

ATTACHMENT 13

Formative Research to Assess How *Facing Forward: Life After Cancer Treatment* Impacts Knowledge, Attitudes, and Practice of Cancer Patients' Follow-Up Care



OMB # 0925-0046-13a
Exp. Date: 10/31/2006

NCI Post Cancer Treatment Survey I

Dear Volunteer,

Thank you for agreeing to provide feedback on one of NCI's publications about life after cancer treatment. Before you begin, please answer these three questions:

- | | |
|--|--|
| Do you read and understand English? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Are you over the age of 21? | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Are you receiving treatment or did you receive treatment at this facility? | <input type="checkbox"/> Yes <input type="checkbox"/> No |

If you said "No" to any of these questions, please stop here and return the survey to the person who gave it to you. If you said "Yes" to all three questions, please continue.

This survey should take approximately 10 minutes to complete and can be done while you are waiting to be seen. The National Cancer Institute (NCI), a cancer research agency that is part of the Federal government, is conducting the survey. NCI would like to know your thoughts and expectations following your cancer treatment. Please keep these things in mind:

- Your participation in this survey is completely voluntary.
- If you agree to participate in this survey, we will also ask you to participate in two additional surveys after this one (one about 6 weeks from now and another about 5 months after that).
- Your decision to complete or not to complete this or any of the follow-up surveys on this topic will not have any effect on your treatment at this facility or any other.
- All responses will be kept confidential and will not be disclosed to anyone but the people conducting the survey, except as otherwise required by law.
- Data will be used and reported without identifying any individuals.
- The only potential risk involved in participating in this survey is any emotional discomfort you may feel when asked to remember details of your cancer treatment.
- You may skip any questions that you prefer not to answer.

Your answers to these questions will help us improve NCI's resources, and therefore make them more useful to cancer patients completing their treatment. To participate in the survey:

1. Tear off and keep this top page so that you have information about the survey, your rights and responsibilities as a participant, as well as NCI's telephone number and Web site address.
2. Read, sign, and tear off the second page, which is a shortened version of this page. It will be retained by this facility.
3. Answer the questions on the following pages.
4. Seal the completed survey in the envelope provided.
5. Return the envelope and the signed consent form to the person who gave you this packet.

If you decide not to complete the survey, tear off the top page to keep NCI's contact information and return the packet to the person who gave it to you. If you have questions while you are completing the survey, please talk to the person who gave you this packet. You are also welcome to contact Joanne Milne, who is overseeing this survey, at (301) 572-0886. Please do not take the survey home.

To learn more about NCI resources, you can call NCI toll-free at 1-800-4-CANCER (1-800-422-6237) or visit NCI's Web site at: www.cancer.gov

NCI Post Cancer Treatment Survey I

Dear Volunteer,

Thank you for agreeing to give us input for an educational resource following cancer treatment. This survey should take approximately 10 minutes to complete and can be done while you are waiting to be seen. The National Cancer Institute (NCI), a cancer research agency that is part of the Federal government, is conducting the survey. NCI would like to know your thoughts and expectations following your cancer treatment. Please keep these things in mind:

- Your participation in this survey is completely voluntary.
- If you agree to participate in this survey, we will also ask you to participate in two additional surveys after this one (one about 6 weeks from now and another about 5 months after that).
- Your decision to complete or not to complete this or any of the follow-up surveys on this topic will not have any effect on your treatment at this facility or any other.
- All responses will be kept confidential and will not be disclosed to anyone but the people conducting the survey, except as otherwise required by law.
- Data will be used and reported without identifying any individuals.
- The only potential risk involved in participating in this survey is any emotional discomfort you may feel when asked to remember details of your cancer treatment.
- You may skip any questions that you prefer not to answer.

Your answers to these questions will help us improve NCI's resources, and therefore make them more useful to cancer patients completing their treatment. To participate in the survey:

1. Tear off and keep the top page so that you have information about the survey, your rights and responsibilities as a participant, as well as NCI's telephone number and Web site address.
2. Read, sign, and tear off the second page, which is a shortened version of the cover page. It will be retained by this facility.
3. Answer the questions on the following pages.
4. Seal the completed survey in the envelope provided.
5. Return the envelope and the signed consent form to the person who gave you this packet.

