

A Writing Workbook

By Jennifer Moye

Companion to the

FACING FORWARD SERIES LIFE AFTER CANCER TREATMENT?

**U.S. Department of
Health and Human Services
National Institutes of Health
National Cancer Institute**

Preface

This is a reading and writing workbook to go along with ? Facing Forward Series: Life After Cancer Treatment? by the National Cancer Institute. In this workbook we try to break down the reading into smaller pieces and to help you apply it to your own life.

Many people cope with a stressful event, such as cancer, by: 1) solving problems; 2) sharing feelings; 3) trying to make some sense of it. Researchers call these problem-focused coping, emotion-focused coping, and meaning-making-focused coping.

Each week this workbook will ask you to write your own answers to questions. There are no right or wrong answers. You should write based on your own life. You do not have to answer every question if you feel it does not apply to you. However, the writing may help you to figure out what the information may mean for you.

After the questions and answers there is open-ended writing or journaling -- meaning no questions and answers, just writing whatever you want. The open-ended journaling may be helpful to you in thinking through feeling sad, angry, happy, or whatever you are feeling.

Some people may want to do the workbook with a loved one or partner. The workbook may be a great chance for you and a loved one to better understand together how your experience with cancer affected both of you and your relationship. It may be helpful to do the workbook alone, as that may lead to some new insights just for you. Then you can share your insights as little or as much as you would like.

Does a drop stay still in the ocean?

*Move with the entirety,
And with the tiniest particular.*

*Be the moisture in an oyster
that helps to form one pearl.*

-Rumi

I am VERY INTERESTED in any comments you have about this workbook. I have enclosed a feedback form at the end of the workbook. If you would like to share your feedback with me, you can cut and paste the feedback page into an email and send it to me at:

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Week One

Getting Started

Week 1 goal: To understand and feel comfortable with the workbook.

Week 1 reading: See below.

We will start reading the NCI booklet next week. This week, please read the introduction below.

1. What is the NCI booklet?

We have provided you with an important booklet from the National Cancer Institute about your life after treatment. The booklet discusses how your cancer and treatment relates to your health care, physical recovery, mind and feelings, social relationships, and various practical matters. The booklet is based upon input from others who have gone through cancer treatment. After reading some things you may think, "me too!" and after reading others, "not me!". Everyone is different. There is no right or wrong way. As the booklet suggests, focus on finding what works for you.

One way in which the NCI booklet may be useful to you is in helping you figure out what to expect from your health now, how to plan for your health care needs, and who you are after cancer, that is, to find yourself again or anew.

2. What is this Workbook?

There is a lot of good information in the NCI booklet. This workbook breaks the reading down into smaller sections over 12 weeks and suggests ways to help you reflect upon and apply the information. Each week we will ask you to read some of the booklet, then answer some questions about the information you have just read. Finally, after taking a moment to relax and quiet your mind, we will ask you to write in your journal.

3. What am I supposed to write?

We suggest that you write about the information you have just read and the questions you have just answered. We also provide some potential writing themes for you. Some of the themes may jump out at you as important; others may make no sense at all. This is private journaling and you may write on any question, theme, or anything else that seems especially important to you at that time.

4. Where and how much should I write?

You may write as little or as much as you like. You may write in the journal, adding extra paper if you need it. Or if you prefer, you may use a computer or typewriter. The instructions are: "just write!". The writing is for you to keep.

Week 1 exercise:

You may find it helpful to take some time to relax and be quiet and still prior to writing. To do so you may wish to close your eyes, clear your mind, and focus on your breathing. Some people refer to such a practice as meditation. There are many ways to do meditation, but they tend to have some things in common (see next page).

1. SOME ELEMENTS OF QUIETING OR MEDITATION

- > **Breathe.** Focus attention on your breathing. Try to slow your breathing so that you are breathing in a deep or comfortable way. It may help to begin with a sigh.
- > **Clear Your Mind.** Passively disregard everyday thoughts. What does this mean? Start by trying to clear your mind of any thoughts. If thoughts or feelings come through your mind, try not to judge those thoughts or yourself, or to cling to those thoughts. Just let them "float" through and then come around to clearing your mind again. Everyone has thoughts or feelings come into their mind at some point.
- > **Optional: Repeat a Word or Phrase.** If it helps, that is, if you feel it is too hard to think of nothing, you can try being more active by repeating a word (e.g., "calm"), phrase (e.g., "here, now, this"), or prayer (e.g., "God have mercy"). Each week we will suggest several words that you may wish to use in your meditation (and writing).

