

*The
Circles of Love
Collection*

**DISCUSSION
GUIDE**

For use with

The Circles of Love Collection

STORIES OF

COMPANIONS & FAMILY MEMBERS

FACING PROSTATE CANCER



The Circles of Love Collection
Discussion Guide

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The medical information and procedures contained in this book pertain to the experiences of the story contributors. They are not intended as medical advice, nor are they intended as a substitute for consulting with a physician or health care provider. All matters pertaining to your health should be supervised by a health care professional.

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INTRODUCTION



In the book, the ***Circles of Love Collection***, we met sixteen families and couples facing prostate cancer. While acknowledging the challenges of the patient, these real-life inspiring stories focused on the invisible patients: the companions, spouse and family members of men with prostate cancer. Their stories provide the reader countless opportunities for reflection and discussion.

The ***Circles of Love Collection Discussion Guide*** is designed to further bring those remarkable stories to life. Each section provides compelling questions to consider and discuss, updates from many of those featured in the ***Circles of Love Collection***, as well as tips and tools.

The Discussion Guide is designed to be used in the following ways:

- Peer-to-Peer Chapters: A complete section with tools and tips for creating a companion and family event is found in the booklet. This section is designed to help create or augment companion and family member support.
- At home: To stimulate discussion among loved ones at home. Patients and family members read a chapter in the ***Circles of Love Collection*** and use the associated discussion questions to share feelings and concerns.
- A tool for readers: Reading stories in the ***Circles of Love Collection*** and considering the associated questions can help raise and resolve important, and sometimes difficult, questions for the reader.

However you chose to use the ***Circles of Love Collection Discussion Guide*** and book, our hopes are that they both serve you well on your journey with prostate cancer.

- Us TOO International Companions & Family Advisory Panel



HOW TO...



Us TOO recognized that prostate cancer is a disease of the patient, the partner or spouse, and the family. While the patient experiences cancer in their body, those closest to the patient have an experience of prostate cancer that is also very real. Companions and family members need help too.

Are you considering organizing an event for companions & family members of men with prostate cancer? Are you wondering where to begin? This section provides ideas, guidelines, encouragement and tools to create a valuable and enjoyable event.



Why Us TOO Peer-to-Peer Self Help Chapters Work For Companions and Family Members Too

Studies indicated men with a strong social help network fare better than men dealing with prostate cancer alone. Studies also indicate men with a spouse or partner, or those in a committed relationship, have overall better mental health and cope far better with nausea, fatigue and pain that accompanies treatment.

The bottom line? It is important for a man with prostate cancer to be open to, and even encourage, their companions and family members' active involvement in their prostate cancer journey. This can be challenging for some men because of one basic reality: while having companions and family members actively involved in prostate cancer care can be excellent for the patient, it can bring challenges and struggle into the lives of those same companions and family members.

Receiving news that your loved one has prostate cancer is traumatizing. Diagnosis, treatment and living with prostate cancer can be a very stressful and emotional time for the patient **and** those people who stand beside him. Days, weeks and even months later, diagnosis can feel like blur. Information overload is very common. How do you care for yourself as you care for your loved one? Where do you find your support?

When men with prostate cancer **and** their family members seek and receive help from others, they all often find it easier to cope. In addition, sharing what you have been through as a patient or family member can be a source of strength for others. This is called 'voluntary peer-to-peer self-help.' This concept is at the core of Us TOO's philosophy and objectives.

Us TOO is dedicated to communicating timely and reliable unbiased information enabling informed choices regarding prostate cancer-related topics, such as: detection, treatment options, pain control, nutrition, mental health, coping strategies and more.

The Circles of Love ***Tools for Companions and Family Members***

The challenges of companions and family members of prostate cancer patients may not show up on a lab chart, yet they are often equally painful and traumatic. Companions and family members can feel helpless, confused and alone. Their lives are also dramatically impacted by the diagnosis and treatment of prostate cancer.

The **Circles of Love** is a resource and support program designed with the caregiver in mind. The purpose of the program is to acknowledge, empower and support companions and family members of men with prostate cancer. Within the Circles of Love you can safely express your thoughts, hopes and fears, as well as find support for the many questions that accompany prostate cancer.

The **Circles of Love Care Kit** includes a variety of components designed with companions and families in mind, including information about intimacy issues, soothing and inspiring music to buoy your spirit, and remarkable stories of companions and families facing prostate cancer. The kit is also provides excellent savings over the cost of purchasing each component separately. The **Circles of Love Care Kit** includes:

- ***What You Need to Know about Prostate Cancer*** (from NCI)
- ***Resource and Referral Guide*** (from NCI)
- ***Intimacy with Impotence: The Couple's Guide to Better Sex After Prostate Disease***, by Ralph and Barbara Alterowitz
- ***The Circles of Love Collection: Stories of Companions and Family Members Facing Prostate Cancer.***
- ***Circles of Love Music CD***

The **Circles of Love Care Kit** is available for purchase:

- Online: www.ustoo.org
- Or by calling Us TOO 1-800-80-USTOO (1-800-808-7866)

All components of the **Circles of Love Care Kit** may be purchased separately. **Circles of Love Care Kits** are available to Us TOO chapter leaders at a reduced price by calling Us TOO at 1-800-808-7866.