If you have questions while you are completing the survey, please talk to the person who gave you this packet. You are also welcome to contact Joanne Milne, who is overseeing this survey, at: (301) 572-0886. Please do not take the survey home. If you understand the rights and responsibilities as outlined above, and are willing to participate in this brief survey, please write your name and sign below. Tear off this sheet, complete the rest of the survey, and give them both back to the person who gave them to you.

Please Print Your Name

Signature

NCI Post Cancer Treatment Survey I

Thank you for participating in this study. Your participation will help us create resources that will help other cancer survivors better understand what to expect after cancer treatment. Please answer each question by marking the appropriate box. When completed, please seal this survey in the envelope provided and return it to the person who gave it to you.

1. The table below lists common symptoms or side effects people may experience after cancer treatment. Please indicate if you have experienced each symptom/side effect and if so, if you know of ways to manage it.

			If Yes, Do You Know How To Manage The Symptoms Or Side Effects?		
			No	Yes <input type="checkbox"/>	<i>I know of many ways</i>
a) Bladder or bowel control symptoms	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Changes with my mouth or teeth	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Changes in social relationships	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Emotional symptoms (e.g., stress, depression, anxiety, anger)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Fatigue (i.e., extreme tiredness)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Lymphedema or swelling	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Memory/concentration changes	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Menopause symptoms	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Pain	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Sexual side effects	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Weight changes (e.g., gain or loss)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Other (Please specify: _____)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What information sources have you preferred to use since your cancer treatment ended? (Please select no more than two).

- Doctor and/or Nurse
- Another type of health care provider (Please specify: _____)
- Patient/survivor
- Support group meeting
- Internet (Primary website(s): _____)
- Printed material(s) (Title: _____)
- Other (Please specify: _____)
- None
- Do not know/Not applicable

3. Please tell us how strongly you agree or disagree with the following statement:

	I Strongly Agree	I Agree	I Disagree	I Strongly Disagree
Now that my cancer treatment has ended, I know where to go for more information if I have questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It would be helpful to have more information about what changes to expect from my body, mind and feelings, and social relationships after cancer treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. How likely are you to do each of the following?

	Very Likely		Not At All Likely			Don't know
	5	4	3	2	1	
a) Contact a cancer organization?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Seek follow-up care (e.g., regular check-ups)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Work out a wellness plan with your doctor to take care of your health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. What is your gender?

- Female
 Male

6. How old are you?

-21-29 45-49 60-64
.....30-39 50-54 65+
.....40-44 55-59

7. What is the highest level of education you have completed?

- Grade school or less
 Some high school
 High school
 Some college/Two-year degree
 Four-year college degree or above

8. What is today's date?

_____Month _____ Day _____Year

9. Are you of Hispanic or Latino origin?

Yes

No

10. Please check the box or boxes that best describe your race.

American Indian or Alaska Native

Asian

Black/African American

Native Hawaiian or Other Pacific Islander

White

11. What type of cancer did you just complete your treatment for? [*Please indicate each site if there are multiple sites.*] _____

12. Is this?

A new cancer

A recurrence

A metastasis

Don't know

13. What type of treatment did you receive for the cancer indicated in question 11? Please include any treatment received as part of a clinical trial. (Check all that apply.)

- Biological therapy (e.g., monoclonal antibody, interferons, interleukins)
- Chemotherapy
- Radiation therapy
- Surgery (e.g., mastectomy, lumpectomy, prostatectomy, excision, or removal of tumors)
- Other (Please specify: _____)
- Don't know

14a. Do you plan on attending any post-treatment counseling or support groups?

- Yes
- No [**Skip to the bottom of the page.**]

14b. If yes, what type of post-treatment counseling do you plan on attending? (Check all that apply.)

- One-on-one sessions
- Support groups
- Other (Please specify: _____)
- None
- Don't know

If this is the first cancer you have been treated for, you are done with the survey. Thank you for taking the time to complete this questionnaire and share your views. You will be contacted in 6-8 weeks about filling out a follow-up questionnaire.

If you have been treated for a cancer prior to this one, please continue to Question 15 on the next page.

