td>
<td></td>
<td></td>
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<tr>
<td>26. Increased appetite</td>
<td></td>
<td></td>
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<tr>
<td>27. Short temper</td>
<td></td>
<td></td>
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<tr>
<td>28. Decreased efficiency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Loss of interest in work/activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Lowered work performance</td>
<td></td>
<td></td>
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<tr>
<td>31. Blind spots, fuzzy vision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Breast sensitivity/tenderness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Avoidance of social affairs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. Cold sweats</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Decreased appetite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Feelings of suffocation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Difficulty healing</td>
<td></td>
<td></td>
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<tr>
<td>38. Bloating</td>
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<td></td>
</tr>
</tbody>
</table>

*Symptoms 18 mos. 5/99*
QUALITY OF LIFE FORM

1. In general, would you say your health is:  (Check one)

   Excellent  Very good  Good  Fair  Poor
   □         □         □       □       □

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

   Limited a lot  Limited a little  Not limited at all
   □         □        □

3. Climbing several flights of stairs.

   Limited a lot  Limited a little  Not limited at all
   □         □        □

During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

   Yes  No
4. Accomplished less than you would like.      □       □

5. Had difficulty performing the work or other activities, for example, it took extra effort.      □       □

During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious)?

   Yes  No
6. Accomplished less than you would like.      □       □

7. Didn’t do work or other activities as carefully as usual.      □       □
8. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Check one)

Not at all  Slightly  Moderately  Quite a bit  Extremely
☐  ☐  ☒  ☐  ☐

9. During the past four weeks, how much did pain interfere with your normal activities (including both work outside the home, housework and family activities)? (Check one)

Not at all  Slightly  Moderately  Quite a bit  Extremely
☐  ☐  ☐  ☐  ☐

These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks:

10. Have you felt calm and peaceful? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
☐  ☐  ☐  ☐  ☐  ☐

11. Did you have a lot of energy? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
☐  ☐  ☐  ☐  ☐  ☐

12. Have you felt downhearted and blue? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
☐  ☐  ☐  ☐  ☐  ☐
Below is a list of statements that other people with your illness have said are important. Please circle the number that best describes how true each statement has been for you *during the past 7 days.*

<table>
<thead>
<tr>
<th>Physical Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat a bit</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. I had a lack of energy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I had nausea.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I had trouble meeting the needs of my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I had pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I was bothered by side effects of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. In general, I felt sick.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I was forced to spend time in bed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

20. How much does your Physical Well-Being affect your quality of life? *(Circle one number.)*

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<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Very Much So</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Social/Family Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat a bit</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I felt distant from my friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. I got emotional support from my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. I got support from my friends and neighbors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. My family had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Family communication about my illness was poor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**If you have a spouse/partner, or are sexually active, please answer questions 26-27. Otherwise, go to question 28.**

26. I felt close to my partner (or main support).                                  | 1          | 2            | 3              | 4           | 5         |
| 27. I was satisfied with my sex life.                                             | 1          | 2            | 3              | 4           | 5         |

28. How much does your Social/Family Well-Being affect your quality of life? *(Circle one number.)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Very Much So</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

*Quality of Life 18 mos. 5/99*
<table>
<thead>
<tr>
<th>Relationship With Doctor</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Some-What</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. I had confidence in my doctor(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. My doctor was available to answer my questions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

31. How much does your **Relationship with your Doctor** affect your quality of life? (*Circle one number.*)

<table>
<thead>
<tr>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Much So</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional Well-Being</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Some-What</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. I felt sad.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>33. I was proud of how I'm coping with my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>34. I was losing hope in the fight against my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>35. I felt nervous.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>36. I worried about dying.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

37. How much does your **Emotional Well-Being** affect your quality of life? (*Circle one number.*)

<table>
<thead>
<tr>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Much So</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Functional Well-Being</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Some-What</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>38. I was able to work (include work in home).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>39. My work (include work in home) was fulfilling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>40. I was able to enjoy life “in the moment.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>41. I had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>42. I was sleeping well.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
</tr>
<tr>
<td>43. I enjoyed my usual leisure pursuits.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td>44. I was content with the quality of my life right now.</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</table>

45. How much does your **Functional Well-Being** affect your quality of life? (*Circle one number.*)

<table>
<thead>
<tr>
<th>Not at all</th>
<th>1</th>
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<th>4</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
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<tbody>
<tr>
<td>Very Much So</td>
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*Quality of Life 18 mos. 5/99*
### Additional Concerns

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<tr>
<th></th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>Very Much</th>
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<tbody>
<tr>
<td>46. I was short of breath.</td>
<td>1</td>
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<tr>
<td>47. I was self-conscious about the way I dressed.</td>
<td>1</td>
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<td>48. My arms were swollen or tender.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>49. I felt sexually attractive.</td>
<td>1</td>
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<td>50. I was bothered by hair loss.</td>
<td>1</td>
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<td>51. I worried about the risk of cancer in other family members.</td>
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<td>2</td>
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<td>52. I worried about the effect of stress on my illness.</td>
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<td>53. I was bothered by a change in weight.</td>
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<td>54. I was able to feel like a woman.</td>
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</table>

55. How much do these **Additional Concerns** affect your quality of life? *(Circle one number.)*

0 1 2 3 4 5 6 7 8 9 10  
Not at all  
Very Much So

### YOUR APPEARANCE

This section asks you about your general perceptions regarding your body. Right now, how satisfied are you with these parts of your body? Please check the appropriate box for the response that best describes your satisfaction with each body part.

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Neutral</th>
<th>Somewhat satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>56. Hair</td>
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<tr>
<td>57. Breasts</td>
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<tr>
<td>58. Arms</td>
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<tr>
<td>59. Face</td>
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<td>60. Waist</td>
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<td>61. Hips</td>
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<td>62. Thighs</td>
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<tr>
<td>63. Overall body</td>
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</table>
How much do you agree or disagree with the following statement? (Check the appropriate box.)

64. The appearance of my breast area is important to me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tbody>
</table>

65. I view myself as a:

☐ Very overweight person
☐ Moderately overweight person
☐ Normal weight person
☐ Moderately thin person
☐ Very thin person

PART III. SEXUALITY

These next questions are about the way health problems may interfere with your sex life. These questions are personal, but your answers are important in understanding how health problems may affect women’s sexuality.

66. Have you been sexually active with a partner during the last 6 months?

☐ No ----> (If no, skip to Question 79).
☐ Yes ----> (If yes, continue to Question 67).

67. How many times have you had sexual intercourse in the past month?

☐ 0 times
☐ 1 - 4 times
☐ 5 - 10 times
☐ 11 or more
For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>68. How often were you aware of wetness in your vagina as you became sexually excited?</td>
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<tr>
<td>69. How often did it take a long time for your vagina to become wet or slippery as you became sexually excited?</td>
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<td>70. During sexual relations, how frequently did you notice dryness of your vagina?</td>
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<td>71. How often did you feel pain or discomfort during vaginal penetration?</td>
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<td>72. How often did you feel satisfied after sexual activity?</td>
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<tr>
<td>73. How often were you satisfied with the frequency of sexual activity?</td>
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<td>74. How frequently did you feel tense or nervous after a sexual experience?</td>
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</tbody>
</table>

For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>75. I avoided having my breast area fondled or kissed.</td>
<td></td>
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<tr>
<td>76. My partner avoided fondling or kissing my breast area.</td>
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<tr>
<td>77. I notice I didn’t hug or kiss my partner much.</td>
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<tr>
<td>78. I notice my partner didn’t hug and kiss me much.</td>
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</tbody>
</table>
PART IV. SLEEP HABITS

The next group of questions ask about your sleep habits. Please check the appropriate box for the one response that best describes how often you experienced these situations in THE PAST 4 WEEKS.

79. Did you have trouble falling asleep?
   - [ ] No, not in the past 4 weeks
   - [ ] Yes, less than once a week
   - [ ] Yes, 1 or 2 times a week
   - [ ] Yes, 3 or 4 times a week
   - [ ] Yes, 5 or more times a week

80. Did you wake up several times a night?
   - [ ] No, not in the past 4 weeks
   - [ ] Yes, less than once a week
   - [ ] Yes, 1 or 2 times a week
   - [ ] Yes, 3 or 4 times a week
   - [ ] Yes, 5 or more times a week

81. Did you wake up earlier than you planned to?
   - [ ] No, not in the past 4 weeks
   - [ ] Yes, less than once a week
   - [ ] Yes, 1 or 2 times a week
   - [ ] Yes, 3 or 4 times a week
   - [ ] Yes, 5 or more times a week

82. Did you have trouble getting back to sleep after you woke up too early?
   - [ ] No, not in the past 4 weeks
   - [ ] Yes, less than once a week
   - [ ] Yes, 1 or 2 times a week
   - [ ] Yes, 3 or 4 times a week
   - [ ] Yes, 5 or more times a week
83. Overall, how was your typical night’s sleep during the past 4 weeks?

☐ Very sound or restful
☐ Sound or restful
☐ Average quality
☐ Restless
☐ Very restless

84. About how many hours of sleep did you get on a typical night during the past 4 weeks?

☐ 5 or less hours
☐ 6 hours
☐ 7 hours
☐ 8 hours
☐ 9 hours
☐ 10 or more hours

PART V. SPIRITUAL BELIEFS

The following questions are about spiritual beliefs. Please check the appropriate box indicating how true the statement has been for you during THE PAST WEEK.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>85. I felt peaceful.</td>
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<tr>
<td>86. I had a reason for living.</td>
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<tr>
<td>87. I felt a sense of purpose in my life.</td>
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<tr>
<td>88. I was able to reach down deep into myself for comfort.</td>
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<tr>
<td>89. I felt a sense of harmony within myself.</td>
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<tr>
<td>90. I found comfort in my faith.</td>
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<tr>
<td>91. I found strength in my faith.</td>
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</tbody>
</table>
92. Where would you place yourself on the following scale, if “0” means that your life is just the way it was before your breast cancer, “+5” means that everything is totally different but better, and “-5” means that everything is totally different but worse. *(Please circle ONE number).*

-5  -4  -3  -2  -1  0   +1  +2  +3  +4  +5

Worse                        Same as before                        Better

PART VI. EMOTIONAL FEELINGS

The following questions consist of groups of statements. After reading each group of statements carefully, check the box next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally, check each one. Be sure to read all the statements in each group before making your choice.

93. □ I do not feel sad.  □ I feel sad.
    □ I am sad all the time and I can’t snap out of it.
    □ I am so sad or unhappy that I can’t stand it.

94. □ I am not particularly discouraged about the future.
    □ I feel discouraged about the future.
    □ I feel I have nothing to look forward to.
    □ I feel that the future is hopeless and that things cannot improve.

95. □ I do not feel like a failure.
    □ I feel I have failed more than the average person.
    □ As I look back on my life, all I can see is a lot of failures.
    □ I feel I am a complete failure as a person.

96. □ I get as much satisfaction out of things as I used to.
    □ I don’t enjoy things the way I used to.
    □ I don’t get real satisfaction out of anything anymore.
    □ I am dissatisfied or bored with everything.
97. □ I don’t feel particularly guilty.
□ I feel guilty a good part of the time.
□ I feel quite guilty most of the time.
□ I feel guilty all of the time.

98. □ I don’t feel I am being punished.
□ I feel I may be punished.
□ I expect to be punished.
□ I feel I am being punished.

99. □ I don’t feel disappointed in myself.
□ I am disappointed in myself.
□ I am disgusted with myself.
□ I hate myself.

100. □ I don’t feel I am any worse than anybody else.
□ I am critical of myself for my weaknesses or mistakes.
□ I blame myself all the time for my faults.
□ I blame myself for everything bad that happens.

101. □ I don’t have any thoughts of killing myself.
□ I have thoughts of killing myself, but I would not carry them out.
□ I would like to kill myself.
□ I would kill myself if I had the chance.

102. □ I don’t cry anymore than usual.
□ I cry more now than I used to.
□ I cry all the time now.
□ I used to be able to cry, but now I can’t cry even though I want to.
103. □ I am no more irritated now than I ever am.
    □ I get annoyed or irritated more easily than I used to.
    □ I feel irritated all the time now.
    □ I don't get irritated at all by the things that used to irritate me.

104. □ I have not lost interest in other people.
    □ I am less interested in other people than I used to be.
    □ I have lost most of my interest in other people.
    □ I have lost all of my interest in other people.

105. □ I make decisions about as well as I ever could.
    □ I put off making decisions more than I used to.
    □ I have greater difficulty in making decisions than before.
    □ I can't make decisions at all anymore.

106. □ I don't feel I look any worse than I used to.
    □ I am worried that I am looking old or unattractive.
    □ I feel that there are permanent changes in my appearance that make me look unattractive.
    □ I believe that I look ugly.

107. □ I can work about as well as before.
    □ It takes an extra effort to get started at doing something.
    □ I have to push myself very hard to do anything.
    □ I can't do any work at all.

108. □ I can sleep as well as usual.
    □ I don't sleep as well as I used to.
    □ I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
    □ I wake up several hours earlier than I used to and cannot get back to sleep.
109. □ I don’t get more tired than usual.
   □ I get tired more easily than I used to.
   □ I get tired from doing almost anything.
   □ I am too tired to do anything.

110. □ My appetite is no worse than usual.
    □ My appetite is not as good as it used to be.
    □ My appetite is much worse now.
    □ I have no appetite at all anymore.

111. □ I haven’t lost much weight, if any, lately.
    □ I have lost more than five (5) pounds.
    □ I have lost more than ten (10) pounds.
    □ I have lost more than fifteen (15) pounds.

112. □ I am no more worried about my health than usual.
    □ I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
    □ I am very worried about physical problems and it’s hard to think of much else.
    □ I am so worried about my physical problems that I cannot think about anything else.

113. □ I have not noticed any recent change in my interest in sex.
    □ I am less interested in sex than I used to be.
    □ I am much less interested in sex now.
    □ I have lost interest in sex completely.
SOCIAL SUPPORT FORM

The following are questions about the support that is available to you.

1. At the present time, about how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? *(Please write the number in the boxes below.)*

   - [ ] Number of close friends and close relatives

People sometimes look to others for companionship, assistance, or other types of support. Currently, how often is each of the following kinds of support available to you if you need it? *(Check one box for each statement.)*

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
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<tbody>
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<tr>
<td></td>
<td>None of the time</td>
<td>A little of the time</td>
<td>Some of the time</td>
<td>Most of the time</td>
<td>All of the time</td>
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<tr>
<td>10.</td>
<td>Someone who hugs you.</td>
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<td>11.</td>
<td>Someone to get together with for relaxation.</td>
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<tr>
<td>12.</td>
<td>Someone to prepare your meals if you were unable to do it yourself.</td>
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<tr>
<td>13.</td>
<td>Someone whose advice you really want.</td>
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<tr>
<td>14.</td>
<td>Someone to do things with to help you get your mind off things.</td>
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<tr>
<td>15.</td>
<td>Someone to help with daily chores if you were sick.</td>
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<tr>
<td>16.</td>
<td>Someone to share your most private worries and fears with.</td>
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<tr>
<td>17.</td>
<td>Someone to turn to for suggestions about how to deal with a personal problem.</td>
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<tr>
<td>18.</td>
<td>Someone to do something enjoyable with.</td>
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<tr>
<td>20.</td>
<td>Someone to love you and make you feel wanted.</td>
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</tbody>
</table>
For the following questions, please check the box that is the most true for you at the present time. (Check only one box for each statement.)