2. ROAD BLOCKS

Sounds simple, right? There are some normal road blocks people face when they try this: too high expectations, "no time," feeling restless, falling asleep, noises from the house or outside, too many thoughts, our anxiety feels worse, old emotions/memories resurface, we worry "am I doing it right," we have strange sensations like floating, dropping, drifting (this is normal).

Here are some suggestions for overcoming road blocks:

- ?? Try to free yourself from expectations; don't try too hard, don't have goals
- ?? Slow down; learn to be quiet instead of stimulated
- ?? Turn off the judgment; be accepting of yourself
- ?? If silence is too hard, use sound (e.g., quiet music, nature sounds)
- ?? If it is hard to keep your mind clear, picture a color or something you find peaceful or safe
- ?? If sleep or anxiety a problem, try keeping your eyes slightly open and focusing on a spot

3. HOW LONG?

You may take as little or as long as you like. Some people suggest about 10 minutes to start. You may want to have a clock near you, and when you think about 10 minutes have passed, check. If not, keep going with the quietness and stillness. Many people find 10 minutes too long, especially at first. In that case, do as little or as much as you like. Even one minute is good. You will repeat this quieting exercise each week. You may find you are able to tolerate more time in quietness and stillness as the weeks go along.

4. MEDITATION OR WRITING THEMES

Each week the workbook will have several words that you may wish to focus on in your meditation or writing. We suggest you look at the words prior to meditation and again prior to writing. These may be helpful during your quiet time or writing. However, you are not required to think or write about these themes.

Week 1 Writing:

In a minute, we would like to suggest that you try taking some time for quietness and stillness. Before you begin, turn the page. Then take some time, about ten minutes if you can, for meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write.

Okay, turn the page, begin.

My Life

Week 2 goal: To reflect upon your recent experiences and begin to understand what got you through

Week 2 reading: Please read the introduction to the NCI booklet, found on pages i-iv.

Week 2 exercise:

1. You've finished your cancer treatment. It might be interesting to consider what has helped you to get through so far. Please look at the list below and see if you think you used any of these things to help you get through. Remember, don't be judgmental towards yourself. None of these can be called "bad" or "good" ways of coping, in fact, if any of them got you through, then they are worthwhile. Put a check next to anything that you think **you** used to get through treatment.

- | | |
|---|---------------------------------------|
| Tried not to close off options | Criticized myself |
| Let my feelings out somehow | Was inspired to be creative |
| Tried to find out as much as I could | Went along with fate |
| Concentrated on the next step | Changed something about myself |
| Hoped for a miracle | Didn't let it get to me |
| Prepared for the worst | Tried to find out as much as I could |
| Sought help from a counselor or clergy | Slept more than usual |
| Wished the situation would go away or be over | Prayed |
| Kept others from knowing how bad things were | Asked a friend or relative for advice |
| Treated the illness as a challenge | Looked for a silver lining |
| Found new faith | Tried not to act too hastily |
| Rediscovered what is important in my life | Tried to forget the whole thing |
| Avoided being with people | Took it out on other people |
| Looked for sympathy or understanding | Depended on others to handle things |
| Thought of how someone I admire would act | |

2. Is there anything else that was useful to you in getting through your treatment?

Week 2 writing:

This week we would like to suggest that you write something about your story of cancer. Each person who has had cancer has their own story of how cancer impacted you and what it means for you. For example, your cancer story can focus on something important you remember, something you feel, or something or someone that helped you get through. As usual, you can write as little or as much as you want -- the whole story or an important part of it. In a moment, turn the page. Then, take some time for quietness and stillness or meditation, like we learned last week. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Week Three

Healthcare

Week 3 goal: To plan for your healthcare wishes after treatment for cancer.

Week 3 reading: Please read the NCI booklet, pages 1-5.