If you had another form of cancer prior to this one, please answer the following questions:

15. What type of cancer did you complete your treatment for in the past? [*Please indicate each site if there were multiple sites.*] _____

16. What type of treatment did you receive for this other cancer? (Check all that apply.)

- Biological therapy (e.g., monoclonal antibody, interferons, interleukins)
- Chemotherapy
- Radiation therapy
- Surgery (e.g., mastectomy, lumpectomy, prostatectomy, excision, or removal of tumors)
- Other (Please specify: _____)
- Don't know

17. How long ago did you complete treatment for this cancer?

- Less than 6 months
- Between 6 months and 1 year
- 1-2 years
- 2-5 years
- More than 5 years

18. If you received follow-up counseling, what type did you receive? (Check all that apply.)

- One-on-one sessions
- Support groups
- Other (Please specify: _____)
- None
- Don't know

Thank you for taking the time to complete this questionnaire and share your views. You will be contacted in 6-8 weeks about filling out a follow-up questionnaire.



NCI Post Cancer Treatment Survey II

Dear Volunteer,

You may recall participating in a survey for the National Cancer Institute (NCI) a few weeks ago. In that survey, we mentioned that we would ask you to participate in two follow-up surveys. This is the first of those surveys examining your thoughts and expectations following cancer treatment. Your participation in this survey will help the NCI improve their materials for life after cancer. This survey should take approximately 10 minutes to complete and can be done while you are waiting to be seen. Please keep these things in mind:

- Your participation in this survey is completely voluntary.
- If you agree to participate in this survey, we will also ask you to participate in one additional survey about 5 months from now.
- Your decision to complete or not to complete this or the follow-up survey will not have any effect on your treatment at this facility or any other.
- All responses will be kept confidential and will not be disclosed to anyone but the people conducting the survey, except as otherwise required by law.
- Data will be used and reported without identifying any individuals.
- The only potential risk involved in participating in this survey is any emotional discomfort you may feel when asked to remember details of your cancer treatment.
- You may skip any questions that you prefer not to answer.

Your answers to these questions will help us improve NCI's resources, and therefore make them more useful to cancer patients completing their treatment. To participate in the survey:

- 1. Tear off and keep this top page so that you have information about the survey, your rights and responsibilities as a participant, as well as NCI's telephone number and Web site address.**
- 2. Read, sign, and tear off the second page, which is a shortened version of this page. It will be retained by this facility.**
- 3. Answer the questions on the following pages.**
- 4. Seal the completed survey in the envelope provided.**
- 5. Return the envelope and the signed consent form to the person who gave you this packet.**

If you decide not to complete the survey, tear off the top page to keep NCI's contact information and return the packet to the person who gave it to you. If you have questions while you are completing the survey, please talk to the person who gave you this packet. You are also welcome to contact Joanne Milne, who is overseeing this survey, at: (301) 572-0886. Please do not take the survey home.

To learn more about NCI resources, you can call NCI toll-free at 1-800-4-CANCER (1-800-422-6237) or visit NCI's Web site at: www.cancer.gov



NCI Post Cancer Treatment Survey II

Dear Volunteer,

Thank you for providing feedback on one of NCI's publications. Your participation in this survey will help the NCI improve their materials about life after cancer. This survey should take approximately 10 minutes to complete and can be done while you are waiting to be seen. Please keep these things in mind:

- Your participation in this survey is completely voluntary.
- If you agree to participate in this survey, we will also ask you to participate in one additional survey about 5 months from now.
- Your decision to complete or not to complete this or the follow-up survey will not have any effect on your treatment at this facility or any other.
- All responses will be kept confidential and will not be disclosed to anyone but the people conducting the survey, except as otherwise required by law.
- Data will be used and reported without identifying any individuals.
- The only potential risk involved in participating in this survey is any emotional discomfort you may feel when asked to remember details of your cancer treatment.
- You may skip any questions that you prefer not to answer.

Your answers to these questions will help us improve NCI's resources, and therefore make them more useful to cancer patients completing their treatment. To participate in the survey:

1. Tear off and keep the top page so that you have information about the survey, your rights and responsibilities as a participant, as well as NCI's telephone number and Web site address.
2. Read, sign, and tear off the second page, which is a shortened version of the cover page. It will be retained by this facility.
3. Answer the questions on the following pages.
4. Seal the completed survey in the envelope provided.
5. Return the envelope and the signed consent form to the person who gave you this packet.