Of the people who are important to you, how many:

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>One</th>
<th>Some</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.</td>
<td>Don’t understand you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22.</td>
<td>Get on your nerves.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23.</td>
<td>Ask too much of you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Don’t include you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>Show that they don’t like you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>Boss you.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>Try to get you to do things you don’t want to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PERSONAL HABITS FORM

These questions are about habits that may affect your health (smoking, alcohol use, weight, and exercise). Please answer each question as accurately as possible.

1. Do you smoke currently?
   - No
   - Yes

   If yes, how many cigarettes do you smoke per day? (1 pack = 20 cigarettes)
   - I smoke occasionally.
   - 0 - 5 cigarettes a day
   - 6 - 20 cigarettes a day
   - 21 - 30 cigarettes a day
   - 31 - 40 cigarettes a day
   - more than 40 cigarettes a day

2. Do you currently drink alcoholic beverages?
   - No
   - Yes

   If yes, about how many alcoholic beverages (beer, wine, or mixed drinks) do you currently drink in an average month?
   - Beverages per month
3. What is your current weight?

[ ] [ ] [ ] pounds

The following questions are about your usual physical activity and exercise. This includes walking and sports.

4. Think about the walking you do outside the home. In the past month, how often did you walk outside the home for more than 10 minutes without stopping? (Mark only one.)

[ ] Rarely or never ---> (Go to Question 5)
[ ] 1-3 times each month ---> (Go to Question 4a)
[ ] 1 time each week ---> (Go to Question 4a)
[ ] 2-3 times each week ---> (Go to Question 4a)
[ ] 4-6 times each week ---> (Go to Question 4a)
[ ] 7 or more times each week ---> (Go to Question 4a)

4a. When you walked outside the home for more than 10 minutes without stopping, how many minutes did you usually walk?

[ ] Less than 20 minutes
[ ] 20-39 minutes
[ ] 40-59 minutes
[ ] 1 hour or more

4b. What was your usual speed?

[ ] Casual strolling or walking (less than 2 miles an hour)
[ ] Average or normal (2-3 miles an hour)
[ ] Fairly fast (3-4 miles an hour)
[ ] Very fast (more than 4 miles an hour)
[ ] Don’t Know
Following are three categories of exercise, (strenuous, moderate, and mild). Not including walking outside the home, how often each week (7 days) do you usually do the following strenuous, moderate, and mild types of exercise?

5. **STRENUOUS OR VERY HARD EXERCISE**. (You work up a sweat and your heart beats fast.) For example, aerobics, aerobic dancing, jogging, tennis, swimming laps.

- □ None ---> (Go to Question 6)
- □ 1 day per week ---> (Go to Question 5a)
- □ 2 days per week ---> (Go to Question 5a)
- □ 3 days per week ---> (Go to Question 5a)
- □ 4 days per week ---> (Go to Question 5a)
- □ 5 or more days per week ---> (Go to question 5a)

5a. How long do you usually exercise like this at one time?

- □ Less than 20 minutes
- □ 20-39 minutes
- □ 40-59 minutes
- □ 1 hour or more

6. **MODERATE EXERCISE** (Not exhausting). For example, biking outdoors, using an exercise machine (like a stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing.

- □ None ---> (Go to Question 7)
- □ 1 day per week ---> (Go to Question 6a)
- □ 2 days per week ---> (Go to Question 6a)
- □ 3 days per week ---> (Go to Question 6a)
- □ 4 days per week ---> (Go to Question 6a)
- □ 5 or more days per week ---> (Go to Question 6a)
6a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more

7. **MILD EXERCISE.** For example, slow dancing, bowling, golf.

☐ None

☐ 1 day per week ---> (Go to Question 7a)
☐ 2 days per week ---> (Go to Question 7a)
☐ 3 days per week ---> (Go to Question 7a)
☐ 4 days per week ---> (Go to Question 7a)
☐ 5 or more days per week ---> (Go to Question 7a)

7a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more
CONTACT INFORMATION FORM

We would like you to update your contact information so that we can keep in touch with you during the study. This information is very important, so please answer these questions completely. Please print the information in the space provided or mark the appropriate box.

1. Has your address changed since our last mailing to you?
   □ No  □ Yes → If yes, please provide current mailing address

   Your Current Mailing Address?
   __________________________________________
   __________________________________________
   __________________________________________

2. Telephone Numbers: Home: Area Code (___ ___) ______ - ________
   Work: Area Code (___ ___) ______ - ________
   Other: Area Code (___ ___) ______ - ________

3. When is the best time to contact you?            Where is the best place to contact you?
   ___________________________ time(s)            □ At home
   Day of week  time(s)                □ At work
   ___________________________ time(s)            □ Other
   Day of week
4. In case we might ever need to contact you by telephone, may we leave a message for you on your answering machine, (if you have one), if we are unable to reach you directly?

☐ No
☐ Yes

5. What is your husband’s or partner’s legal name? (This information will help us keep in contact with you during the study. Please leave this blank if you are not currently married or with a long-term partner.)

_________________________  _____  ____________________________
First MI Last

6. Please provide the names of two relatives or friends, not living in your household, who are likely to know how to contact you if we are unable to reach you.

Name: ____________________________
Address: ____________________________

Phone Number: Area Code (___ ___) ___ ___ - ___ ___ ___

Relationship to you: ____________________________

Name: ____________________________
Address: ____________________________

Phone Number: Area Code (___ ___) ___ ___ - ___ ___ ___

Relationship to you: ____________________________
MENSTRUAL CYCLE MAINTENANCE
AND
QUALITY OF LIFE

Two-Year Follow-up Survey

Clinical Coordinating Center

Wake Forest University School of Medicine
Department of Public Health Sciences
Winston-Salem, North Carolina 27157-1063
(336) 716-2116

Funded by
The U.S. Army Medical Research and Material Command:
Breast Cancer Research Program A
DEMOGRAPHIC FOLLOW-UP FORM

YOUR BACKGROUND

The following questions are about your background. We would like to see if you have had any changes in your personal situation in the past year. Please mark the appropriate box for each question.

1. What is your marital status?

☐ Never married
☐ Presently married
☐ Living in a marriage-like relationship
☐ Divorced
☐ Separated
☐ Widowed

2. Which category below best describes the highest level of formal education you have completed? (Choose the one best answer).

☐ No formal education
☐ Grade school (1st through 8th grade)
☐ Some high school (9th through 11th grade)
☐ High school diploma or G.E.D.
☐ Business or vocational training school after high school graduation
☐ Some college (but a college degree was not obtained)
☐ Associate Degree (A.D. or A.A.)
☐ College graduate or Baccalaureate Degree (B.A. or B.S.)
☐ Some college or professional school after college graduation
☐ Master’s Degree
☐ Doctoral Degree (Ph.D., M.D., J.D., D.D.S., etc.)
3. What was your total family income (before taxes) from all sources last year? (Check one box below. This information is important for describing the women in the study as a group and is kept strictly confidential).

☐ Less than $10,000
☐ $10,000 to $19,999
☐ $20,000 to $34,999
☐ $35,000 to $49,999
☐ $50,000 to $74,999
☐ $75,000 to $100,000
☐ More than $100,000

4. What type of health insurance do you have? (If you have more than one type of insurance, please mark the box for your primary source of insurance.)

☐ HMO
☐ Group Health Insurance
☐ V.A./Military Sponsored
☐ Individual Health Insurance (includes CHAMPUS)
☐ Medicaid
☐ Disability Insurance
☐ None
☐ Other (Please list: ______________________)

5. What is your current employment status? (Check the box that best describes you.)

☐ Unemployed/Looking for work → (Go to question 8)
☐ Retired → (Go to question 8)
☐ Full-time Homemaker → (Go to question 8)
☐ Employed - full-time → (Go to question 6)
☐ Employed - part-time → (Go to question 6)
☐ Disabled, unable to work → (Go to question 8)
☐ Student → (Go to question 8)
☐ Other (Please list: ______________________) → (Go to question 8)
6. If you are employed, which category best describes your occupation?

☐ Professional, Technical & Related Occupations (such as teachers/professors, nurses, lawyers, physicians & engineers)

☐ Managers, Administrators, or Proprietors (such as sales managers, real estate agents, or postmasters)

☐ Clerical & Related Occupations (such as secretaries, clerks or mail carriers)

☐ Sales Occupations (such as salespersons, demonstrators, agents and brokers)

☐ Service Occupations (such as police, cooks, or hairdressers)

☐ Skilled Crafts, Service Repair Persons, & Related Occupations (such as carpenters, appliance repair, or telephone line workers)

☐ Equipment or Vehicle Operators & Related Occupations (such as drivers, railroad brakemen or sewer workers)

☐ Laborers (such as helpers, longshoremen, or warehouse workers)

☐ Farmers (owners, managers, operators or tenants)

☐ Members of the military

☐ Other (please describe):

7. This following is a list of employment issues that a person might have. For each statement, indicate whether this has happened to you since your diagnosis. If it did occur, indicate whether you believe this situation was related to your diagnosis. (Circle the answers that are most true for you on each line.)

Since your diagnosis have you:

a. believed you could not change jobs for fear of losing your health insurance?

☐ No

☐ Yes (If yes, was it related to your diagnosis?)

☐ No

☐ Yes
b. lost your health insurance due to sick leave?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

c. been fired or laid off?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

d. been demoted?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

e. been denied a promotion?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

f. been denied a wage increase?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes
g. had your work responsibilities limited unnecessarily?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

h. been promoted?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

8. This following is a list of insurance issues that a person might have. For each statement, indicate whether this has happened to you since your diagnosis. If it did occur, indicate whether you believe this situation was related to your diagnosis. (Circle the answers that are most true for you on each line.)

Since your diagnosis have:

a. you been denied health insurance?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

b. you been denied life insurance?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes
c. your health insurance rates increased?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

d. your life insurance rates increased?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

e. you had a health benefit payment denied?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

f. you had trouble changing from group health
to individual health insurance?
   □ No
   □ Yes (If yes, was it related to your diagnosis?)
      □ No
      □ Yes

9. Please give the date you completed this form: □ □ □ / □ □ / □ □ □
   Month / Day / Year
PART 1

MEDICAL & REPRODUCTIVE HISTORY
FOLLOW-UP QUESTIONNAIRE

The following questions ask about health professionals you may have seen in the past 6 months. This information will help us describe in general terms the kinds of services being used.

1. In the past six months, which of the following doctors or other health professionals have you seen? (Please Check all that apply)

- None
- Acupuncturist
- Allergist
- Cardiologist
- Chiropractor
- Dentist
- Dermatologist
- Ear/Nose/Throat Doctor
- Eye Doctor
- Marital Counselor
- Gastroenterologist
- General Practitioner
- Gynecologist
- Infertility Specialist
- Internist
- Massage Therapist
- Neurologist
- Sexual Therapist

- Family Therapist
- Nutritionist
- Obstetrician
- Medical Oncologist/Chemotherapist
- Orthopedic Surgeon
- Homeopathic/Herbalist/Naturopathic
- Pain Control Professional
- Alternative Therapist (Homeopath, herbalist, naturopathologist, etc.)
- Physical Therapist
- Plastic Surgeon
- Psychiatrist
- Clinical Psychologist
- Radiologist
- Rheumatologist
- Social Worker
- Organized Support Group
- Surgeon
- Urologist
- Other: ____________________
2. In the past 6 months, have you been seen at an emergency room?

☐ No
☐ Yes → For what reason: ________________________________

3. In the past 6 months, have you been hospitalized or had surgery? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>If yes, for what reason?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Hospitalized?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Had surgery?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Has anything else changed regarding either your mental or physical health status? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>What has changed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Mental Health?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Physical Health?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. Have you had any biopsies in the past 6 months?

☐ No

☐ Yes → If yes, what was biopsied? ________________________________

Why was this biopsied? ________________________________

6. In the past 6 months, have you had a re-occurrence of breast cancer?

☐ No

☐ Yes → If yes, how was this diagnosis made. (For example, biopsy, lab tests)? ________________________________

7. Have you been diagnosed with any other cancer in the past 6 months?

☐ No

☐ Yes → If yes, what type? ________________________________

How was this diagnosis made? (For example, biopsy, lab tests)? ________________________________
PART II  

REPRODUCTIVE HISTORY

The following questions ask about your menstrual cycles and reproductive history. We are very interested in this information so that we can understand more about women’s health during their childbearing years. Some of the questions ask you to give dates or the number of times when certain things happened. If you are not sure about the exact date or number of times, please give your best estimate.

1. What was the date of the first day of your last menstrual period (your best guess)?

   
   
   Month   Day   Year

2. In the past 6 months, have you been sexually active with a male partner:

   
   [ ] No  → Go to question 6
   [ ] Yes  → Go to question 3

3. Which method of birth control are you and your partner using currently? (Check all that apply.)

   
   [ ] No method
   [ ] Condoms (rubbers)
   [ ] Birth control pills
   [ ] Foams/jellies/suppositories
   [ ] Sponge
   [ ] Withdrawal (pulling out)
   [ ] Diaphragm
   [ ] Safe periods (rhythm or counting days)
   [ ] Norplant
   [ ] Cervical cap
   [ ] Tubal ligation (tubes tied)
   [ ] Vasectomy
   [ ] Other (Please describe: ____________)
   [ ] Don’t know

4. In the past month, how many times have you had sexual intercourse without using contraception?

   
   [ ] [ ] Times
5. **In the past 6 months, have you become pregnant?**
   - [ ] No
   - [ ] Yes → If yes, are you pregnant now?
     - [ ] No
     - [ ] Yes

6. **In the past month, have you had any hot flashes or night sweats (hot flashes that occur during sleep)?**
   - [ ] No
   - [ ] Yes → If yes, how many have you had in the **past week**?
     - [ ] [ ] [ ] hot flashes/night sweats
FAMILY HISTORY UPDATE

Please update the following grid about the **history of breast cancer** among your female relatives. If you do not have a full-blooded relative in one of the categories listed below, please leave that line blank. (MARK ONLY ONE BOX PER LINE.)

1. Did this relative have breast cancer?

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>Don’t know if she had breast cancer</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>How old was she when her first breast cancer occurred?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less than 45</td>
<td>45 or older</td>
</tr>
<tr>
<td>a.</td>
<td>Mother</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b.</td>
<td>Sister 1</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c.</td>
<td>Sister 2</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d.</td>
<td>Sister 3</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e.</td>
<td>Sister 4</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f.</td>
<td>Daughter 1</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g.</td>
<td>Daughter 2</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>h.</td>
<td>Daughter 3</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I.</td>
<td>Daughter 4</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>j.</td>
<td>Maternal grandmother (your mother’s mother)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>k.</td>
<td>Paternal grandmother (your father’s mother)</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Please update the following grid about the **history of ovarian cancer** among your female relatives. If you do not have a full-blooded relative in one of the categories listed below, please leave that line blank. (MARK ONLY ONE BOX PER LINE.)