Week 3 exercise:

1. As you get your healthcare now, some issues, such as monitoring your body for cancer will likely fall to your oncologist. Other issues, like addressing day to day health concerns and residual effects of your cancer treatment, may be addressed by your primary care doctor.

2. First, let's make a list of your healthcare team.

Who is your oncologist: _____

Who is your primary care doctor: _____

Were there any other important healthcare providers (nurses, counselors, social workers, family, friends, spouse/partner, etc):

3. In a few words, write about an experience or approach that a doctor or healthcare provider used that you **did not** like, or where you **did not** feel in control:

4. In a few words, write about an experience or approach that a doctor or healthcare provider used that **you liked**, or where **you felt more in control**:

Focusing on how the good experience differed from the bad experience, answer the following questions:

5. Contrasting the good and bad experience, what helped you to feel more powerful or in control as a patient?

6. What would you like from your healthcare providers?

7. What do you wish you could change now about your health?

8. Was there anything you did, including seeking support from family or friends, that helped you to confront a bad healthcare experience? If not, is there anything you wish you would have done?

Week 3 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Feeling Better

Week 4 goal: To explore options and begin to plan for improving your health and working with your healthcare providers.

Week 4 reading: Please read the NCI booklet, pages 6-13

Week 4 exercise:

1. Are there things you would like to do to improve your health now? If so what:

2. Pages 6-7 of the NCI booklet talk about things you might like to change. Place a check next to any **you** might try:

Learning more about nutrition	Losing weight
Eating healthier	Gaining weight
Exercising more	Drinking more water
Quitting smoking	Vitamins and minerals
Cutting down on drinking	Other: _____

3. Do you ever find it difficult to talk to your doctor? If so, why, what happens, what is hard:

4. Pages 8-9 of the NCI booklet talk about things to ask your doctor. Place a check next to things **you** want to discuss:

What symptoms should I expect to have now and for how long
What tests will I need
How often will I see you
What are the warning signs that cancer is coming back
Fears I have

5. Pages 9-10 of the NCI booklet talk about things you can bring with you to your doctor. Place a check next to things **you** want to bring to your doctor:

- List of physical problems such as
fatigue, low energy, insomnia, weight changes, sexual changes
- List of medicines
- Pain log
- Notes on emotional concerns you are having
- Notes on changes in your family medical history
- A friend for support
- Remaining questions
- Paper for notes
- Tape recorder

6. Imagine yourself feeling better. What would that feel like?

7. What are your priorities now for your health?

8. Based on some of the answers above and other ideas, what might help you to feel more self confident about your health care?

Week 4 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Options

Week 5 goal: To explore options for feeling better

Week 5 reading: Please read the NCI booklet, pages 14-16

Week 5 exercise:

1. Pages 14-16 of the NCI booklet lists some helpful services. Are you already doing any of these? Which ones?

2. If so, how are they helping? Practically? Emotionally? Other ways?

3. Are there any services from pages 14-16 that you are interested in starting?

4. Back on page 10 of the NCI booklet (last week's reading) the booklet talks about ? complementary and alternative medicine? . On the next page, check if **you** are already doing these or would like to try them.

Already doing	Might try	
_____	_____	Meditation
_____	_____	Visual imagery
_____	_____	Biofeedback
_____	_____	Hypnosis
_____	_____	Self-help group
_____	_____	Yoga
_____	_____	Massage therapy
_____	_____	Chiropractic care
_____	_____	Acupuncture
_____	_____	Homeopathy or Naturopathy
_____	_____	Reiki or Therapeutic Touch
_____	_____	Megavitamin therapy
_____	_____	Herbal treatments
_____	_____	Special diets (e.g., macrobiotic)

5. What interests you about those treatments? How might they help you?

Week 5 Writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

My Body

Week 6 goal: To explore feelings about your body and ideas for helping your body

Week 6 reading: Please read the NCI booklet, pages 19-39. This section describes specific problems. You may skip over a section if it describes a problem that is not relevant to you. Stop when it comes to sexuality – we'll do that next week.

Week 6 exercise:

1. Earlier, during week two, you thought about your story of cancer. What is the story of your body? What are some adjectives you would use to describe your body before cancer? What are some words you would use to describe your body now?