If you have questions while you are completing the survey, please talk to the person who gave you this packet. You are also welcome to contact Joanne Milne, who is overseeing this survey, at: (301) 572-0886. Please do not take the survey home. If you understand the rights and responsibilities as outlined above, and are willing to participate in this brief survey, please write your name and sign below. Tear off this sheet, complete the rest of the survey, and give them both back to the person who gave them to you.

Please Print Your Name

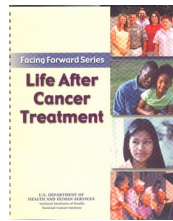
Signature

NCI Post Cancer Treatment Survey II

Please answer each question by marking the appropriate box. Answer the questions based on your reading and use of the booklet *Facing Forward: Life After Cancer Treatment* that was given to you at the end of your last doctor appointment. Please read each question carefully. Unless otherwise instructed, select only one answer for each question. When completed, please seal this survey in the envelope provided and return it to the person who gave it you.

1. Have you read the NCI booklet, *Facing Forward: Life After Cancer Treatment*? If you are not sure, please ask the person who gave you this survey for a copy of the booklet.

- Yes
- No [Skip to Question 7.]
- Don't know [Skip to Question 7.]



2. Overall, how helpful was this booklet?

- It was very helpful.
- It was somewhat helpful.
- It was not very helpful.
- It was not helpful at all.

3. How helpful was the information you read in the Facing Forward booklet for...

	It Was Very Helpful	It Was Somewhat Helpful	It Was Not Very Helpful	Don't Know
a) getting follow-up care (e.g., regular check-ups), after cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) identifying the common side effects of treatment on your body (e.g., fatigue, pain)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) identifying the common feelings you may have after cancer treatment (e.g., fear, stress, anger)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) understanding changes in the way family, friends, or co-workers may relate to you after cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. After reading the Facing Forward booklet, I felt I knew more about...

	I Strongly Agree	I Agree	I Disagree	I Strongly Disagree	Don't Know
a) communicating with my doctor to get the most out of my visits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) creating a wellness plan with my doctor to improve my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) changes I can make in my life to lower my chances of having other health problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) how to deal effectively with memory and concentration problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) how to deal effectively with physical symptoms I may have now or in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) how to deal effectively with feelings and fears that I may have as a result of treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) ways to improve how I relate to family, friends, and co-workers after cancer treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) cancer organizations and resources that are available to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. After reading the Facing Forward booklet, how confident are you about your ability to...

	Extremely Confident		Not At All Confident			Don't know
	5	4	3	2	1	
a) communicate with your doctor to get the most out of visits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) create a wellness plan with your doctor to improve your health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) make changes in your life to lower your chance of having other health problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) deal effectively with memory and concentration problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) deal effectively with physical symptoms you may have now or in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) deal effectively with feelings or fears you may have now or in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) improve the way you relate to family, friends, and co-workers after cancer treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) contact cancer organizations to obtain resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. During the next 6 months, how likely are you to try some of the tips or suggestions in the booklet about...

	Very Likely		Not At All Likely			Don't know
	5	4	3	2	1	
a) talking to your doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) dealing effectively with physical symptoms or side effects you may have now or in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) dealing effectively with feelings or fears you may have now or in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) improving the way you relate to family, friends, or co-workers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) contacting any of the organizations listed in the resources section booklet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. The table below lists common symptoms or side effects people may experience after cancer treatment. Please indicate if you have experienced each symptom/side effect and if so, if you know of ways to manage it.

			If Yes, Do You Know How To Manage The Symptoms Or Side Effects?		
			No	Yes <input type="checkbox"/>	<i>I know of many ways</i>
a) Bladder or bowel control symptoms	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Changes with my mouth or teeth	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Changes in social relationships	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Emotional symptoms (e.g., stress, depression, anxiety, anger)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Fatigue (i.e., extreme tiredness)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Lymphedema or swelling	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Memory/concentration changes	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Menopause symptoms	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Pain	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Sexual side effects	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Weight changes (e.g., gain or loss)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Other (Please specify: _____)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Since completing treatment, how many one-on-one counseling sessions and/or a support group meetings have you attended?

of one-on-one sessions _____

of support group meetings _____

9. Counseling and support group sessions are designed to help with issues you face during your cancer experience. Generally, how well did these sessions accomplish this goal?

