

How Patients Experience Adjuvant Endocrine Therapy for Breast Cancer: An Online Survey of Symptoms, Adherence, and Medical Team Support

1. Have you been diagnosed with breast cancer (ductal, lobular or any other type)?
 - Yes
 - No: disqualified

2. Was your breast cancer estrogen or progesterone receptor (ER/PR) positive?
 - Yes
 - I am not sure
 - No: disqualified

3. Did your oncology team recommend endocrine / hormonal therapy?
This may include one or more of the following:
Tamoxifen (Nolvadex, Soltamox and others)
Toremifene (Fareston)
Raloxifene (Evista)
Anastrozole (Arimidex)
Exemestane (Aromasin)
Letrozole (Femara)
Fulvestrant (Faslodex)
Leuprolide (Lupron), Triptorelin (Triptodur, Trelstar and others), Goserelin (Zoladex and others)
 - Yes
 - No: disqualified

4. Did you take or are you currently taking any form of endocrine therapy?
This may include one or more of the following:
Tamoxifen (Nolvadex, Soltamox)
Toremifene (Fareston)
Raloxifene (Evista)
Anastrozole (Arimidex)
Exemestane (Aromasin)
Letrozole (Femara)
Fulvestrant (Faslodex)
Leuprolide (Lupron), Triptorelin (Triptodur, Trelstar), Goserelin (Zoladex)
 - Yes: skip to question 6
 - No

5. If your oncology team recommended endocrine therapy **but you did not start**, please list reasons why. Please check all that apply:
 - Concern about side effects
 - Concern about secondary cancers (cancers that might be caused by the medication)
 - Concern about the impact on my general health or other health conditions
 - Concern that benefit was small or benefit did not outweigh risk

- Concern about cost
- Did not like the idea of taking a prescription medication
- Other

All respondents to question 5 will skip to question 25

6. What endocrine therapy medications have you taken or are you currently taking for breast cancer treatment? Please check all that apply, and include medications prescribed if you were treated more than once or if you are being treated for metastatic breast cancer.
 - Tamoxifen (Nolvadex, Soltamox and others)
 - Toremifene (Fareston)
 - Raloxifene (Evista)
 - Anastrozole (Arimidex)
 - Exemestane (Aromasin)
 - Letrozole (Femara)
 - Fulvestrant (Faslodex)
 - Leuprolide (Lupron), Triptorelin (Triptodur, Trelstar and others), Goserelin (Zoladex and others)
 - Other (please specify)

7. What was your understanding of the goals or potential benefits of endocrine therapy? Please check all that apply:
 - Reduce the risk of the same breast cancer returning in the same breast
 - Reduce the risk of a new breast cancer developing in the same or other breast
 - Reduce the risk of the breast cancer spreading to other areas of the body, such as bones, liver, lung or brain (metastatic breast cancer / Stage 4)
 - Control or treat breast cancer that has already spread outside the breast to other areas of the body, such as bones, liver, lung, or brain (metastatic breast cancer / stage 4)
 - Other (please specify)

8. Were you having menstrual periods at the time when you started endocrine therapy? Please choose the response that best fits your situation:
 - Yes – I was having menstrual periods (check this option even if cycles were irregular or intermittent)
 - No, my periods had already stopped naturally (I went through female menopause)
 - No, I had a surgical removal of my uterus and/or ovaries (hysterectomy oophorectomy), with or without the addition of medications
 - No, my periods stopped due to medications (may include chemotherapy, endocrine therapy, or testosterone therapy)
 - Does not apply, my sex at birth was male
 - I do not remember

9. Are you currently taking endocrine therapy?
 - Yes
 - No: skip to question 11

10. How long have you been taking endocrine therapy? Please estimate **total** treatment time, including if you have taken more than one medication, or if you stopped and re-started for any reason.