2. **Did this relative have ovarian cancer?**

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>Don’t know if she had ovarian cancer</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Sister 1</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>c. Sister 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>d. Sister 3</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>e. Sister 4</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>f. Daughter 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Daughter 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. Daughter 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Daughter 4</td>
<td></td>
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<tr>
<td>j. Maternal grandmother (your mother’s mother)</td>
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<td></td>
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<tr>
<td>k. Paternal grandmother (your father’s mother)</td>
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</table>
CURRENT MEDICATIONS

1. Please list below all of the **prescription medications** you are taking currently. (Write “none” if you are not taking any prescription medications at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
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<tbody>
<tr>
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</tbody>
</table>

2. Please list below all of the **non-prescription medications or supplements** you are taking currently. (Write “none” if are not taking any non-prescription medications or supplements at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>
TREATMENT EXPECTATIONS

1. We are interested in your expectations regarding the treatments you received over the past year. For each of the treatments listed below, how did your expectations before treatment compare with the actual treatment you received? Better than expected, the same as you expected, or worse than you expected? (Mark one box for each line.)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Not Applicable. (Did not have this treatment.)</th>
<th>Worse Than Expected</th>
<th>Same As Expected</th>
<th>Better Than Expected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lumpectomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mastectomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reconstructive Surgery</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Radiation</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Tamoxifen</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Bone Marrow Transplant</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
SWELLING FORM

The following questions concern swelling in your arm and/or hand. Please mark the appropriate box(es) for each question.

1. In the past 6 months, has any swelling occurred in your arm or hand on the same side that you had your lumpectomy or mastectomy?

   [ ] No → (Go to question 8)
   [ ] Yes → (Continue to question 2)
   [ ] Don’t know → (Go to question 8)

2. Do you believe the start of your swelling was related to any of the following?

   Yes  No  Don’t Know
   [ ] Radiation treatment
   [ ] Breast reconstruction
   [ ] Infection or injury to arm / hand
   [ ] Weather changes
   [ ] General use of your arm
   [ ] Exercise
   [ ] Airplane travel
   [ ] Other: Please describe: ________________________________

________________________________________
2a. How soon after you had surgery and/or began treatment did this swelling occur?

☐ Less than 1 week
☐ 1 week to 4 weeks
☐ 1 month to 3 months
☐ 4 months to 6 months
☐ 7 months to 9 months
☐ 10 months to 12 months
☐ 13 months to 15 months

2b. Where does (did) the swelling occur? (Check all that apply)

☐ Hand
☐ Upper Arm
☐ Lower Arm

2c. Do (did) you consider the swelling to be mostly?

☐ Mild
☐ Moderate
☐ Severe

3. Does (did) the swelling interfere with any of the following?

Yes ☐ No ☐
☐ Clothing that you wear
☐ Your ability to do routine activities, such as household chores or grooming.
☐ Exercise
☐ Your appearance
☐ Other, please describe: ________________________________
4. Does (did) swelling seem to get worse with any of the following?

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<thead>
<tr>
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<th>Don’t Know</th>
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<tbody>
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<td>Yes</td>
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Other: Please describe: __________________________________________


5. Prior to your breast cancer diagnosis, did you notice swelling in your hand and/or arm with any of the following? (Check all that apply)

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<th>Don’t Know</th>
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Other: Please describe: __________________________________________
6. Did you seek treatment for this swelling in the past 6 months?

☐ No → If no, why not?

☐ Yes → If yes, what type of treatment did you receive? (Check all that apply)

☐ Compression therapy by machine
☐ Glove / Sleeve Compression / Garment
☐ Physical therapy
☐ Manual lymphatic drainage
☐ Bandaging technique
☐ Other, please describe: ____________________________________________

7. Do you have swelling now?

☐ No → (Go to question 8)
☐ Yes → (Continue to question 7a)

7a. If yes, how long have you had swelling?

☐ Less than 1 week
☐ 2 - 4 weeks
☐ 1 - 3 months
☐ 4 - 6 months
☐ 7 - 9 months
☐ 10 - 12 months
8. In the past 6 months, do you remember any breaks in your skin, infected hang nails, or slight skin injuries in your arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 9)
☐ Yes → (Continue to question 8a)
☐ Don’t Know → (Continue to question 9)

8a. If yes, did you receive antibiotics?

☐ Yes
☐ No
☐ Don’t know

9. In the past 6 months, did you have any infection in the arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 10)
☐ Yes → (Continue to question 9a)
☐ Don’t Know → (Continue to question 10)

9a. If yes, did you receive antibiotics by mouth?

☐ No
☐ Yes
☐ Don’t know
9b. If yes, did you receive antibiotics by injection?

- [ ] No
- [ ] Yes
- [ ] Don’t know

10. Do you have pain in the affected arm and/or hand? (Check one box for each site)

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<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>hand</td>
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<tr>
<td>arm</td>
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</table>
SYMPTOMS QUESTIONNAIRE

Below are statements about symptoms some people may experience. For each statement, check the appropriate box for the response that best describes how bothersome the symptom was for you during the past month. If you did not have the problem, check the box under the column titled “symptom did not occur”. Please do not skip any questions. Mark only one box on each line.

If you experienced the symptom, use the following key to indicate how bothersome it was:

- **Mild** = symptom did not interfere with usual activities.
- **Moderate** = symptom interfered somewhat with usual activities.
- **Severe** = symptom was so bothersome that usual activities could not be performed.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1. Fatigue or low energy level</td>
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<td>2. Mouth ulcers</td>
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<td>3. Restless sleep</td>
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<td>4. Sleeping too much</td>
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<td>5. Nervousness or shakiness inside</td>
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<td>6. Mood changes</td>
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<td>7. Feeling depressed</td>
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<td>8. Lightheadedness when standing up</td>
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<td>9. Faintness or dizziness at rest</td>
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<td>10. Headaches</td>
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<td>11. Swelling of ankles or feet</td>
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<td>12. Diarrhea</td>
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<tr>
<td>Symptom</td>
<td>Symptom did not occur</td>
<td>Symptom Occurred and Was:</td>
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<td>13. Constipation</td>
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<td>14. Abdominal pain/cramps</td>
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<td>15. Vaginal dryness</td>
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<td>16. Muscle pain/ache/or cramp</td>
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<td>17. Weight gain</td>
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<td>18. Weight loss</td>
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<td>19. General aches and pains</td>
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<td>20. Hot flashes</td>
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<td>21. Joint pains</td>
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<tr>
<td>22. Night sweats</td>
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<td>23. Aches in back of neck and skull</td>
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<tr>
<td>24. Forgetfulness</td>
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<td></td>
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<td>25. Difficulty concentrating</td>
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<td>26. Increased appetite</td>
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<td>27. Short temper</td>
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<td>28. Decreased efficiency</td>
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<td>29. Loss of interest in work/activities</td>
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<td>30. Lowered work performance</td>
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<td>31. Blind spots, fuzzy vision</td>
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<td>32. Breast sensitivity/tenderness</td>
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<td>33. Avoidance of social affairs</td>
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<tr>
<td>34. Cold sweats</td>
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<tr>
<td>35. Decreased appetite</td>
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<tr>
<td>36. Feelings of suffocation</td>
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<tr>
<td>37. Difficulty healing</td>
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<tr>
<td>38. Bloating</td>
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</tbody>
</table>
QUALITY OF LIFE FORM

PART I. ACTIVITIES

1. In general, would you say your health is:  (Check one)

   Excellent □  Very good □  Good □  Fair □  Poor □

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.

   Limited a lot □  Limited a little □  Not limited at all □

3. Climbing several flights of stairs.

   Limited a lot □  Limited a little □  Not limited at all □

During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. Accomplished less than you would like.
   □  □

5. Had difficulty performing the work or other activities, for example, it took extra effort.
   □  □

During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious)?
6. Accomplished less than you would like.  
   Yes ☐ No ☐

7. Didn’t do work or other activities as carefully as usual.  
   ☐ ☐

8. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Check one)
   Not at all □ Slightly □ Moderately □ Quite a bit □ Extremely □

9. During the past four weeks, how much did pain interfere with your normal activities (including both work outside the home, housework and family activities)? (Check one)
   Not at all □ Slightly □ Moderately □ Quite a bit □ Extremely □

These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks:

10. Have you felt calm and peaceful? (Check one)
   All of the time □ Most of the time □ A good bit of the time □ Some of the time □ A little of the time □ None of the time □

11. Did you have a lot of energy? (Check one)
   All of the time □ Most of the time □ A good bit of the time □ Some of the time □ A little of the time □ None of the time □

12. Have you felt downhearted and blue? (Check one)
   All of the time □ Most of the time □ A good bit of the time □ Some of the time □ A little of the time □ None of the time □
Below is a list of statements that other people with your illness have said are important. Please circle the number that best describes how true each statement has been for you during the past 7 days.

### Physical Well-Being

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<thead>
<tr>
<th></th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
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</thead>
<tbody>
<tr>
<td>13. I had a lack of energy.</td>
<td>1</td>
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<tr>
<td>14. I had nausea.</td>
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<tr>
<td>15. I had trouble meeting the needs of my family.</td>
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<td>16. I had pain.</td>
<td>1</td>
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<td>17. I was bothered by side effects of treatment.</td>
<td>1</td>
<td>2</td>
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<tr>
<td>18. In general, I felt sick.</td>
<td>1</td>
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<td>19. I was forced to spend time in bed.</td>
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<td>2</td>
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20. How much does your Physical Well-Being affect your quality of life? (Circle one number.)

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<th>Very Much So</th>
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<tr>
<td></td>
<td>Not at all</td>
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### Social/Family Well-Being

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<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
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<tbody>
<tr>
<td>21. I felt distant from my friends</td>
<td>1</td>
<td>2</td>
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<tr>
<td>22. I got emotional support from my family.</td>
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<td>2</td>
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<tr>
<td>23. I got support from my friends and neighbors.</td>
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<td>24. My family had accepted my illness.</td>
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<tr>
<td>25. Family communication about my illness was poor.</td>
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If you have a spouse/partner, or are sexually active, please answer questions 26-27. Otherwise, go to question 28.

26. I felt close to my partner (or main support). | 1 | 2 | 3 | 4 | 5 |
27. I was satisfied with my sex life. | 1 | 2 | 3 | 4 | 5 |
28. How much does your Social/Family Well-Being affect your quality of life? (Circle one number.)

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<tr>
<td>Relationship With Doctor</td>
<td>Not At All</td>
<td>A Little Bit</td>
<td>Some-what</td>
<td>Quite a bit</td>
<td>Very Much</td>
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<td>29. I had confidence in my doctor(s).</td>
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<tr>
<td>30. My doctor was available to answer my questions.</td>
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31. How much does your Relationship with your Doctor affect your quality of life? (Circle one number.)

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<tr>
<td>Very Much So</td>
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<thead>
<tr>
<th>Emotional Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very Much</th>
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<tbody>
<tr>
<td>32. I felt sad.</td>
<td>1</td>
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<tr>
<td>33. I was proud of how I’m coping with my illness.</td>
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<td>34. I was losing hope in the fight against my illness.</td>
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<td>35. I felt nervous.</td>
<td>1</td>
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<td>36. I worried about dying.</td>
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37. How much does your Emotional Well-Being affect your quality of life? (Circle one number.)

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<tr>
<th>Not at all</th>
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<th>7</th>
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<tr>
<td>Very Much So</td>
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<thead>
<tr>
<th>Functional Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very Much</th>
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<tbody>
<tr>
<td>38. I was able to work (include work in home).</td>
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<td>39. My work (include work in home) was fulfilling.</td>
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<td>40. I was able to enjoy life “in the moment.”</td>
<td>1</td>
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<td>41. I had accepted my illness.</td>
<td>1</td>
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<td>42. I was sleeping well.</td>
<td>1</td>
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<tr>
<td>43. I enjoyed my usual leisure pursuits.</td>
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<td>2</td>
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<tr>
<td>44. I was content with the quality of my life right now.</td>
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<td>5</td>
</tr>
</tbody>
</table>

45. How much does your Functional Well-Being affect your quality of life? (Circle one number.)

<table>
<thead>
<tr>
<th>Not at all</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Much So</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Additional Concerns

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>46</td>
<td>I was short of breath.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>47</td>
<td>I was self-conscious about the way I dressed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>48</td>
<td>My arms were swollen or tender.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>49</td>
<td>I felt sexually attractive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>50</td>
<td>I was bothered by hair loss.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>51</td>
<td>I worried about the risk of cancer in other family members.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>52</td>
<td>I worried about the effect of stress on my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>53</td>
<td>I was bothered by a change in weight.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>54</td>
<td>I was able to feel like a woman.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>55</td>
<td>How much do these Additional Concerns affect your quality of life? (Circle one number.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Not at all</td>
<td>Very Much So</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### PART II. YOUR APPEARANCE

This section asks you about your general perceptions regarding your body. Right now, how satisfied are you with these parts of your body? Please check the appropriate box for the response that best describes your satisfaction with each body part.

<table>
<thead>
<tr>
<th>Number</th>
<th>Body Part</th>
<th>Very dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Neutral</th>
<th>Somewhat satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>56</td>
<td>Hair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>57</td>
<td>Breasts</td>
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<td></td>
</tr>
<tr>
<td>58</td>
<td>Arms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>59</td>
<td>Face</td>
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<tr>
<td>60</td>
<td>Waist</td>
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<tr>
<td>61</td>
<td>Hips</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>62</td>
<td>Thighs</td>
<td></td>
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<tr>
<td>63</td>
<td>Overall body</td>
<td></td>
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</tbody>
</table>
How much do you agree or disagree with the following statement? (Check the appropriate box.)

64. The appearance of my breast area is important to me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

65. I view myself as a:

- [ ] Very overweight person
- [ ] Moderately overweight person
- [ ] Normal weight person
- [ ] Moderately thin person
- [ ] Very thin person

PART III. SEXUALITY

These next questions are about the way health problems may interfere with your sex life. These questions are personal, but your answers are important in understanding how health problems may affect women's sexuality.

66. Have you been sexually active with a partner during the last 6 months?

- [ ] No ---> (If no, skip to Question 79).
- [ ] Yes ---> (If yes, continue to Question 67).

67. How many times have you had sexual intercourse in the past month?

- [ ] 0 times
- [ ] 1 - 4 times
- [ ] 5 - 10 times
- [ ] 11 or more
For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>68. How often were you aware of wetness in your vagina as you became sexually excited?</td>
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<tr>
<td>69. How often did it take a long time for your vagina to become wet or slippery as you became sexually excited?</td>
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<td>70. During sexual relations, how frequently did you notice dryness of your vagina?</td>
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<tr>
<td>71. How often did you feel pain or discomfort during vaginal penetration?</td>
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<tr>
<td>72. How often did you feel satisfied after sexual activity?</td>
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<tr>
<td>73. How often were you satisfied with the frequency of sexual activity?</td>
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<tr>
<td>74. How frequently did you feel tense or nervous after a sexual experience?</td>
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</tbody>
</table>

For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>75. I avoided having my breast area fondled or kissed.</td>
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<tr>
<td>76. My partner avoided fondling or kissing my breast area.</td>
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<tr>
<td>77. I notice I didn't hug or kiss my partner much.</td>
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<tr>
<td>78. I notice my partner didn't hug and kiss me much.</td>
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</tbody>
</table>
PART IV. SLEEP HABITS

The next group of questions ask about your sleep habits. Please check the appropriate box for the one response that best describes how often you experienced these situations in THE PAST 4 WEEKS.