Very Well				Not Well At All	
5	4	3	2	1	Don't know/ Not Applicable

10. What is today's date?

_____Month _____ Day _____Year

11. Please share any additional comments or suggestions you have for changing or improving the booklet.

12. We greatly appreciate your feedback. If you are willing to complete another survey in about 5 months on this same topic, please provide us with the information below.

Name: _____

Mailing address: _____

City: _____

State: _____ **Zip code:** _____

Email address: _____

Thank you for completing this survey.
Please remember to return it to the person who gave it to you.



NCI Post Cancer Treatment Survey III

December XX, 2005

Name
Street address
City, state and zip code

Dear Mr/Mrs/Ms _____,

You may recall participating in a survey for the National Cancer Institute (NCI) several months ago. In that survey, you shared your thoughts about dealing with life after cancer treatment. We also asked if you would be willing to participate in another survey. You agreed to participate, and gave us your mailing address. Through this follow-up survey, NCI is measuring any changes in your thoughts and expectations following your cancer treatment. We are asking for your participation in this survey to help NCI improve their materials for life after cancer. This survey should take approximately 10 minutes to complete. Please keep these things in mind:

- Your participation in this survey is completely voluntary.
- Your decision to complete or not to complete this survey will not impact your ability to seek follow-up care or treatment.
- All responses will be kept confidential and will not be disclosed to anyone but the people conducting the survey, except as otherwise required by law.
- Data will be used and reported without identifying any individuals.
- The only potential risk involved in participating in this survey is any emotional discomfort you may feel when asked to remember details of your cancer treatment.
- You may skip any questions that you prefer not to answer.

Your answers to these questions will help us improve NCI's resources, and therefore to make them more useful to cancer patients completing their treatment. To participate in the survey:

1. Tear off and keep this top page so that you have information about the survey, your rights and responsibilities as a participant, as well as NCI's telephone number and Web site address.
2. Read and sign the second page, which is a shortened version of this page.
3. Answer the questions on the following pages.
4. Seal the completed survey in the self-addressed stamped envelope provided.
5. Place it in the mail to be returned to us.

If you have questions while you are completing the survey, you are welcome to contact Joanne Milne, who is overseeing this survey, at: (301) 572-0886.

To learn more about NCI resources, you can call NCI toll-free at 1-800-4-CANCER (1-800-422-6237) or visit NCI's Web site at: www.cancer.gov



NCI Post Cancer Treatment Survey III

Dear Mr/Mrs/Ms _____,

Through this follow-up survey, NCI is measuring any changes in your thoughts and expectations following your cancer treatment. We are asking for your participation in this survey to help NCI improve their materials for life after cancer. This survey should take approximately 10 minutes to complete. Please keep these things in mind:

- Your participation in this survey is completely voluntary.
- Your decision to complete or not to complete this survey will not impact your ability to seek follow-up care or treatment.
- All responses will be kept confidential and will not be disclosed to anyone but the people conducting the survey, except as otherwise required by law.
- Data will be used and reported without identifying any individuals.
- The only potential risk involved in participating in this survey is any emotional discomfort you may feel when asked to remember details of your cancer treatment.
- You may skip any questions that you prefer not to answer.

Your answers to these questions will help us improve NCI's resources, and therefore make them more useful to cancer patients completing their treatment. To participate in the survey:

1. Tear off and keep the top page so that you have information about the survey, your rights and responsibilities as a participant, as well as NCI's telephone number and Web site address.
2. Read and sign this page, which is a shortened version of the cover page.
3. Answer the questions on the following pages.
4. Seal the completed survey in the self-addressed stamped envelope provided.
5. Place it in the mail to be returned to us.

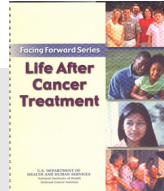
If you have questions while you are completing the survey, you are welcome to contact Joanne Milne, who is overseeing this survey, at: (301) 572-0886. If you understand the rights and responsibilities as outlined above, and are willing to participate in this brief survey, please write your name and sign below.