- Less than 5 years
- 5 years
- 5-10 years
- Greater than 10 years
- I am not sure

All respondents to question 10 will skip to question 12

11. How long did you take endocrine therapy? Please estimate **total** treatment time, including if you have taken more than one medication, or if you stopped and re-started for any reason.

- Less than 5 years
- 5 years
- 5-10 years
- Greater than 10 years
- I am not sure

12. Did you take or are you taking the endocrine therapy as prescribed? Please choose the best option for your situation.

- Yes, I took the treatment as prescribed
- Yes, I skipped pills, reduced the dose, took a treatment “break” or stopped treatment **with the approval of my medical team**
- No – I skipped pills, reduced the dose, took a treatment “break” or stopped treatment **against my medical team’s recommendation**
- No – I skipped pills, reduced the dose, took a treatment “break” or stopped treatment and **did not inform my medical team**
- Other (please specify)

13. Did you experience or are you experiencing any symptoms that you would consider to be side effects from endocrine therapy?

- Yes
- No: skip to question 25

14. What side effects did you experience or are you currently experiencing that you attribute to the endocrine therapy? Please check all that apply.

- Cardiac and Vascular– may include elevated cholesterol, blood clots, stroke
- Cognitive / Mood – may include mood swings, irritability, prolonged sadness or depression, forgetfulness, difficulty concentrating, fatigue, psychological distress, anxiety, impact on ability to work / hold a job / perform daily functions, insomnia
- Eyes – may include blurry vision, decreased night vision, cataracts
- General Physical Changes – may include weight gain, dry skin, unhappy with body image, breast tenderness or sensitivity, generalized body aches, hair thinning or hair loss

- Gastrointestinal – may include nausea, vomiting, constipation, diarrhea, abnormal liver function blood tests, fatty liver
- Genitourinary – may include urinary incontinence (leakage), urinary tract infections, vaginal dryness, vaginal discharge, irregular vaginal bleeding, genital itching, ovarian cysts, uterine (endometrial) cancer
- Musculoskeletal – may include joint pains, bone pain, muscle pains, muscle stiffness, bone loss including osteopenia / osteoporosis, bone fracture
- Sexual – may include decreased libido (sex drive), pain or difficulty with sexual intercourse, erectile dysfunction
- Vasomotor – may include hot flashes, night sweats, sleep disturbance due to night sweats
- High cost of medication / “financial toxicity”
- Other

15. Did you discuss or attempt to discuss side effects of the endocrine therapy with a member of your medical team? Medical team refers to your medical oncologist, surgeon, radiation oncologist, primary care physician, other physician (including naturopathic doctor), treatment nurse, nurse practitioner, nurse navigator, physician assistant or medical assistant.

- Yes
- No: skip to question 18
- Other

16. Which member of your medical team did you discuss endocrine therapy side effects with? Please check all that apply

- Oncology team doctors: medical oncologist, surgeon or radiation oncologist
- Other oncology team members: nurse practitioner, nurse, physician assistant, medical assistant
- Primary care doctor, OB-Gyn or their team members including nurse practitioner, nurse, physician assistant, medical assistant
- Other doctor or specialist or their team members including nurse practitioner, nurse, physician assistant, medical assistant
- Other (please specify)

17. Please note how you felt in discussing or attempting to discuss side effects of the endocrine therapy with a member of your treatment team. Please check all that apply.

- I felt comfortable and supported by my medical team
- I felt uncomfortable or embarrassed but felt supported by my medical team
- I felt the medical team did not feel comfortable or felt embarrassed discussing side effects
- I did not feel there was enough time to discuss side effects of treatment / I felt rushed
- I felt that the medical team did not believe my side effects were related to the medication
- I was made to feel that I should be better able to handle or manage the side effects
- Other (please specify)

All respondents to question 17 will skip to question 19

18. If you did not discuss side effects with your medical team, please explain why. Please check all that apply.

- Did not feel comfortable discussing some side effects
- Other more important issues to discuss during visit, not enough time during visit
- Tried to discuss but medical team did not listen or were dismissive
- Other (please specify)