79. Did you have trouble falling asleep?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week

80. Did you wake up several times a night?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week

81. Did you wake up earlier than you planned to?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week

82. Did you have trouble getting back to sleep after you woke up too early?
   - No, not in the past 4 weeks
   - Yes, less than once a week
   - Yes, 1 or 2 times a week
   - Yes, 3 or 4 times a week
   - Yes, 5 or more times a week
83. Overall, how was your typical night's sleep during the past 4 weeks?

☐ Very sound or restful
☐ Sound or restful
☐ Average quality
☐ Restless
☐ Very restless

84. About how many hours of sleep did you get on a typical night during the past 4 weeks?

☐ 5 or less hours
☐ 6 hours
☐ 7 hours
☐ 8 hours
☐ 9 hours
☐ 10 or more hours

PART V. SPIRITUAL BELIEFS

The following questions are about spiritual beliefs. Please check the appropriate box indicating how true the statement has been for you during THE PAST WEEK.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>85. I felt peaceful.</td>
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<tr>
<td>86. I had a reason for living.</td>
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<tr>
<td>87. I felt a sense of purpose in my life.</td>
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<tr>
<td>88. I was able to reach down deep into myself for comfort.</td>
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<tr>
<td>89. I felt a sense of harmony within myself.</td>
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<tr>
<td>90. I found comfort in my faith.</td>
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</tr>
<tr>
<td>91. I found strength in my faith.</td>
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</tr>
</tbody>
</table>
92. Where would you place yourself on the following scale, if “0” means that your life is just the way it was before your breast cancer, “+5” means that everything is totally different but better, and “-5” means that everything is totally different but worse. (Please circle ONE number).

-5  -4  -3  -2  -1  0  +1  +2  +3  +4  +5

Worse  Same as before  Better

PART VI. EMOTIONAL FEELINGS

The following questions consist of groups of statements. After reading each group of statements carefully, check the box next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally, check each one. Be sure to read all the statements in each group before making your choice.

93. □ I do not feel sad.
□ I feel sad.
□ I am sad all the time and I can’t snap out of it.
□ I am so sad or unhappy that I can’t stand it.

94. □ I am not particularly discouraged about the future.
□ I feel discouraged about the future.
□ I feel I have nothing to look forward to.
□ I feel that the future is hopeless and that things cannot improve.

95. □ I do not feel like a failure.
□ I feel I have failed more than the average person.
□ As I look back on my life, all I can see is a lot of failures.
□ I feel I am a complete failure as a person.

96. □ I get as much satisfaction out of things as I used to.
□ I don’t enjoy things the way I used to.
□ I don’t get real satisfaction out of anything anymore.
□ I am dissatisfied or bored with everything.
97. I don’t feel particularly guilty.
   I feel guilty a good part of the time.
   I feel quite guilty most of the time.
   I feel guilty all of the time.

98. I don’t feel I am being punished.
   I feel I may be punished.
   I expect to be punished.
   I feel I am being punished.

99. I don’t feel disappointed in myself.
   I am disappointed in myself.
   I am disgusted with myself.
   I hate myself.

100. I don’t feel I am any worse than anybody else.
   I am critical of myself for my weaknesses or mistakes.
   I blame myself all the time for my faults.
   I blame myself for everything bad that happens.

101. I don’t have any thoughts of killing myself.
   I have thoughts of killing myself, but I would not carry them out.
   I would like to kill myself.
   I would kill myself if I had the chance.

102. I don’t cry anymore than usual.
   I cry more now than I used to.
   I cry all the time now.
   I used to be able to cry, but now I can’t cry even though I want to.
103. ☐ I am no more irritated now than I ever am.
    ☐ I get annoyed or irritated more easily than I used to.
    ☐ I feel irritated all the time now.
    ☐ I don’t get irritated at all by the things that used to irritate me.

104. ☐ I have not lost interest in other people.
    ☐ I am less interested in other people than I used to be.
    ☐ I have lost most of my interest in other people.
    ☐ I have lost all of my interest in other people.

105. ☐ I make decisions about as well as I ever could.
    ☐ I put off making decisions more than I used to.
    ☐ I have greater difficulty in making decisions than before.
    ☐ I can’t make decisions at all anymore.

106. ☐ I don’t feel I look any worse than I used to.
    ☐ I am worried that I am looking old or unattractive.
    ☐ I feel that there are permanent changes in my appearance that make me look unattractive.
    ☐ I believe that I look ugly.

107. ☐ I can work about as well as before.
    ☐ It takes an extra effort to get started at doing something.
    ☐ I have to push myself very hard to do anything.
    ☐ I can’t do any work at all.

108. ☐ I can sleep as well as usual.
    ☐ I don’t sleep as well as I used to.
    ☐ I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
    ☐ I wake up several hours earlier than I used to and cannot get back to sleep.
109. ᵉ I don’t get more tired than usual.
 ᵉ I get tired more easily than I used to.
 ᵉ I get tired from doing almost anything.
 ᵉ I am too tired to do anything.

110. ᵉ My appetite is no worse than usual.
 ᵉ My appetite is not as good as it used to be.
 ᵉ My appetite is much worse now.
 ᵉ I have no appetite at all anymore.

111. ᵉ I haven’t lost much weight, if any, lately.
 ᵉ I have lost more than five (5) pounds.
 ᵉ I have lost more than ten (10) pounds.
 ᵉ I have lost more than fifteen (15) pounds.

112. ᵉ I am no more worried about my health than usual.
 ᵉ I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
 ᵉ I am very worried about physical problems and it’s hard to think of much else.
 ᵉ I am so worried about my physical problems that I cannot think about anything else.

113. ᵉ I have not noticed any recent change in my interest in sex.
 ᵉ I am less interested in sex than I used to be.
 ᵉ I am much less interested in sex now.
 ᵉ I have lost interest in sex completely.
SOCIAL SUPPORT FORM

The following are questions about the support that is available to you.

1. At the present time, about how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? (Please write the number in the boxes below.)

   Number of close friends and close relatives

People sometimes look to others for companionship, assistance, or other types of support. Currently, how often is each of the following kinds of support available to you if you need it? (Check one box for each statement.)

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Someone to help you if you were confined to bed.</td>
<td></td>
<td></td>
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<tr>
<td>3. Someone you can count on to listen to you when you need to talk.</td>
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<tr>
<td>4. Someone to give you good advice about a crisis.</td>
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<tr>
<td>5. Someone to take you to the doctor if you needed it.</td>
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<tr>
<td>6. Someone who shows you love and affection.</td>
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<tr>
<td>7. Someone to have a good time with.</td>
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<tr>
<td>8. Someone to give you information to help you understand a situation.</td>
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<tr>
<td>9. Someone to confide in or talk to about yourself or your problems.</td>
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</tr>
<tr>
<td></td>
<td>None of the time</td>
<td>A little of the time</td>
<td>Some of the time</td>
<td>Most of the time</td>
<td>All of the time</td>
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</tr>
<tr>
<td>10.</td>
<td>Someone who hugs you.</td>
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<tr>
<td>11.</td>
<td>Someone to get together with for relaxation.</td>
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<tr>
<td>12.</td>
<td>Someone to prepare your meals if you were unable to do it yourself.</td>
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<tr>
<td>13.</td>
<td>Someone whose advice you really want.</td>
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<tr>
<td>14.</td>
<td>Someone to do things with to help you get your mind off things.</td>
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<tr>
<td>15.</td>
<td>Someone to help with daily chores if you were sick.</td>
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<tr>
<td>16.</td>
<td>Someone to share your most private worries and fears with.</td>
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<tr>
<td>17.</td>
<td>Someone to turn to for suggestions about how to deal with a personal problem.</td>
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<tr>
<td>18.</td>
<td>Someone to do something enjoyable with.</td>
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<tr>
<td>20.</td>
<td>Someone to love you and make you feel wanted.</td>
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</tbody>
</table>
For the following questions, please check the box that is the most true for you at the present time. (Check only one box for each statement.)

Of the people who are important to you, how many:

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>One</th>
<th>Some</th>
<th>Most</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Don’t understand you.</td>
<td></td>
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<tr>
<td>22. Get on your nerves.</td>
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<tr>
<td>23. Ask too much of you.</td>
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<tr>
<td>25. Don’t include you.</td>
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<tr>
<td>26. Show that they don’t like you.</td>
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<tr>
<td>27. Boss you.</td>
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<tr>
<td>28. Try to get you to do things you don’t want to do.</td>
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</tbody>
</table>
PERSONAL HABITS FORM

These questions are about habits that may affect your health (smoking, alcohol use, weight, and exercise). Please answer each question as accurately as possible.

1. Do you smoke currently?

   □ No
   □ Yes

   If yes, how many cigarettes do you smoke per day? (1 pack = 20 cigarettes)

   □ I smoke occasionally.
   □ 0 - 5 cigarettes a day
   □ 6 - 20 cigarettes a day
   □ 21 - 30 cigarettes a day
   □ 31 - 40 cigarettes a day
   □ more than 40 cigarettes a day

2. Do you currently drink alcoholic beverages?

   □ No
   □ Yes

   If yes, about how many alcoholic beverages (beer, wine, or mixed drinks) do you currently drink in an average month?

   □ □ □ Beverages per month
3. What is your current weight?

[ ] [ ] [ ] pounds

The following questions are about your usual physical activity and exercise. This includes walking and sports.

4. Think about the walking you do outside the home. In the past month, how often did you walk outside the home for more than 10 minutes without stopping? (Mark only one.)

- [ ] Rarely or never ---> (Go to Question 5)
- [ ] 1-3 times each month ---> (Go to Question 4a)
- [ ] 1 time each week ---> (Go to Question 4a)
- [ ] 2-3 times each week ---> (Go to Question 4a)
- [ ] 4-6 times each week ---> (Go to Question 4a)
- [ ] 7 or more times each week ---> (Go to Question 4a)

4a. When you walked outside the home for more than 10 minutes without stopping, how many minutes did you usually walk?

- [ ] Less than 20 minutes
- [ ] 20-39 minutes
- [ ] 40-59 minutes
- [ ] 1 hour or more

4b. What was your usual speed?

- [ ] Casual strolling or walking (less than 2 miles an hour)
- [ ] Average or normal (2-3 miles an hour)
- [ ] Fairly fast (3-4 miles an hour)
- [ ] Very fast (more than 4 miles an hour)
- [ ] Don’t Know
Following are three categories of exercise, (strenuous, moderate, and mild). Not including walking outside the home, how often each week (7 days) do you usually do the following strenuous, moderate, and mild types of exercise?

5. **STRENuous OR VERY HARD EXERCISE**. (You work up a sweat and your heart beats fast.) For example, aerobics, aerobic dancing, jogging, tennis, swimming laps.

   - [ ] None ---> (Go to Question 6)
   - [ ] 1 day per week ---> (Go to Question 5a)
   - [ ] 2 days per week ---> (Go to Question 5a)
   - [ ] 3 days per week ---> (Go to Question 5a)
   - [ ] 4 days per week ---> (Go to Question 5a)
   - [ ] 5 or more days per week ---> (Go to question 5a)

5a. How long do you usually exercise like this at one time?

   - [ ] Less than 20 minutes
   - [ ] 20-39 minutes
   - [ ] 40-59 minutes
   - [ ] 1 hour or more

6. **MODERATE EXERCISE** (Not exhausting). For example, biking outdoors, using an exercise machine (like a stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing.

   - [ ] None ---> (Go to Question 7)
   - [ ] 1 day per week ---> (Go to Question 6a)
   - [ ] 2 days per week ---> (Go to Question 6a)
   - [ ] 3 days per week ---> (Go to Question 6a)
   - [ ] 4 days per week ---> (Go to Question 6a)
   - [ ] 5 or more days per week ---> (Go to Question 6a)
6a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more

7. MILD EXERCISE. For example, slow dancing, bowling, golf.

☐ None
☐ 1 day per week ---» (Go to Question 7a)
☐ 2 days per week ---» (Go to Question 7a)
☐ 3 days per week ---» (Go to Question 7a)
☐ 4 days per week ---» (Go to Question 7a)
☐ 5 or more days per week ---» (Go to Question 7a)

7a. How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more
We are interested in how your life, in general, has been since your diagnosis.

1. What major challenges have you faced since your diagnosis?

2. What positive experiences have you had? (For example, things you learned about yourself, how you interact with your family, etc.)
LIFE EVENTS

Below are things that sometimes happen to people. Please try to think back over the past year to remember if any of these things happened. (Mark only one box on each line.)

<table>
<thead>
<tr>
<th>Over the past year:</th>
<th>YES, and it upset me:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NO</td>
</tr>
<tr>
<td>1. Did you have any major problems with money.</td>
<td></td>
</tr>
<tr>
<td>2. Did you or a family member or close friend lose their jobs or retire?</td>
<td></td>
</tr>
<tr>
<td>3. Did you have a major conflict with children?</td>
<td></td>
</tr>
<tr>
<td>4. Did you have a divorce or break-up with a spouse or partner?</td>
<td></td>
</tr>
<tr>
<td>5. Did a family member or close friend have a divorce or breakup?</td>
<td></td>
</tr>
<tr>
<td>6. Did a close friend or family member die or have a serious illness (other than your spouse or partner.)</td>
<td></td>
</tr>
<tr>
<td>7. Did you have any major accidents, disasters, muggings, unwanted sexual experiences, robberies, or similar events?</td>
<td></td>
</tr>
<tr>
<td>8. Did your spouse or partner die or have a serious illness?</td>
<td></td>
</tr>
<tr>
<td>9. Were you physically abused by a family member or close friend?</td>
<td></td>
</tr>
<tr>
<td>10. Were you verbally abused by a family member or close friend?</td>
<td></td>
</tr>
<tr>
<td>11. Did a pet die?</td>
<td></td>
</tr>
</tbody>
</table>
CONTACT INFORMATION FORM

We would like you to update your contact information so that we can keep in touch with you during the study. This information is very important, so please answer these questions completely. Please print the information in the space provided or mark the appropriate box.

1. Has your address changed since our last mailing to you?
   □ No  □ Yes → If yes, please provide current mailing address

   Your Current Mailing Address?

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

2. Telephone Numbers: Home: Area Code (___) ___-______
   Work: Area Code (___) ___-______
   Other: Area Code (___) ___-______

3. When is the best time to contact you? Where is the best place to contact you?

   ________________________________ time(s)
   Day of week

   ________________________________ time(s)
   Day of week

   □ At home
   □ At work
   □ Other

   □ At home
   □ At work
   □ Other
4. In case we might ever need to contact you by telephone, may we leave a message for you on your answering machine, (if you have one), if we are unable to reach you directly?

☐ No
☐ Yes

5. What is your husband’s or partner’s legal name? (This information will help us keep in contact with you during the study. Please leave this blank if you are not currently married or with a long-term partner.)