Please Print Your Name

Signature

NCI Post Cancer Treatment Survey III

Please answer each question by marking the appropriate box. When completed, please return the questionnaire in the self-addressed stamped envelope provided. All references to the booklet are to the NCI booklet, *Facing Forward: Life After Cancer Treatment*. To help refresh your memory, the cover of the booklet looks like this:



1. Have you read the NCI booklet, *Facing Forward: Life After Cancer Treatment*?

- Yes
- No [Skip to Question 4.]
- Don't Know [Skip to Question 4.]

2. After reading the booklet, I felt I knew more about ...

	I Strongly Agree	I Agree	I Disagree	I Strongly Disagree	Don't Know
a) communicating with my doctor to get the most out of my visits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) creating a wellness plan with my doctor to improve my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) changes I can make in my life to lower my chances of having other health problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) how to deal effectively with memory and concentration problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) how to deal effectively with physical symptoms I may have now or in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) how to deal effectively with feelings and fears that I may have as a result of treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) ways to improve how I relate to family, friends, and co-workers after cancer treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) cancer organizations and resources that are available to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. After reading the booklet, how confident are you in your ability to...

	Extremely Confident			Not At All Confident		Don't know
	5	4	3	2	1	
a) communicate with your doctor to get the most out of visits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) create a wellness plan with your doctor to improve your health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) make changes in your life to lower your chance of having other health problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) deal effectively with memory and concentration problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) deal effectively with physical symptoms you may have now or in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) deal effectively with feelings or fears you may have now or in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) improve the way you relate to family, friends, and co-workers after cancer treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) contact cancer organizations to obtain resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. The table below lists common symptoms or side effects people may experience after cancer treatment. Please indicate if you have experienced each symptom/side effect and if so, if you know of ways to manage it.

			If Yes, Do You Know How To Manage The Symptoms Or Side Effects?		
			No	Yes ☐ 	<i>I know of many ways</i>
a) Bladder or bowel control symptoms	☐	☐ 	☐	☐	☐
b) Changes with my mouth or teeth	☐	☐ 	☐	☐	☐
c) Changes in social relationships	☐	☐ 	☐	☐	☐
d) Emotional symptoms (e.g., stress, depression, anxiety, anger)	☐	☐ 	☐	☐	☐
e) Fatigue (i.e., extreme tiredness)	☐	☐ 	☐	☐	☐
f) Lymphedema or swelling	☐	☐ 	☐	☐	☐
g) Memory/concentration changes	☐	☐ 	☐	☐	☐
h) Menopause symptoms	☐	☐ 	☐	☐	☐
i) Pain	☐	☐ 	☐	☐	☐
j) Sexual side effects	☐	☐ 	☐	☐	☐
k) Weight changes (e.g., gain or loss)	☐	☐ 	☐	☐	☐
l) Other (Please specify: _____)	☐	☐ 	☐	☐	☐

5. Since completing treatment, how many one-on-one counseling sessions and/or a support group meetings have you attended?

of one-on-one sessions _____

of support group meetings _____

6. In the past 6 months, did you...

	Yes	No
a) contact any of the organizations listed in the resources section of the booklet?	<input type="checkbox"/>	<input type="checkbox"/>
c) seek follow-up care (e.g., regular check-ups)?	<input type="checkbox"/>	<input type="checkbox"/>
d) create a wellness plan with your doctor to improve your health?	<input type="checkbox"/>	<input type="checkbox"/>

7. During the next 6 months, how likely are you to try some of the tips or suggestions in the booklet about...

	Very At All					Not	Don't know/Did not read the booklet
	Likely	Likely					
	5	4	3	2	1		
a) talking to your doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
b) dealing effectively with physical symptoms or side effects you may have now or in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c) dealing effectively with feelings or fears you may have now or in the future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
d) improving the way you relate to family, friends, or co-workers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
e) contacting any of the organizations listed in the resources section of the booklet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

8. What is today's date?

_____Month _____ Day _____Year

9. What additional information would you like to see made available to help patients deal with life after cancer treatment?

The National Cancer Institute would like to thank you for taking the time to complete this questionnaire and share your views. With your help, we are able to constantly improve the materials we provide to patients, their families, and healthcare providers.