All respondents to question 18 will skip to question 21

19. Did your medical team provide suggestions for how to manage the side effects of endocrine therapy?

- Yes
- No: skip to question 21

20. What suggestions regarding how to manage side effects did you receive from your medical team? Please check all that apply:

- Alter treatment schedule including temporarily stopping treatment or decreasing dose (cut pills in half, take every other day, etc.), switching to a different medication, or permanently stopping treatment
- Prescription medication for cholesterol, hot flashes, depression, anxiety, pain or other symptoms
- Vaginal lubricants, vaginal estrogen, menopausal hormone therapy (includes "bioidentical" or synthetic pills or cream), pelvic floor (Kegel) exercises
- Dress in layers, wear cotton clothing, use a fan, drink cool liquids, avoid alcohol, avoid caffeine, avoid spicy foods
- Hysterectomy and/or oophorectomy (removal of uterus and/or ovaries)
- Healthy diet, exercise program, physical therapy
- Yoga, Tai chi, Qi gong, massage therapy, acupuncture, Reiki or other integrative therapy; meditation and other relaxation techniques (such as breathing exercises, guided imagery)
- Vitamins, supplements, herbs, medical marijuana
- Referral to a non-oncology specialist (such as eye doctor, neurologist, pain specialist, naturopathic or integrative medicine doctor, etc.)
- In person or online support group, or one-on-one meeting with another patient
- Website with information about side effects and how to manage them or "app" to help track and manage side effects
- Referral to financial counselor, payment assistance program
- Other (please specify)

21. What information regarding how to manage side effects did you obtain from family, friends, internet or others – **not your medical team**? Please check all that apply:

- Altering treatment schedule including temporarily stopping treatment or decreasing dose (cut pills in half, take every other day, etc.), switching to a different medication, or permanently stopping treatment

- Prescription medication for cholesterol, hot flashes, depression, anxiety, pain or other symptoms
- Vaginal lubricants, vaginal estrogen, menopausal hormone therapy (includes “bioidentical” or synthetic pills or cream), pelvic floor (Kegel) exercises
- Hysterectomy and/or oophorectomy (removal of uterus and/or ovaries)
- Healthy diet, exercise program, physical therapy
- Yoga, Tai chi, Qi gong, massage therapy, acupuncture, Reiki or other integrative therapy; meditation and other relaxation techniques (such as breathing exercises, guided imagery)
- Vitamins, supplements, herbs, medical marijuana
- Referral to a non-oncology specialist (such as eye doctor, neurologist, pain specialist, naturopathic or integrative medicine doctor, etc.)
- In person or online support group, or one-on-one meeting with another patient
- Website with information about side effects and how to manage them or "app" to help track and manage side effects
- Referral to financial counselor, payment assistance program
- Other (please specify)

22. What treatments, if any, **did you find to be helpful in managing side effects**? Please check all that apply:

- Altering treatment schedule including temporarily stopping treatment or decreasing dose (cut pills in half, take every other day, etc.), switching to a different medication, or permanently stopping treatment
- Prescription medication for cholesterol, hot flashes, depression, anxiety, pain or other symptoms
- Vaginal lubricants, vaginal estrogen, menopausal hormone therapy (includes “bioidentical” or synthetic pills or cream), pelvic floor (Kegel) exercises
- Hysterectomy and/or oophorectomy (removal of uterus and/or ovaries)
- Healthy diet, exercise program, physical therapy
- Yoga, Tai chi, Qi gong, massage therapy, acupuncture, Reiki or other integrative therapy; meditation and other relaxation techniques (such as breathing exercises, guided imagery)
- Vitamins, supplements, herbs, medical marijuana
- Referral to a non-oncology specialist (such as eye doctor, neurologist, pain specialist, naturopathic or integrative medicine doctor, etc.)
- In person or online support group, or one-on-one meeting with another patient
- Website with information about side effects and how to manage them or "app" to help track and manage side effects
- Referral to financial counselor, payment assistance program
- Other (please specify)

23. If you stopped endocrine therapy earlier than recommended, what were the reasons for stopping early? Please check all that apply.