__________________________________________
First   MI      Last

6. Please provide the names of two relatives or friends, not living in your household, who are likely to know how to contact you if we are unable to reach you.

Name: _______________________________________
Address: ___________________________________

__________________________________________
Phone Number: Area Code (___ ___) ___ ___ - ___ ___ ___
Relationship to you: ___________________________

Name: _______________________________________
Address: ___________________________________

__________________________________________
Phone Number: Area Code (___ ___) ___ ___ - ___ ___ ___
Relationship to you: ___________________________
MENSTRUAL CYCLE MAINTENANCE
AND
QUALITY OF LIFE

30-Month Follow-up Survey

Clinical Coordinating Center

Wake Forest University School of Medicine
Department of Public Health Sciences
Winston-Salem, North Carolina 27157-1063
(336) 713-4268

Funded by
The U.S. Army Medical Research and Material Command:
Breast Cancer Research Program A
PART I

MEDICAL and REPRODUCTIVE HISTORY FOLLOW-UP QUESTIONNAIRE

The following questions ask about health professionals you may have seen in the past 6 months. This information will help us describe in general terms the kinds of services being used.

1. In the past six months, which of the following doctors or other health professionals have you seen? (Please Check all that apply)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>☐ None</td>
<td>☐ Family Therapist</td>
</tr>
<tr>
<td>☐ Acupuncturist</td>
<td>☐ Nutritionist</td>
</tr>
<tr>
<td>☐ Allergist</td>
<td>☐ Obstetrician</td>
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<tr>
<td>☐ Cardiologist</td>
<td>☐ Medical Oncologist/Chemotherapist</td>
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<tr>
<td>☐ Chiropractor</td>
<td>☐ Orthopedic Surgeon</td>
</tr>
<tr>
<td>☐ Dentist</td>
<td>☐ Homeopathic/Herbalist/Naturopathic</td>
</tr>
<tr>
<td>☐ Dermatologist</td>
<td>☐ Pain Control Professional</td>
</tr>
<tr>
<td>☐ Ear/Nose/Throat Doctor</td>
<td>☐ Alternative Therapist (Homeopath, herbist, naturopathologist, etc.)</td>
</tr>
<tr>
<td>☐ Eye Doctor</td>
<td>☐ Physical Therapist</td>
</tr>
<tr>
<td>☐ Marital Counselor</td>
<td>☐ Plastic Surgeon</td>
</tr>
<tr>
<td>☐ Gastroenterologist</td>
<td>☐ Psychiatrist</td>
</tr>
<tr>
<td>☐ General Practitioner</td>
<td>☐ Clinical Psychologist</td>
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<tr>
<td>☐ Gynecologist</td>
<td>☐ Radiologist</td>
</tr>
<tr>
<td>☐ Infertility Specialist</td>
<td>☐ Rheumatologist</td>
</tr>
<tr>
<td>☐ Internist</td>
<td>☐ Social Worker</td>
</tr>
<tr>
<td>☐ Massage Therapist</td>
<td>☐ Organized Support Group</td>
</tr>
<tr>
<td>☐ Neurologist</td>
<td>☐ Surgeon</td>
</tr>
<tr>
<td>☐ Sexual Therapist</td>
<td>☐ Urologist</td>
</tr>
<tr>
<td></td>
<td>☐ Other:__________</td>
</tr>
</tbody>
</table>
2. In the past 6 months, have you been seen at an emergency room?

☐ No

☐ Yes → For what reason: ________________________________

3. In the past 6 months, have you been hospitalized or had surgery? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>If yes, for what reason?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Hospitalized?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Had surgery?</td>
<td></td>
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</tbody>
</table>

4. Has anything else changed regarding either your mental or physical health status? Please mark one box for each line item (a) and (b).

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>What has changed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Mental Health?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Physical Health?</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
5. Have you had any biopsies in the past 6 months?

☐ No
☐ Yes → If yes, what was biopsied? 

Why was this biopsied? 

6. In the past 6 months, have you had a recurrence of breast cancer?

☐ No
☐ Yes → If yes, how was this diagnosis made. (For example, biopsy, lab tests)? 

7. Have you been diagnosed with any other cancer in the past 6 months?

☐ No
☐ Yes → If yes, what type? 

How was this diagnosis made? (For example, biopsy, lab tests)? 

8. Today’s date is: 

Month / Day / Year
PART II  

REPRODUCTIVE HISTORY

The following questions ask about your menstrual cycles and reproductive history. We are very interested in this information so that we can understand more about women's health during their childbearing years. Some of the questions ask you to give dates or the number of times when certain things happened. If you are not sure about the exact date or number of times, please give your best estimate.

1. What was the date of the first day of your last menstrual period (your best guess)?

   Month - Day - Year

2. In the past 6 months, have you been sexually active with a male partner:

   □ No → Go to question 6
   □ Yes → Go to question 3

3. Which method of birth control are you and your partner using currently? (Check all that apply.)

   □ No method
   □ Condoms (rubbers)
   □ Birth control pills
   □ Foams/jellies/suppositories
   □ Sponge
   □ Withdrawal (pulling out)
   □ Diaphragm
   □ Safe periods (rhythm or counting days)
   □ Norplant
   □ Cervical cap
   □ Tubal ligation (tubes tied)
   □ Vasectomy
   □ Other (Please describe: __________)
   □ Don’t know
4. In the past month, how many times have you had sexual intercourse without using contraception?
   
   ☐ ☐ Times

5. In the past 6 months, have you become pregnant?
   
   ☐ No
   ☐ Yes → If yes, are you pregnant now?
   
       ☐ No
       ☐ Yes

6. In the past month, have you had any hot flashes or night sweats (hot flashes that occur during sleep)?
   
   ☐ No
   ☐ Yes → If yes, how many have you had in the past week?
   
       ☐ ☐ ☐ hot flashes/night sweats
PART III

CURRENT MEDICATIONS

1. Please list below all of the **prescription medications** you are taking currently. (Write “none” if you are not taking any prescription medications at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
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<tbody>
<tr>
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</table>

2. Please list below all of the **non-prescription medications or supplements** you are taking currently. (Write “none” if are not taking any non-prescription medications or supplements at this time.)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Dosage</th>
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SWELLING FORM

The following questions concern swelling in your arm and/or hand. Please mark the appropriate box(es) for each question.

1. In the past 6 months, has any swelling occurred in your arm or hand on the same side that you had your lumpectomy or mastectomy?
   - [ ] No → (Go to question 8)
   - [ ] Yes → (Continue to question 2)
   - [ ] Don’t know → (Go to question 8)

2. Do you believe the start of your swelling was related to any of the following?
   - [ ] Yes
   - [ ] No
   - [ ] Don’t Know
   - Radiation treatment
   - Breast reconstruction
   - Infection or injury to arm / hand
   - Weather changes
   - General use of your arm
   - Exercise
   - Airplane travel
   - Other: Please describe: ____________________________

Swelling 30 mos. 7/00
2a. How soon after you had surgery and/or began treatment did this swelling occur?

☐ Less than 1 week
☐ 1 week to 4 weeks
☐ 1 month to 3 months
☐ 4 months to 6 months
☐ 7 months to 9 months
☐ 10 months to 12 months
☐ 13 months to 15 months

2b. Where does (did) the swelling occur? (Check all that apply)

☐ Hand
☐ Upper Arm
☐ Lower Arm

2c. Do (did) you consider the swelling to be mostly?

☐ Mild
☐ Moderate
☐ Severe

3. Does (did) the swelling interfere with any of the following?

Yes ☐ No ☐

☐ Clothing that you wear
☐ Your ability to do routine activities, such as household chores or grooming.
☐ Exercise
☐ Your appearance

Other, please describe: _____________________________
4. Does (did) swelling seem to get worse with any of the following?

<table>
<thead>
<tr>
<th>Don't</th>
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<tbody>
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<td>Yes</td>
<td>No</td>
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Other: Please describe: ____________________________________________________________

5. Prior to your breast cancer diagnosis, did you notice swelling in your hand and/or arm with any of the following? (Check all that apply)

<table>
<thead>
<tr>
<th>Don't</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
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<td>☐</td>
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</table>

Other: Please describe: ____________________________________________________________

Swelling 30 mos. 7/00
6. Did you seek treatment for this swelling in the past 6 months?

☐ No → If no, why not?

☐ Yes → If yes, what type of treatment did you receive? (Check all that apply)

☐ Compression therapy by machine
☐ Glove / Sleeve Compression / Garment
☐ Physical therapy
☐ Manual lymphatic drainage
☐ Bandaging technique
☐ Other, please describe: ____________________________

7. Do you have swelling now?

☐ No → (Go to question 8)
☐ Yes → (Continue to question 7a)

7a. If yes, how long have you had swelling?

☐ Less than 1 week
☐ 2 - 4 weeks
☐ 1 - 3 months
☐ 4 - 6 months
☐ 7 - 9 months
☐ 10 - 12 months
8. In the past 6 months, do you remember any breaks in your skin, infected hang nails, or slight skin injuries in your arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 9)
☐ Yes → (Continue to question 8a)
☐ Don’t Know → (Continue to question 9)

8a. If yes, did you receive antibiotics?

☐ Yes
☐ No
☐ Don’t know

9. In the past 6 months, did you have any infection in the arm or hand on the same side that you had your lumpectomy or mastectomy?

☐ No → (Go to question 10)
☐ Yes → (Continue to question 9a)
☐ Don’t Know → (Continue to question 10)

If yes, did you:

9a. receive antibiotics by mouth?

☐ No
☐ Yes
☐ Don’t know
If yes, did you:

9b. receive antibiotics by injection?

- [ ] No
- [ ] Yes
- [ ] Don’t know

10. Do you have pain in the affected arm and/or hand? (Check one box for each site)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hand and arm</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SYMPTOMS QUESTIONNAIRE

Below are statements about symptoms some people may experience. For each statement, check the appropriate box for the response that best describes how bothersome the symptom was for you during the past month. If you did not have the problem, check the box under the column titled “symptom did not occur”. Please do not skip any questions. **Mark only one box on each line.**

If you experienced the symptom, use the following key to indicate how bothersome it was:

- **Mild** = symptom did not interfere with usual activities.
- **Moderate** = symptom interfered somewhat with usual activities.
- **Severe** = symptom was so bothersome that usual activities could not be performed.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mild</td>
</tr>
<tr>
<td>1. Fatigue or low energy level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Mouth ulcers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Restless sleep</td>
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</tr>
<tr>
<td>4. Sleeping too much</td>
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<td></td>
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<tr>
<td>5. Nervousness or shakiness inside</td>
<td></td>
<td></td>
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<tr>
<td>6. Mood changes</td>
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<tr>
<td>7. Feeling depressed</td>
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<tr>
<td>8. Lightheadedness when standing up</td>
<td></td>
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<tr>
<td>9. Faintness or dizziness at rest</td>
<td></td>
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<tr>
<td>10. Headaches</td>
<td></td>
<td></td>
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<tr>
<td>11. Swelling of ankles or feet</td>
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<td></td>
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<tr>
<td>12. Diarrhea</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Symptoms 30 mos. 7/00*
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Symptom did not occur</th>
<th>Symptom Occurred and Was:</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Constipation</td>
<td></td>
<td></td>
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<tr>
<td>14. Abdominal pain/cramps</td>
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<tr>
<td>15. Vaginal dryness</td>
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<tr>
<td>16. Muscle pain/ache/or cramp</td>
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<tr>
<td>17. Weight gain</td>
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<tr>
<td>18. Weight loss</td>
<td></td>
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<tr>
<td>19. General aches and pains</td>
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<td>20. Hot flashes</td>
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<tr>
<td>21. Joint pains</td>
<td></td>
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</tr>
<tr>
<td>22. Night sweats</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>23. Aches in back of neck and skull</td>
<td></td>
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<tr>
<td>24. Forgetfulness</td>
<td></td>
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<tr>
<td>25. Difficulty concentrating</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>26. Increased appetite</td>
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<td></td>
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<tr>
<td>27. Short temper</td>
<td></td>
<td></td>
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<tr>
<td>28. Decreased efficiency</td>
<td></td>
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<tr>
<td>29. Loss of interest in work/activities</td>
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<tr>
<td>30. Lowered work performance</td>
<td></td>
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<tr>
<td>31. Blind spots, fuzzy vision</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>32. Breast sensitivity/tenderness</td>
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<td></td>
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<tr>
<td>33. Avoidance of social affairs</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>34. Cold sweats</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Decreased appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Feelings of suffocation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Difficulty healing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Bloating</td>
<td></td>
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</tr>
</tbody>
</table>

*Symptoms 30 mos. 7/00*
QUALITY OF LIFE FORM

1. In general, would you say your health is: (Check one)
   Excellent    Very good   Good   Fair   Poor

   □           □           □      □       □

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.
   Limited a lot   Limited a little   Not limited at all

   □           □           □

3. Climbing several flights of stairs.
   Limited a lot   Limited a little   Not limited at all

   □           □           □

During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

4. Accomplished less than you would like.
   Yes       No

   □           □

5. Had difficulty performing the work or other activities, for example, it took extra effort.

   Yes       No

   □           □

During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you would like.
   Yes       No

   □           □

7. Didn’t do work or other activities as carefully as usual.
   Yes       No

   □           □
8. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (Check one)

Not at all  Slightly  Moderately  Quite a bit  Extremely

9. During the past four weeks, how much did pain interfere with your normal activities (including both work outside the home, housework and family activities)? (Check one)

Not at all  Slightly  Moderately  Quite a bit  Extremely

These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks:

10. Have you felt calm and peaceful? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time

11. Did you have a lot of energy? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time

12. Have you felt downhearted and blue? (Check one)

All of the time  Most of the time  A good bit of the time  Some of the time  A little of the time  None of the time
Below is a list of statements that other people with your illness have said are important. Please circle the number that best describes how true each statement has been for you during the past 7 days.

<table>
<thead>
<tr>
<th>Physical Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. I had a lack of energy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I had nausea.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I had trouble meeting the needs of my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I had pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I was bothered by side effects of treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. In general, I felt sick.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I was forced to spend time in bed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

20. How much does your Physical Well-Being affect your quality of life? (Circle one number.)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Very Much So</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social/Family Well-Being</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I felt distant from my friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. I got emotional support from my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. I got support from my friends and neighbors.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. My family had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Family communication about my illness was poor.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

If you have a spouse/partner, or are sexually active, please answer questions 26-27. Otherwise, go to question 28.