Before cancer:

After cancer:

2. Pages 19-39 of the NCI booklet lists some potential problems you may have. Place a check by things that bother **you**:

- | | |
|----------------------------------|-------------------------------------|
| Fatigue | Low energy |
| Pain | Problems with memory |
| Lymphedema or swelling | Insomnia |
| Problems with mouth or teeth | Everything ? takes more time to do? |
| Problems with weight and eating | Stomach aches |
| Loss of bladder or bowel control | Head aches |
| Menopause symptoms | Back aches |
| Other: | |

3. Did you read anything in the booklet that might help you with these? Write down any specific suggestions from the booklet you might try.

4. Did your experience with cancer and treatment affect your body in any positive ways? If so how?

5. If you were to talk to your body, what would you say?

6. If your body were to talk to you, what would it say?

7. Can your body teach you anything now?

8. On the next page draw a picture of your body. It doesn't have to be a good picture, just one that expresses your feelings about your body. You can also use special lines, colors, or words to show your feelings about different parts of your body

Drawing of my body:

Week 6 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Week 6 themes:

Flesh

Blood

Week 7 goal: To explore avenues for pleasure

Week 7 reading: Please read the NCI booklet, pages 40-44.

Week 7 exercise:

1. Almost all cancer survivors struggle at times with changes in sexuality or just being physically intimate. Some changes might be very low or high sexual desire, want more or less sexual time, afraid or avoiding sex, want more lusty sex, want touch without sex, embarrassed about sex, too tired for sex, having more or less dreams and fantasy, enjoying masturbation more or less, easier/harder to achieve orgasms, sensitive to touch, more pain with sex, more pleasure with sex, not satisfied with your partner, want to hug more or less, want to kiss more or less, etc. What changes have you noticed?

2. Are there feelings or emotions that may make physical closeness to another person difficult?

3. It may help to move away from thinking about what ? works? and ? doesn?t work? to consider what is good. What do you appreciate about yourself?

4. It may help to consider all the types of pleasures you enjoy. What is your favorite food? Where do you go for your favorite meal? What is your favorite smell? What colors do you like? What places make you feel calm? What places do you find beautiful? What sort of touch and textures do you like? What sounds have been special to you? List below a favorite experience for your senses -- smell, sight, sound, taste, touch.

5. Think about some sensuous pleasures you might enjoy in the weeks to come, such as buying yourself flowers, repainting a room a favorite color, reading a book, listening to music, going out to a restaurant, cooking a special food, spending time with a favorite friend, child, or pet. List below one or two things you might do in the coming weeks to give yourself pleasure.

6. Is there anything you might take away from your experience of illness that could enhance your sexual pleasure (or your experience of pleasure, lust, or love)?

Week 7 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Frets and Fears

Week 8 goal: To understand, expect, and when possible, plan for fears

Week 8 reading: Please read the NCI booklet, pages 47-53 (stop at ? Dealing with Depression?).

Week 8 exercise:

1. What are some of your fears?

2. Sometimes fears are more subtle and enduring and come up as ? stress? . Do you feel under stress? What is the stress about?

3. Page 49 of the NCI booklet talks about things that could cause you to worry. Place a check next to anything that increases **your** fear and stress:

- Exams
- Being at a doctor?s office or hospital
- Hearing others talk about illness
- Anniversaries of things you went through during your diagnosis and treatment
- Birthdays
- Sickness of friends and family
- Death of someone by cancer
- Encountering something from your treatment
- Other: _____

4. Everyone dies at some point. People with cancer, even if considered cured, may think about it more. What are your feelings and fears about dying?

5. When you experience intense fear or anxiety, how long does it last?

6. What helps you to feel better with your fears and stress? What is comforting? For example, things on pages 52-53 and also talking to a loved one, eating ? comfort? food, exercising, distracting yourself with a project or activity, just allowing yourself to feel bad for a while, focusing on what you can control, emphasizing the present, etc.

Week 8 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Reconciliation

Week 9 goal: To recognize depression and to appreciate the importance of mourning

Week 9 reading: Please read the NCI booklet, pages 53-64 (stop at ? Finding meaning?)