- Cardiac and Vascular– may include elevated cholesterol, blood clots, stroke
- Cognitive / Mood – may include mood swings, irritability, prolonged sadness or depression, forgetfulness, difficulty concentrating, fatigue, psychological

distress, anxiety, impact on ability to work / hold a job / perform daily functions, insomnia

- Eyes – may include blurry vision, decreased night vision, cataracts
- General Physical changes – may include weight gain, dry skin, unhappy with body image, breast tenderness or sensitivity, generalized body aches, hair thinning or hair loss
- Gastrointestinal – may include nausea, vomiting, constipation, diarrhea, abnormal liver function blood tests, fatty liver
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- High cost of medication / “financial toxicity”
- Musculoskeletal – may include joint pains, bone pain, muscle pains, muscle stiffness, bone loss including osteopenia / osteoporosis, bone fracture
- Sexual – may include decreased libido (sex drive), pain or difficulty with sexual intercourse, erectile dysfunction
- Vasomotor – may include hot flashes, night sweats, sleep disturbance due to night sweats
- High cost of medication / “financial toxicity”
- Did not want to take medications or supplements for side effects
- Did not have sufficient support from my medical team
- I took the full course of endocrine therapy as prescribed
- Other (please specify)

24. Please provide any advice or suggestions for a medical team that could help you feel more supported or that could help you better manage side effects of endocrine therapy. Please check all that apply:

- An office visit (in person or online / virtual) to specifically discuss medication side effects
- Access to an oncology social worker to discuss issues related to endocrine therapy
- Access to a financial counselor to discuss financial issues/concerns
- In-person or online support group of patients with current or past experience taking endocrine therapy, one-on-one meeting with current or former patient, or other patient-to-patient support
- A website that provides clear information about side effects and how to manage them
- An “app” offered by the medical team that includes information and allows you to check in with your team
- Other (please specify)

25. What was your *approximate age* at **initial** diagnosis of breast cancer? If you have had breast cancer more than once or if you have developed metastatic breast cancer (spread to other parts of the body) please provide age at **first / initial** diagnosis.

26. What was your **breast cancer stage** at **initial** diagnosis? If you have had breast cancer more than once or if you have developed metastatic breast cancer (spread to other parts of the body) please provide stage at **first / initial** diagnosis.

- Stage 0 / DCIS / ductal carcinoma in-situ / intraductal / non-invasive
- Stage 1, 2, or 3 invasive breast cancer
- Stage 4 metastatic breast cancer at diagnosis / de novo metastatic
- I do not know

27. How long has it been since your **initial** diagnosis of breast cancer?

If you have had breast cancer more than once or if you have developed metastatic breast cancer (spread to other parts of the body) please use time since **first / initial** diagnosis.

- Less than 1 year
- 1-5 years
- 6-10 years
- Greater than 10 years

28. Are you currently living with metastatic breast cancer? Metastatic breast cancer is breast cancer that has spread to lung, liver, bone, brain or other parts of the body. It is also referred to as Stage 4 breast cancer. This **does not** include spread to underarm lymph nodes.

- Yes
- No

29. What is your current age?

30. What is your gender?

- Female / Woman
- Male / Man
- Trans Female / Trans Woman
- Trans Male / Trans Man
- Gender Queer
- Decline to state

31. What sex were you assigned at birth?

- Female
- Male
- Decline to state

32. In which country do you live?

33. What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
- High school degree or equivalent (GED)

- Some college, but no degree
- Associate (2 year) degree
- Bachelor (4 year) degree
- Graduate degree

Thank you for taking the time to participate in this study. Your opinion is valuable, and results will be posted when they are available.