26. I felt close to my partner (or main support).

27. I was satisfied with my sex life.

28. How much does your Social/Family Well-Being affect your quality of life? (Circle one number.)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Very Much So</td>
</tr>
</tbody>
</table>

*Quality of Life 30 mos. 7/00*
<table>
<thead>
<tr>
<th>Relationship With Doctor</th>
<th>Not At All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. I had confidence in my doctor(s).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. My doctor was available to answer my questions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

31. How much does your Relationship with your Doctor affect your quality of life? (Circle one number.)

| Not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very Much So |

<table>
<thead>
<tr>
<th>Emotional Well-Being</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. I felt sad.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>33. I was proud of how I’m coping with my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>34. I was losing hope in the fight against my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>35. I felt nervous.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>36. I worried about dying.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

37. How much does your Emotional Well-Being affect your quality of life? (Circle one number.)

| Not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very Much So |

<table>
<thead>
<tr>
<th>Functional Well-Being</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>38. I was able to work (include work in home).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>39. My work (include work in home) was fulfilling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>40. I was able to enjoy life “in the moment.”</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>41. I had accepted my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>42. I was sleeping well.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>43. I enjoyed my usual leisure pursuits.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>44. I was content with the quality of my life right now.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

45. How much does your Functional Well-Being affect your quality of life? (Circle one number.)

| Not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Very Much So |

*Quality of Life 30 mos. 7/00*
Additional Concerns

46. I was short of breath.                       1   2   3   4   5
47. I was self-conscious about the way I dressed. 1   2   3   4   5
48. My arms were swollen or tender.               1   2   3   4   5
49. I felt sexually attractive.                   1   2   3   4   5
50. I was bothered by hair loss.                  1   2   3   4   5
51. I worried about the risk of cancer in other family members. 1   2   3   4   5
52. I worried about the effect of stress on my illness. 1   2   3   4   5
53. I was bothered by a change in weight.         1   2   3   4   5
54. I was able to feel like a woman.              1   2   3   4   5

55. How much do these Additional Concerns affect your quality of life? (Circle one number.)

0     1     2     3     4     5     6     7     8     9     10
Not at all  Very Much So

YOUR APPEARANCE

This section asks you about your general perceptions regarding your body. Right now, how satisfied are you with these parts of your body? Please check the appropriate box for the response that best describes your satisfaction with each body part.

<table>
<thead>
<tr>
<th></th>
<th>Very dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Neutral</th>
<th>Somewhat satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>56.</td>
<td>Hair</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>57.</td>
<td>Breasts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>58.</td>
<td>Arms</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>59.</td>
<td>Face</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60.</td>
<td>Waist</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>61.</td>
<td>Hips</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>62.</td>
<td>Thighs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>63.</td>
<td>Overall body</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
How much do you agree or disagree with the following statement? (Check the appropriate box.)

64. The appearance of my breast area is important to me.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

65. I view myself as a:

- [ ] Very overweight person
- [ ] Moderately overweight person
- [ ] Normal weight person
- [ ] Moderately thin person
- [ ] Very thin person

PART III. SEXUALITY

These next questions are about the way health problems may interfere with your sex life. These questions are personal, but your answers are important in understanding how health problems may affect women’s sexuality.

66. Have you been sexually active with a partner during the last 6 months?

- [ ] No ——> (If no, skip to Question 79).
- [ ] Yes ——> (If yes, continue to Question 67).

67. How many times have you had sexual intercourse in the past month?

- [ ] 0 times
- [ ] 1 - 4 times
- [ ] 5 - 10 times
- [ ] 11 or more
For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>68. How often were you aware of wetness in your vagina as you became sexually excited?</td>
<td></td>
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</tr>
<tr>
<td>69. How often did it take a long time for your vagina to become wet or slippery as you became sexually excited?</td>
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</tr>
<tr>
<td>70. During sexual relations, how frequently did you notice dryness of your vagina?</td>
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<tr>
<td>71. How often did you feel pain or discomfort during vaginal penetration?</td>
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</tr>
<tr>
<td>72. How often did you feel satisfied after sexual activity?</td>
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<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>73. How often were you satisfied with the frequency of sexual activity?</td>
<td></td>
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</tr>
<tr>
<td>74. How frequently did you feel tense or nervous after a sexual experience?</td>
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</tbody>
</table>

For the following questions, please check the box for the response that best describes your sexual feelings and experiences **DURING THE PAST MONTH**.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>75. I avoided having my breast area fondled or kissed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>76. My partner avoided fondling or kissing my breast area.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>77. I notice I didn't hug or kiss my partner much.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>78. I notice my partner didn't hug and kiss me much.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Quality of Life 30 mos. 7/00*
PART IV. SLEEP HABITS

The next group of questions ask about your sleep habits. Please check the appropriate box for the one response that best describes how often you experienced these situations in THE PAST 4 WEEKS.

79. Did you have trouble falling asleep?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week

80. Did you wake up several times a night?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week

81. Did you wake up earlier than you planned to?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week

82. Did you have trouble getting back to sleep after you woke up too early?
   □ No, not in the past 4 weeks
   □ Yes, less than once a week
   □ Yes, 1 or 2 times a week
   □ Yes, 3 or 4 times a week
   □ Yes, 5 or more times a week
83. Overall, how was your typical night’s sleep during the past 4 weeks?
   □ Very sound or restful
   □ Sound or restful
   □ Average quality
   □ Restless
   □ Very restless

84. About how many hours of sleep did you get on a typical night during the past 4 weeks?
   □ 5 or less hours
   □ 6 hours
   □ 7 hours
   □ 8 hours
   □ 9 hours
   □ 10 or more hours

PART V. SPIRITUAL BELIEFS

The following questions are about spiritual beliefs. Please check the appropriate box indicating how true the statement has been for you during THE PAST WEEK.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>85. I felt peaceful.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>86. I had a reason for living.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>87. I felt a sense of purpose in my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>88. I was able to reach down deep into myself for comfort.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>89. I felt a sense of harmony within myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>90. I found comfort in my faith.</td>
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<td>91. I found strength in my faith.</td>
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</table>
92. Where would you place yourself on the following scale, if “0” means that your life is just the way it was before your breast cancer, “+5” means that everything is totally different but better, and “-5” means that everything is totally different but worse. (Please circle ONE number).

-5  -4  -3  -2  -1  0  +1  +2  +3  +4  +5
Worse  Same as before  Better

PART VI. EMOTIONAL FEELINGS

The following questions consist of groups of statements. After reading each group of statements carefully, check the box next to the one statement in each group which best describes the way you have been feeling the past week, including today. If several statements within a group seem to apply equally, check each one. Be sure to read all the statements in each group before making your choice.

93.  
☐ I do not feel sad.
☐ I feel sad.
☐ I am sad all the time and I can’t snap out of it.
☐ I am so sad or unhappy that I can’t stand it.

94.  
☐ I am not particularly discouraged about the future.
☐ I feel discouraged about the future.
☐ I feel I have nothing to look forward to.
☐ I feel that the future is hopeless and that things cannot improve.

95.  
☐ I do not feel like a failure.
☐ I feel I have failed more than the average person.
☐ As I look back on my life, all I can see is a lot of failures.
☐ I feel I am a complete failure as a person.

96.  
☐ I get as much satisfaction out of things as I used to.
☐ I don’t enjoy things the way I used to.
☐ I don’t get real satisfaction out of anything anymore.
☐ I am dissatisfied or bored with everything.
97. □ I don’t feel particularly guilty.
    □ I feel guilty a good part of the time.
    □ I feel quite guilty most of the time.
    □ I feel guilty all of the time.

98. □ I don’t feel I am being punished.
    □ I feel I may be punished.
    □ I expect to be punished.
    □ I feel I am being punished.

99. □ I don’t feel disappointed in myself.
    □ I am disappointed in myself.
    □ I am disgusted with myself.
    □ I hate myself.

100. □ I don’t feel I am any worse than anybody else.
    □ I am critical of myself for my weaknesses or mistakes.
    □ I blame myself all the time for my faults.
    □ I blame myself for everything bad that happens.

101. □ I don’t have any thoughts of killing myself.
    □ I have thoughts of killing myself, but I would not carry them out.
    □ I would like to kill myself.
    □ I would kill myself if I had the chance.

102. □ I don’t cry anymore than usual.
    □ I cry more now than I used to.
    □ I cry all the time now.
    □ I used to be able to cry, but now I can’t cry even though I want to.
103. □ I am no more irritated now than I ever am.  
□ I get annoyed or irritated more easily than I used to.  
□ I feel irritated all the time now.  
□ I don’t get irritated at all by the things that used to irritate me.

104. □ I have not lost interest in other people.  
□ I am less interested in other people than I used to be.  
□ I have lost most of my interest in other people.  
□ I have lost all of my interest in other people.

105. □ I make decisions about as well as I ever could.  
□ I put off making decisions more than I used to.  
□ I have greater difficulty in making decisions than before.  
□ I can’t make decisions at all anymore.

106. □ I don’t feel I look any worse than I used to.  
□ I am worried that I am looking old or unattractive.  
□ I feel that there are permanent changes in my appearance that make me look unattractive.  
□ I believe that I look ugly.

107. □ I can work about as well as before.  
□ It takes an extra effort to get started at doing something.  
□ I have to push myself very hard to do anything.  
□ I can’t do any work at all.

108. □ I can sleep as well as usual.  
□ I don’t sleep as well as I used to.  
□ I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.  
□ I wake up several hours earlier than I used to and cannot get back to sleep.
109. □ I don’t get more tired than usual.
    □ I get tired more easily than I used to.
    □ I get tired from doing almost anything.
    □ I am too tired to do anything.

110. □ My appetite is no worse than usual.
    □ My appetite is not as good as it used to be.
    □ My appetite is much worse now.
    □ I have no appetite at all anymore.

111. □ I haven’t lost much weight, if any, lately.
    □ I have lost more than five (5) pounds.
    □ I have lost more than ten (10) pounds.
    □ I have lost more than fifteen (15) pounds.

112. □ I am no more worried about my health than usual.
    □ I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
    □ I am very worried about physical problems and it’s hard to think of much else.
    □ I am so worried about my physical problems that I cannot think about anything else.

113. □ I have not noticed any recent change in my interest in sex.
    □ I am less interested in sex than I used to be.
    □ I am much less interested in sex now.
    □ I have lost interest in sex completely.
SOCIAL SUPPORT FORM

The following are questions about the support that is available to you.

1. At the present time, about how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?  (Please write the number in the boxes below.)

   □ □ Number of close friends and close relatives

People sometimes look to others for companionship, assistance, or other types of support. Currently, how often is each of the following kinds of support available to you if you need it?  (Check one box for each statement.)

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
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<tbody>
<tr>
<td>2. Someone to help you if you were confined to bed.</td>
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<td>3. Someone you can count on to listen to you when you need to talk.</td>
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<td>4. Someone to give you good advice about a crisis.</td>
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<td>5. Someone to take you to the doctor if you needed it.</td>
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<td>6. Someone who shows you love and affection.</td>
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<td>7. Someone to have a good time with.</td>
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<td>8. Someone to give you information to help you understand a situation.</td>
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<td>9. Someone to confide in or talk to about yourself or your problems.</td>
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<tr>
<td></td>
<td>None of the time</td>
<td>A little of the time</td>
<td>Some of the time</td>
<td>Most of the time</td>
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<td>10.</td>
<td>Someone who hugs you.</td>
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<td>11.</td>
<td>Someone to get together with for relaxation.</td>
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<td>12.</td>
<td>Someone to prepare your meals if you were unable to do it yourself.</td>
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<td>13.</td>
<td>Someone whose advice you really want.</td>
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<td>14.</td>
<td>Someone to do things with to help you get your mind off things.</td>
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<td>15.</td>
<td>Someone to help with daily chores if you were sick.</td>
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<td>16.</td>
<td>Someone to share your most private worries and fears with.</td>
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<td>17.</td>
<td>Someone to turn to for suggestions about how to deal with a personal problem.</td>
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<td>18.</td>
<td>Someone to do something enjoyable with.</td>
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<td>20.</td>
<td>Someone to love you and make you feel wanted.</td>
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</table>
For the following questions, please check the box that is the most true for you at the present time. (Check only one box for each statement.)

Of the people who are important to you, how many:

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>One</th>
<th>Some</th>
<th>Most</th>
<th>All</th>
</tr>
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<tbody>
<tr>
<td>21. Don’t understand you.</td>
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<td>22. Get on your nerves.</td>
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<td>23. Ask too much of you.</td>
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<td>25. Don’t include you.</td>
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<td>26. Show that they don’t like you.</td>
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<td>27. Boss you.</td>
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<td>28. Try to get you to do things you don’t want to do.</td>
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</table>
PERSONAL HABITS FORM

These questions are about habits that may affect your health (smoking, alcohol use, weight, and exercise). Please answer each question as accurately as possible.

1. Do you smoke currently?
   [ ] No
   [ ] Yes

   If yes, how many cigarettes do you smoke per day? (1 pack = 20 cigarettes)
   [ ] I smoke occasionally.
   [ ] 0 - 5 cigarettes a day
   [ ] 6 - 20 cigarettes a day
   [ ] 21 - 30 cigarettes a day
   [ ] 31 - 40 cigarettes a day
   [ ] more than 40 cigarettes a day

2. Do you currently drink alcoholic beverages?
   [ ] No
   [ ] Yes

   If yes, about how many alcoholic beverages (beer, wine, or mixed drinks) do you currently drink in an average month?
   [ ] [ ] [ ] Beverages per month

Personal Habits 30 mos. 7/00
3. What is your current weight?

[ ] ___ ___ pounds

The following questions are about your usual physical activity and exercise. This includes walking and sports.

4. Think about the walking you do outside the home. In the past month, how often did you walk outside the home for more than 10 minutes without stopping? (Mark only one.)

[ ] Rarely or never   ---> (Go to Question 5)
[ ] 1-3 times each month ---> (Go to Question 4a)
[ ] 1 time each week   ---> (Go to Question 4a)
[ ] 2-3 times each week ---> (Go to Question 4a)
[ ] 4-6 times each week ---> (Go to Question 4a)
[ ] 7 or more times each week ---> (Go to Question 4a)

4a. When you walked outside the home for more than 10 minutes without stopping, how many minutes did you usually walk?

[ ] Less than 20 minutes
[ ] 20-39 minutes
[ ] 40-59 minutes
[ ] 1 hour or more

4b. What was your usual speed?

[ ] Casual strolling or walking (less than 2 miles an hour)
[ ] Average or normal (2-3 miles an hour)
[ ] Fairly fast (3-4 miles an hour)
[ ] Very fast (more than 4 miles an hour)
[ ] Don’t Know
Following are three categories of exercise, (strenuous, moderate, and mild). Not including walking outside the home, how often each week (7 days) do you usually do the following strenuous, moderate, and mild types of exercise?

5. **STRENUOUS OR VERY HARD EXERCISE.** (You work up a sweat and your heart beats fast.) For example, aerobics, aerobic dancing, jogging, tennis, swimming laps.

   - None ---> (Go to Question 6)
   - 1 day per week ---> (Go to Question 5a)
   - 2 days per week ---> (Go to Question 5a)
   - 3 days per week ---> (Go to Question 5a)
   - 4 days per week ---> (Go to Question 5a)
   - 5 or more days per week ---> (Go to Question 5a)

5a. How long do you usually exercise like this at one time?

   - Less than 20 minutes
   - 20-39 minutes
   - 40-59 minutes
   - 1 hour or more

6. **MODERATE EXERCISE** (Not exhausting). For example, biking outdoors, using an exercise machine (like a stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing.