Week 9 exercise:

1. The reading today discusses depression. Page 54 of the NCI booklet lists signs of depression, do any apply to you?

2. If so, does anyone know what you are feeling? Who could you tell what you are feeling (e.g., friend, family member, doctor)?

3. Pages 55-60 of the NCI booklet describe other concerns such as changes in memory, feeling upset about your body, feeling angry, feeling alone. Do you feel any of these things at times? Which ones?

4. Cancer may involve losses -- from very real losses like body tissue and hair, to more abstract losses like a loss of a sense of faith or control. One of the steps in feeling better after a stressful experience is to take stock of losses and allow yourself time for mourning. Know that sadness, although painful, gets better with time. Take a moment now and list all the losses you feel you have experienced since being diagnosed with cancer.

5. Right now, which loss(es) are the hardest for you?

6. How have you been dealing with those losses?

Week 9 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

<h1>Week Ten</h1> <h2>Growth</h2>
--

Week 10 goal: To recognize and consider new strengths and insights

Week 10 reading: Please read the NCI booklet, pages 64-69

Week 10 exercise:

1. In weeks eight and nine you considered the anxiety and sadness that having cancer may have brought. While not to diminish these, today's reading described potential growth or new insights some people have with cancer. These may be new changes or just new found appreciation of old things. List below any of the new insights or lessons you think cancer may have brought to you (e.g., appreciate life, appreciate friends, feeling stronger, new goals, etc).

2. Some people feel that the experience with illness may have increased their interest to try something new -- perhaps something they have always wanted to do in their personal life, volunteer, work, or social lives. Are there any interests or new missions you want to explore now (e.g., I want to volunteer at ..., I want to make time to explore ...)? If so, list these.

3. Has having cancer changed your religious or spiritual beliefs, or how you look at life or the world? If so how?

4. Is there anything you can take from your experience with cancer into your spiritual practices?

Week 10 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Week Eleven

Friendship

Week 11 goal: To consider how cancer affected your social life

Week 11 reading: Please read the NCI booklet, pages 71-82

Week 11 exercise:

1. Did any friends, family, partners, or co-workers show support? How? What surprised you?

2. Did anyone let you down during your diagnosis and treatment for cancer? Who? How? How do you feel about it?

3. How did it feel for you to depend on others?

4. If single, how has having cancer affected your dating? If partnered, how has it affected your relationship with your partner?

5. If you have children, how has having cancer affected your relationship with your children?

6. Who do you feel closer to now? Who do you feel more distant from now?

7. Is there anyone that you feel it would be helpful to talk to about your feelings about what happened, positively or negatively, during your cancer treatment? Who? What do you want to discuss?

Week 11 writing:

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

Integration

Week 12 goal: To review what you've learned and think about the future

Week 12 reading: Please read the NCI booklet, pages 85-113 (you may skim the resource list)

Week 12 exercise:

1. This week it is time to take stock in what you have learned about yourself, your needs, and your story. Please review back through the pages of this workbook. What are your main physical symptoms or health concerns now?

2. How do you hope to work with your doctor to address these?

3. What are the main things you may try to improve your own health? (E.g., change nutrition, exercise, try a complementary treatment?)

4. What are your strongest emotional concerns now -- Feelings about fear, losses, sadness, anger, isolation?

5. What have you learned during the past 12 weeks about yourself?

6. Have you had any big insights or flashes of new understanding?

7. What would you tell another cancer survivor about life after a cancer diagnosis? What do you wish someone would have told you?

Week 12 writing:

During week two we suggested that you write about your “story.” This week we would like to you to write that story again. As before, each person who has had cancer has their own story of how cancer impacted you and what it means for you; what you remember, feel, or what got you through. As usual, you can write as little or as much as you want -- the ? whole? story or an important part of it.

In a moment, turn the page. After you turn the page, take some time for quietness and stillness or meditation. When you are finished with your time of quietness, begin writing. Write about anything that is on your mind. Just write. Okay, turn the page. Begin.

9: Reconciliation _____

Comments:

10: Growth _____

Comments:

11: Friendship _____

Comments:

12: Integration _____

Comments:

If you have any other comments or anything else you would like to share, please do!

Please “cut and paste” these two pages and email them to me at: jennifer.moye@med.va.gov.

Thank you!