   - None ---> (Go to Question 7)
   - 1 day per week ---> (Go to Question 6a)
   - 2 days per week ---> (Go to Question 6a)
   - 3 days per week ---> (Go to Question 6a)
   - 4 days per week ---> (Go to Question 6a)
   - 5 or more days per week ---> (Go to Question 6a)
6a.  How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more

7.  MILD EXERCISE. For example, slow dancing, bowling, golf.

☐ None
☐ 1 day per week  ---> (Go to Question 7a)
☐ 2 days per week  ---> (Go to Question 7a)
☐ 3 days per week  ---> (Go to Question 7a)
☐ 4 days per week  ---> (Go to Question 7a)
☐ 5 or more days per week  ---> (Go to Question 7a)

7a.  How long do you usually exercise like this at one time?

☐ Less than 20 minutes
☐ 20-39 minutes
☐ 40-59 minutes
☐ 1 hour or more
CONTACT INFORMATION FORM

We would like you to update your contact information so that we can keep in touch with you during the study. This information is very important, so please answer these questions completely. Please print the information in the space provided or mark the appropriate box.

1. **Has your address changed since our last mailing to you?**
   - [ ] No
   - [ ] Yes → **If yes, please provide current mailing address**

   Your Current Mailing Address:
   ___________________________________________________________
   ___________________________________________________________
   ___________________________________________________________

2. **Telephone Numbers:**
   - **Home:** Area Code (___ ___) ______ - ______
   - **Work:** Area Code (___ ___) ______ - ______
   - **Other:** Area Code (___ ___) ______ - ______

3. **When is the best time to contact you?**
   - Day of week time(s)

   Where is the best place to contact you?
   - [ ] At home
   - [ ] At work
   - [ ] Other

   Day of week time(s)
   - [ ] At home
   - [ ] At work
   - [ ] Other
4. In case we might ever need to contact you by telephone, may we leave a message for you on your answering machine, (if you have one), if we are unable to reach you directly?

[ ] No
[ ] Yes

5. What is your husband's or partner's legal name? (This information will help us keep in contact with you during the study. Please leave this blank if you are not currently married or with a long-term partner.)

__________________________________________   ______  ____________________________
First        MI         Last

6. Please provide the names of two relatives or friends, not living in your household, who are likely to know how to contact you if we are unable to reach you.

Name: ____________________________________________
Address: __________________________________________

Phone Number:          Area Code (___) ___-____
Relationship to you: ________________________________________

Name: ____________________________________________
Address: __________________________________________

Phone Number:          Area Code (___) ___-____
Relationship to you: ________________________________________
Appendix F

SEPTEMBER 2000

Patient I.D.: □ - □ - □□□□ Acrostic: □□□□

IF YOU'VE NOT HAD ANY BLEEDING DURING THIS MONTH, CHECK THIS BOX: □

OTHERWISE, for each day you bled or spotted, please check the appropriate box below referring to information on ANY vaginal BLEEDING or SPOTTING you may have. A BLEEDING day is defined as a day on which your blood loss requires the use of a tampon or pad. A SPOTTING day is defined as a day on which your blood loss does not require the use of a tampon or pad.

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
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<tr>
<td></td>
<td></td>
<td>□ Spotting Bleeding:</td>
<td>□ Light</td>
<td>□ Medium</td>
<td>□ Heavy</td>
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<td>3</td>
<td>4</td>
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<td>□ Spotting Bleeding:</td>
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This calendar and the questionnaires you complete are for research purposes only. No doctor who is treating you will see these forms. If you have any questions or concerns - whether emotional, physical, or about your menstrual cycles - please discuss them with your doctor.

Call Judy at 336-716-2116 or Kathy at 336-716-9486 if you have questions.
NEWS From the Menstrual Cycle Maintenance and Quality of Life in Young Women with Breast Cancer Study

Spring 2000

A Message From the Coordinating Center

Hello from everyone at the Coordinating Center. First, I want to thank everyone who provided feedback on our first newsletter. For me, hearing from participants is one of the highlights of my day. Thanks for your calls, e-mails and notes.

Spring is a time of new beginnings and new growth. In this newsletter several cancer survivors share their stories in hopes of providing inspiration to you so that your own experience with cancer can lead to personal growth. We also highlight the staff at the Memorial Sloan-Kettering Cancer Center, and share some information about what our participants are like. Enclosed with the newsletter is the 1999 Breast Cancer Handbook from SELF magazine. In the magazine you will find an article about Jeanne Petrek, the lead investigator at Memorial Sloan Kettering, Myths about breast cancer, Portrait’s of Survivors, and a list of important resources that may be of interest. We hope you will enjoy the newsletter and perhaps pass it on to a friend. One of our participants was kind enough to share a great cookie recipe. I’ve made it twice and it was a hit.

The new millennium is an exciting and yet challenging time for scientific research. Every week new articles are released describing research to detect, and treat breast cancer. Better surgical techniques are being developed, new drug therapies are being tested, and interventions are being implemented to help with the physical and emotional problems encountered by patients and their families. What the countless lectures and research articles don’t tell you, is perhaps the most important piece of information. None of these advancements would have been possible without women like you participating in research in the hopes of making a difference for women in the future. As one of our participants has said, ” here’s Hoping for a Cancer-Free New Millennium”.

Judy Bahnson

QOLSN: March 2000
New Books

Eileen Marian, author of the book Chemotherapy Gives New Meaning to A Bad Hair Day, says, "Disease isn't funny, humor, however, is healing." The book is a cartoon book that helps individuals find humor in difficult situations.

Pat Kelly, one of our Project Coordinators in Texas was familiar with the book and recommended it for our Newsletter. I called Eileen to get the story behind the book. In 1992 Eileen says, "Life was good. I was 44, eating healthy, exercising and taking time for myself to live on life's terms when I was diagnosed with breast cancer." She relates that coping with surgery and facing radiation treatment was a piece of cake compared to confronting the fears of her teenage son. Eileen said that, humor was included in her bag of tools to help her live through this life crisis. "Over the next few years," she says, "humor took on a life of its own" as she was diagnosed with another breast cancer and then colon cancer. Eileen says, "From the start of this journey, I quickly learned the importance of being an empowered patient; to speak up and ask questions and not to stop until I got the answer." She found groups to be educational and supportive at various stages of her disease. In addition, she says, "I used the safety of a journal to revel my fears and confusion that I wouldn't share with another person."

Eileen's cousin was diagnosed with breast cancer several years later, and she began to send her little notes with humorous statements and drawings related to some of the tests that cancer patients go through. Those simple drawing and statements grew to become a book.

Eileen's book has some wonderful light hearted cartoons. In addition, she provides thought provoking sayings and space for writing your own thoughts.

Eileen says, "Cancer is a horrible disease, but it has helped me a great deal to learn about myself. It continues to teach me lessons and has given me permission to take risks necessary to live life to the fullest regardless of how many days, weeks, or years I have."

Want to see the book? Check out www.metroplexweb.com/oas or you can order the book for $15.15 from On a Shoestring, P.O. Box 831537, Richardson Texas 75083

Laughter is the best medicine. It's free and doesn't have to be filled with insurance.
Who's Participating in the Study?

We now have 523 women enrolled in the Menstrual Cycle Maintenance and Quality of Life After Breast Cancer Study. For those of you receiving the newsletter for the first time, we have four Clinical Centers enrolling participants: Memorial Sloan Kettering in New York; M.D. Anderson and Presbyterian Hospital in Texas; and Wake Forest University Baptist Medical Center in North Carolina.

Age of participants
The average age of our participants at entry into this study is 39 years old.
1% are age 21 - 25
3% are age 26 - 30
33% are age 31 - 39
49% are age 40 - 45
14% are 45 years old or older.

Educational Status
2% have less than a high school education
9% graduated from high school or received a GED
63% had some college or are college graduates
26% have a Master's or Doctoral degree

Racial Status
86% are White
6% are African American
4% are Hispanic
3% are Asian
1% are American Indian

Employment Status
17% work full time as homemakers
56% are employed full time at a paid job
13% are employed part time at a paid job
6% are on disability

Marital Status
75% are married or have a live-in relationship
15% have never been married
10% are separated, divorced or widowed.

Seventy-four percent of our participants have children.

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INFORMATIVE WEB SITES
The following web-site was recommended by one of our study participants.

Health Insurance Rights:  
www.georgetown.edu/research/ihcrp/hpaa  
This site lists, by state, consumer guides to getting and keeping health insurance and/or switching health insurance if you have a pre-existing condition. Participant Linda Pollitz writes, "This site was/is the brainchild of a breast cancer survivor (my sister)."

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If you know of other web sites that participants might find interesting or useful, let us know and we will put them in our next newsletter.

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Who's Who at the Memorial Sloan-Kettering Cancer Center Clinic Site

Jeanne Petrek - Principal Investigator
Dr. Jeanne Petrek, Principal Investigator for the study at the Memorial Sloan-Kettering Cancer Center in New York, grew up in Ohio and received her MD from Case Western Reserve in Cleveland. She is an attending breast surgeon at Memorial Sloan-Kettering and the Director of the Surgical Program at the Evelyn H. Lauder Breast Center. She is also an Associate Professor of Surgery at the Cornell University School of Medicine, and she serves on the Breast Cancer Council of the National Society of the American Cancer Society. She has authored several books and many scientific articles on breast cancer.

Ten years ago, Dr. Petrek developed a special interest in breast cancer in young women and the issues they face, such as the ability to have children after breast cancer treatment, problems of lymphedema and in issues associated with their quality of life. At that time, very little research was being done on women, and no research was being done with young women with breast cancer. In hopes of making a difference to science and young women, Dr. Petrek began to focus on breast surgery and the problems associated with breast cancer. She was the primary motivator in planning the study in which you are now participating in.

In her leisure time, Dr. Petrek enjoys outdoor activities, such as, hiking, snorkeling and rafting. She lives in Manhattan with her husband and two children.

Joanna Winawer, Study Coordinator
Joanna grew up in New York City. After receiving her B.S. in Classical Humanities from the University of Wisconsin at Madison, she spent a year traveling and studying in Israel. Medicine has been a life long interest for Joanna, who decided to gain some experience in the field before applying to medical school. When Joanna isn't working, she enjoys traveling, hiking, swimming, going to the opera, and devouring sushi!

Lisa Loudon - Research Coordinator
For the first 23 years of her life, Lisa lived in the quiet country side of Virginia. Her future husband convinced her to leave the country...and move to the city....New York City. Lisa says she went from one extreme to another, and what an experience! She says, although she loves the city, her heart belongs to Virginia.

Lisa has worked at Memorial Sloan-Kettering for five years. She started as a medical secretary where she enjoyed working with patients and learning about the disease. Dr. Petrek then offered her the opportunity to work with her as her research coordinator which Lisa enjoys. "I am very excited to be a part of this very important study", she says.

Lisa says she has the typical Type B personality; fairly laid back and calm. When I first met her, I would have agreed with that. However, last year she was working full-time, going to school, and doing an internship while she was pregnant! Sounds Type A to me. In May of 1999 she finished her Masters in Childhood Development. In June, she gave birth to her first child, James Anthony, and life really got busy.
Participant Profile

Last week while I was working on this Newsletter, I received a call from one of our participants, Ricka Powers, who apologized that some of her study forms were late. When she said she had been incredibly busy I asked her what was going on. “I’m running for the House of Representatives in Minnesota,” she said. After chatting for a few minutes, I told Ricka I was working on the Newsletter and asked her if she wanted to share her experience with our other study participants. She was happy to do so.

Ricka was 39 when she found she had Stage II breast cancer. For three years her HMO had been reassuring her that her growing lump was not breast cancer. Ricka says, “I finally arranged my own biopsy against my doctor’s wishes, and received the diagnosis. She was assigned a general surgeon but insisted on a second opinion with a surgical oncologist experienced with breast cancer. She says, “I spent three days pleading for a second opinion, and finally gave up and went on my own to Hennepin County Medical Center so I could have a surgical oncologist perform my lumpectomy and auxiliary lymph node dissection”.

“My HMO battle continued, and with the support of the Medical Center and the National Breast Cancer Coalition, I was asked to speak at the White House with President Clinton, Vice President Gore, Secretary Donna Shalala, Alexix Herman, and AMA Board member, Dr. Regina Benjamin, in support of the Patients Bill of Rights.”

Two days after her first chemotherapy treatment she was asked to meet with the Vice President again and a month later with the National Breast Cancer Coalition.

“Instead of focusing on my healing, my energy was used in battling my HMO, which took place during my chemotherapy treatment,” she said. In the end, her HMO did pay for her medical bills.

So how did she get through it all? Ricka says, “Thanks to the strength that God has given me, I’m standing on solid ground and ready to start my life over with new meaning and challenges. I am passionate about health care, and I am driven to take my personal experience and the voice of the community, and transform them into constructive activism. I’m running for the House of Representatives because one of God’s greatest miracles is to enable ordinary people to do extraordinary things.”

Ricka says, “I decided to share my story with you because it gives me the opportunity to reassure you that we will get through the horror of our diagnosis, chemotherapy, radiation, and endless treatments. Our hair will slowly grow back again, and as we awkwardly remove our hat or wig for the first time and go out into the crowd looking like Gl Jane, perhaps we will think of all the breast cancer survivors: a ballet of warriors on the front line against cancer. We come to terms with fear and cast it out in prayer. We conquer healing through faith. We experience the metamorphosis of a new sense of forgiveness, examine our demands on ourselves and others, and speak love more openly and freely.”
"My sisters in survival," she says, "you can't be brave if you've only had good things happen to you." Ricka closes with a stanza from a poem she wrote while battling cancer:

We can do great things
Only small things with great love.
And when you think it's impossible, well,
Reality is what you rise above.

I'm sure all of us wish Ricka luck in her fight for health care reform and patients rights, and her race in the House of Representatives. Win or lose, there is no doubt she is a woman who is making a difference and is certainly a winner.

Ricka can be reached at rickapowers@isd.net

QUICK RECIPES

The following recipe was sent in by one of our participants. It was quick and tasted great. You can experiment using different types of jam in this recipe. For example, I used ½ jar of peach jam and ½ a jar of raspberry and that was good too.

Raspberry Preserves Snack Bars

1 package vanilla cake mix
2 ½ cups Oatmeal (uncooked)
3/4 cup melted butter

12 oz. Jar of raspberry preserves
1 tablespoon of water

Pre-heat oven to 375 degrees. Grease a 13 X 9 inch pan. Combine cake mix and oatmeal. Add butter and stir until mixture is crumbly. Pat ½ the mixture in the bottom of the pan. Mix water and preserves and spread on top. Sprinkle the remaining crumbs over the preserves and pat down firmly to make it even. Bake 20 - 25 minutes and enjoy!

We Would Like To Hear From You!

We welcome any questions or thoughts you have for the newsletter. Please drop us a line. Fold the paper in half and staple or tape it closed. We have put our address on the back for your convenience. You may also e-mail us at: jbahnsen@wfubmc.edu
Appendix H

MENSTRUAL CYCLE MAINTENANCE AND QUALITY OF LIFE AFTER BREAST CANCER TREATMENT

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About 15% of the 175,000 estimated cases of invasive breast cancer this year will occur in women of childbearing age, and the majority will be long-term survivors. Most will undergo adjuvant chemotherapy and almost half will suffer therapy-induced menopause. Even without desire for childbearing, the quality of life of these young patients may be compromised by premature menopause with typical symptoms of hot flashes, sleep disturbances, decreased libido, and vaginal dryness.

Very little is known about the drugs and dosage causing premature menopause, although such a risk profile could be critical to the clinician and to the young patient in decision-making about chemotherapy. This is especially true since the improved survival following chemotherapy appears independent of menopause induction.

Since no prospective study exists, this current research was undertaken. The goal is to accrue 800 young breast cancer patients within eight months of diagnosis, obtaining extensive baseline and treatment data and following them for medical and reproductive events. These women have consented to report bleeding through a daily calendar and health-related quality of life as related to the menopausal state. Specific questionnaires are administered every six months: Rand Health Status Profile Short Form-12, FACT-B (Functional Assessment of Cancer Therapy-Breast), Self-Concept Scale, Watts Sexual Functioning Questionnaires, Sleep Disturbance Scale, Spirituality Subscale, Beck Depression Inventory, and Medical Outcomes Study/Social Support Questionnaire.

Eligible women must be less than age 45 with regular menstrual periods pre-diagnosis since menstrual cycle maintenance is used as the surrogate of ovarian function. Accrual began January 1998 and there are more than 500 study subjects at present. Publication of results is planned for January 2002.

The U.S. Army Medical Research and Materiel Command under DAMD17-96-1-6292 supported this work.
Pregnancy after Breast Cancer

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PREGNANCY AFTER BREAST CANCER

ABSTRACT

BACKGROUND: The issue of having children after breast cancer treatment is extremely important, since as many as 10% of the 175,000 new cases of invasive breast cancer estimated for 1999 occur in women of childbearing age.

METHODS: Data on pregnancy in breast cancer survivors are scanty and consist only of retrospective data. This paper reviews the published literature on pregnancy after breast cancer, including the four recent large scale, population based studies.

RESULTS: The survival of women with breast carcinoma is not decreased in any of the published reports. However, several biases due to study design may be present in the retrospective studies which justify the concern over the conclusions.

CONCLUSIONS: A prospective study on pregnancy after breast carcinoma treatment is needed. To address these issues we are presently accruing patients for a large, multicenter study of young breast carcinoma patients funded by the Army Breast Cancer Research fund. (1-877-636-7562)
INTRODUCTION

The issue about safety after treatment of breast cancer is of great concern for the breast cancer survivor as well as her physician. Many women are delaying childbearing for different reasons (educational, professional, and personal) and it is becoming increasingly more common for them to undergo breast cancer diagnosis and treatment before completing their childbearing. The delay in childbearing to age 30’s or 40’s occurs concordantly with an increasing incidence of breast cancer in those ages. Ten percent of the 175,000 new cases of breast cancer estimated for 1999 occur in women of childbearing age.\(^{(1)}\) Physicians have stressed the complete rehabilitation of breast cancer patients, and successfully reassuming life roles. It is thus natural following the completion of therapy for the patient to inquire about an integral and treasured part of life – pregnancy and childbearing.

The hormonal influence of mammary carcinogenesis is well known. The effects of first full term pregnancy, age at menarche/menopause, usage of postmenopausal hormone replacement are definite factors in the pathogenesis of breast cancer. Aside from carcinogenesis, the importance of breast cancer promotion by the endogenous hormonal milieu has been recognized for over 100 years. Beatson, in 1896, noted regression after oophorectomy in premenopausal patients with advanced local disease.\(^{(2)}\) The possible promotional effects of endogenous ovarian or placental hormone production on causing acceleration of the growth rate of micrometastases, or stimulation of dormant micrometastases evaluated are of concern in patients with breast cancer.

Few studies have evaluated women who become pregnant after breast cancer treatment. There are several retrospective studies, each with a limited number of patients, and only recently
population-based studies have been published. A presently ongoing large prospective
multicenter study sponsored by the Army Breast Cancer Research program will help to address
some of these issues.

RETROSPECTIVE SERIES
The earlier literature stated that at least 7% of women who did not undergo oophorectomy
underwent one or more pregnancies. Seventy percent of these pregnancies were to be expected
in the first five years after cancer treatment. (3) Adjuvant cytotoxic chemotherapy depletes the
number of fertile patients by causing premature menopause, but as many as 11% had a deliberate
or unplanned pregnancy in a short-term chemotherapy study. (4) From the scanty literature
available it has been generally observed that breast cancer patients who subsequently become
pregnant have good survival rates, often the same or sometimes better than patients with no
subsequent pregnancy. (5,6)

There have been sporadic retrospective studies from single institutions with each
comprising less than 100 patients. In 1954, White reported that eight (67%) of the patients who
became pregnant lived at least 5 years, and 58% survived ten years. (7) In 1962 a series of 52
patients from Memorial Hospital had an overall five year survival rate of 52%. (8) Another
similar-sized study reported in 1969 (9) included 53 patients with five and ten year survival rates
of 77% and 69% respectively. In 1970 Cooper reported a 75% five-year survival rate in 32
patients. (10) Fifty percent of patients in a 1973 series survived five years. (11)

Case matching studies were also performed in order to lessen the influence of pregnancy
occurring only in those with a good prognosis. Peters, et al., in 1965 matched ninety-six patients
with subsequent pregnancy over several decades with patients with similar age and clinical
stage. (12) The patients with subsequent pregnancy had a longer disease-free and overall survival
than those without subsequent pregnancy. In an analysis from 1970, Cooper (19) matched each of
40 patients who subsequently became pregnant with two controls as determined by the clinical
stage, age, status of lymph node involvement, and equal survival at least to the time of
pregnancy. The patients with subsequent pregnancy had a survival time superior to that of the
controls.

Memorial Sloan-Kettering Cancer Center reported an 80% 5-year survival rate for 41
Stage I and II (AJCC classification) patients after subsequent pregnancy who were collected over
30 years. No detrimental effect was noted of subsequent pregnancy even among patients with
positive axillary lymph nodes or among those who had a pregnancy less than 2 years following
mastectomy. (13) In a 1986 nationwide French study, the ten year survival rate of 68 patients who
had subsequent pregnant was 71%. The survival of the negative-node patients was 90% at ten
years with no difference between cases and controls. (14) In 1989 Ariel and Kempner found that
subsequent pregnancies did not affect overall prognosis in a large private practice experience. (15)
The largest series is by Clark et.al, (16) of 136 patients diagnosed over five decades at the
Princess Margaret Hospital in Toronto and is an update of the series reported by Peters in
1965.(13) They reported an excellent overall five year survival rate of 78%.

Data on subsequent pregnancy have also been reported in the analysis of adjuvant
chemotherapy trials, showing similar recurrence rates and survival for patients who had
undergone subsequent pregnancy compared to those who did not. (4) Recently a study from
Athens was reported with twenty-one patients under the age of 35 who had a pregnancy after
treatment for breast cancer. The recurrence rate and survival of the 21 women was similar to
patients of similar age and stage without pregnancy. (17)
INTERVAL

Three retrospective studies have examined the question of the timing of the subsequent pregnancy on breast cancer prognosis. The effect of interval length between breast cancer diagnosis and pregnancy affects prognosis because women who defer a pregnancy for many years are also those who have remained disease-free for greater periods.

Clark and Chua (16) found that 72% of their patients became pregnant within two years of treatment. Those who became pregnant within six months had a comparatively poor prognosis -- a five-year survival rate of 54% compared with a 78% five-year survival rate among those who waited six months to two years to become pregnant after breast cancer diagnosis. Those who waited five years or more to become pregnant had 100% five-year survival from that point. The data are consistent with the fact that the longer survival after diagnosis is, per se, an indicator of the patients' better prognosis (whether pregnancy occurs or not). The French series (14) and the Memorial Hospital series, (13) which are smaller, do not find a statistically significant difference between outcome of patients based on the interval.

RETROSPECTIVE STUDY - POSSIBLE RECOLLECTION BIAS

How much reliance can be placed on these optimistic reports to allow us to adequately advise patients on subsequent pregnancy after breast cancer treatment? Since pregnancy is not coded as a disease or coded in any other way by the Record Room or Tumor Registry, cases over the previous decades are not found systematically, as is the situation with the Memorial Hospital series. (13) Even if a chart or tumor registry review of all premenopausal women had been undertaken, the occurrence of subsequent pregnancy may not be noted.
The Methods section of all of the retrospective series ignores the question of the denominator, the total number of patients with subsequent pregnancies. The largest series states simply, "We have reviewed patients whose case histories are currently available." Since cases over the decades have been obtained in these reports from the many clinicians' memories, and since it is human nature to remember those who have been seen more recently, the design of these studies is predisposed to find and report on the patients who are alive, a recollection bias.

For all of these reasons, each report probably contains a small fraction of such patients from that institution. For example, consider a typical series, that from Memorial Sloan-Kettering Cancer Center: over 30 years, 41 Stage I and II patients were found who became pregnant after breast cancer treatment and they had an outstanding 80% 5-year survival. However, based on the numbers and ages of women seen in those 30 years, as I was able to obtain from the Memorial Hospital Tumor Registry, and assuming only 7% of breast cancer patients less than 40 years became pregnant, this study should have reported on at least 450 women. Therefore, the patients reported from Memorial Hospital represent a highly selected subset, possibly 10% or so of the total who became pregnant after breast cancer treatment. It may be that this subset does not represent the whole.

POPULATION- BASED REPORTS

In an effort to avoid recollection bias, four large population based studies have been published since 1994. The first three studies are similar because they all depend upon the National Health Service record keeping and a unique identifying number that is assigned to each person at birth and is used for every hospitalization and every reportable event such as a cancer diagnosis.
Finland - The Finnish population based study used the personal identification number of women diagnosed with breast cancer and searched the national birth certificate registry for those numbers in the years following the women’s diagnosis. They found 91 breast cancer patients with subsequent deliveries. They found 471 breast cancer controls without subsequent births matched for stage, age and living at least as many years as the case to which they were matched. Those with a subsequent birth had statistically better survival rates than controls of the same age and stage with no subsequent births. The controls had a 4.8 fold (CI 2.2 – 10.3) increased risk of death compared with those who delivered after the diagnosis of breast cancer.

The flaw of national cancer registry information is that only dates of breast cancer diagnosis and death for both cases (with subsequent pregnancy) and controls (without subsequent pregnancy) were available, with no information on recurrence data. It is likely that breast cancer patients who chose to become pregnant and give birth were disease free, as opposed to an unknown proportion of controls who had a recurrence at the time of matching (but had not yet died). Thus, this bias would have contributed to controls having a poor survival rate and thereby making the cases appear to have a particularly good survival rate. The authors termed this bias “a healthy mother effect” in the title to denote the flaw that tumor registry data could not overcome.

Sweden - The next published study is from the Stockholm Breast Cancer Study Group. This Swedish study in 1995 also addressed the influence of subsequent pregnancy on breast cancer prognosis. The study population consisted of 2,119 women with primary operable breast cancer who were less than 50 years of age and treated in the Stockholm region between 1971 and 1988. The study population was matched to the inpatient care registry -- by computerized record linkage through use of the unique personal identification number -- to obtain information about the patient’s pregnancy history. A total of 50 pregnancies in 2,119 patients occurred after the
diagnosis of breast cancer. The relative hazard for these patients adjusted for nodal status and age was 0.48 (95% CI 0.18 – 1.29) at a median follow-up of 7 years (range 1-19 years).

This was also the first study to report on estrogen receptor status, which was recorded in 70% of patients. The women with subsequent pregnancies had better survival rates if their cancer had positive estrogen receptors, which at first seems counter-intuitive. However, this finding is probably related to the mere fact that positive receptors predict better survival rates in general and less likelihood of micrometastatic disease.

**Denmark** - The Danish (20) study used computer linkage of the national records of Denmark on births, abortions, and breast cancer diagnosis. The authors identified 173 women, of 5725 with primary breast cancer, 45 years or younger, who became pregnant after treatment for breast cancer. Women who had a full-term pregnancy after treatment had a non-significantly reduced risk of dying (relative risk of 0.55 CI 0.28 – 1.06) compared with other women with no full term pregnancy.

In this study (18) the authors made an attempt to adjust for recurrence. Because virtually all women who undergo subsequent pregnancy are recurrence-free, the need of appropriate recurrence-free controls is key for matching. In the Danish study computer - matched linkage was accomplished on 93% of women, and information on recurrence was available on 82%. A national survey, however, may not have complete information on recurrence which is often obtained from office records. For example, the date when the patient suspected recurrence would influence her desire and likelihood of becoming pregnant at that point. Furthermore, in an attempt to include as many pregnancies as possible they entered cases up until 1994, and thus some had one year of follow-up.
USA - In 1999, this issue was analyzed with Surveillance Epidemiology and End Results (SEER) data in Washington State with a population-based cohort of 618 women less than 40 years old diagnosed with Stage I and II breast cancer between 1983 and 1992. The investigators began collecting reproductive event data in 1994 when 119 of the 618 patients were dead. Questions concerning births, induced and spontaneous abortions, and timing of breast cancer recurrence were asked of the patients themselves or of the husbands or relatives of the deceased in the 70% of proxies who could be located. Reproductive events were obtained on a total of 520 women. The “cases” are 53 women who had a pregnancy after breast cancer diagnosis with 36 having a live birth. These were matched with control breast cancer patients without subsequent pregnancies who had the same stage and a recurrence-free survival time equal to the interval between diagnosis and pregnancy of the women who became pregnant.

There was a non-significant increased relative risk of dying with a completed pregnancy (as opposed to induced or spontaneous abortion) after breast cancer treatment (RR = 1.1; 95% CI, 0.4-3.7) overall and for those with positive lymph nodes (RR = 1.4; 95% CI, 0.4-5.2). If under-reporting of pregnancies was greater among the dead women, the adverse prognosis with subsequent pregnancy would be underestimated.

PROSPECTIVE STUDY

Population-based studies try to avoid the recollection bias prevalent in the retrospective studies, but add other biases, particularly in the choice of controls for the matching. The four studies above show no statistically significant detriment to subsequent pregnancy after breast cancer treatment. However, peculiar biases to each type of retrospective study design exist.
Until the issue is subjected to a prospective study, the effect of subsequent pregnancy is not really known. Only a prospective study provides comprehensive information on each patient at baseline including clinical characteristics, treatment variables and follow-up for medical status and recurrence, as well as any reproductive events. However, a prospective trial design is lengthy, as well as expensive, with results obtained perhaps ten years after its inception. The design of an ideal prospective study would include accruing breast cancer patients at diagnosis in order to have the extensive and comprehensive baseline data. We at Memorial Sloan-Kettering Cancer Center have launched such a prospective study starting in January 1998 with accrual of young women within eight months of diagnosis, collecting data on menstrual cycles, quality of life, and any reproductive events. More than 500 participants have been accrued. One of our short-term goals is the study of premature menopause, addressing symptoms, and sexual dysfunction. The statistical center is Wake Forest University, which is handling similar data for Women’s Health Intervention, a study of women undergoing “natural” menopause. Our long-term goal is to obtain information on subsequent pregnancies. No in-patient visits are necessary; all data is obtained by mail and phone. The study intervention consists of medical record data, menstrual cycle diaries, and questionnaires. Patient referrals can be directed to Dr. Petrek (1-877-636-7562). Unfortunately statistics on survival following subsequent pregnancy will be forthcoming only after the next several years.
REFERENCES