Hosting An Event For Companions and Family Members

Some Us TOO chapters currently have many companions and family members actively participating in their chapter meetings and events. Some chapters find that only prostate cancer patients are attending the meetings, but would like to encourage companions and family members to participate as well.

Have you wondered how to create an event or on-going source of peer-to-peer support for companions and family members of prostate cancer patients? This section provides tools to get the ball rolling and keep it rolling as well.

THE INVITATION

Some companions and family members do not attend chapter events for any number of reasons. Some don't attend simply because they have never been asked. A simple, sincere, welcoming invitation can make all the difference to someone seeking hope.

If you are currently participating in an Us TOO chapter, many of the same ideas that helped start your chapter can be easily implemented here.

- Select a date (or a series of dates) for a companion and family event
- Determine the location and time of the event
- Ask for volunteers to provide refreshments
- Select a volunteer leader for the companions and family portion of the event
- Gather your materials for the discussion portion of your event (outlined in the following section.)

A flier is found on the following page which is designed to provide an easy-to-use invitation for your companions and families event:

- Carefully clip the flier out
- Make copies
- Fill in the date, time, location, contact, and other pertinent information
- Hang it up and pass it out.



*Someone
you love
has prostate
cancer*



If this caught your attention, here are some things you should know:

- ✓ More people are living with cancer now than ever before, and new ways to treat cancer are being discovered.
- ✓ Having cancer doesn't necessarily mean a person will die from it.
- ✓ Nothing you did or didn't do caused your family member to get cancer.
- ✓ Companions and family members of prostate cancer patients deserve and need care too.
- ✓ CARE IS NOW AVAILABLE FOR YOU. ALL ARE WELCOME.

Receiving the news that you or a loved one has prostate cancer is traumatizing, often leading to feelings of fear, helplessness, guilt, isolation and anger. No one needs to face prostate cancer alone. Us TOO International provides the forum for sharing, caring and learning for both men with prostate cancer and their loved ones. Us TOO is a grassroots organization started in 1990 by prostate cancer survivors to serve prostate cancer survivors, their spouses/companions and families. Us TOO is dedicated to communicating timely and reliable information enabling informed choices regarding detection and treatment of prostate cancer. Ultimately, Us TOO strives to enhance the quality of life for all those affected by prostate cancer.

CHAPTER NAME:

CHAPTER CONTACT:

PHONE:

MEETING LOCATION:

MEETING DATE(S):

MEETING TIME:

Preparing to Lead a Discussion With Companions and Family Members

Often times, companion and family events bring both the patient and his companion or/and family members. By being there together they have indicated that are facing prostate cancer together, or perhaps they are looking for tools to work together on this challenge. Provide some part of the meeting where they can all be together, then encourage the patients to gather for sharing and discussion separately, as the companions and family members also gather separately for discussion.

PREPARATION

As you prepare to lead a companions & families discussion:

- Select one story from the ***Circles of Love Collection*** as your discussion tool for the evening. See the table of contents of this discussion guide for a brief summary of the key issues, insights and challenges discussed in each chapter.
- Read the story at least once to become familiar with the contributors, their challenges, joys and concerns.
- Review the corresponding questions in this discussion guide and consider how you might respond to the questions yourself.

USING THIS DISCUSSION GUIDE:

You will need:

1. One or more copies of the book, ***The Circles of Love Collection – Stories of Companions & Families Facing Prostate Cancer*** (book available through Us TOO, distributed to Us TOO chapters in the **Circles of Love Care Kit** June 2005.)

*(Note: If funds allow, purchase extra copies of **The Circles of Love Collection** for participants to purchase if they desire. If funds are not available, you have permission to photo copy the pages of the story you select for the discussion.)*

2. At least one copy of ***The Circles of Love Collection Discussion Guide***.

At the Event For Companions and Family Members

HOSPITALTY IDEAS

Sometimes it can be frightening to enter a group of strangers alone. Those first minutes after walking through the door can be stressful, even for those eager to connect with others who are traveling the same path.

Hospitality Idea #1: Post someone at the door to welcome people. Ask them their name, tell them you are glad they are there, invite them to wear a name tag and share a little bit about themselves. Ask them why they came and introduce them to at least one other person.

People come for a variety of reasons but most are looking for helpful information and affirmation.

Hospitality Idea #2: Place some support materials (Us TOO HotSheet newsletters, brochures, books, pamphlets, fliers, videos and DVD's) on a table for people to review. Provide sheets of paper and pencils for people to write down titles that sound interesting. Have someone knowledgeable stand by the table to answer questions about how and where to order resource materials.

Most people enjoy refreshments when they attend a function. If possible, provide healthy refreshments that mirror a healthy prostate cancer diet.

Hospitality Idea #3: Provide healthy nutrition bars or a bowl of fresh fruit instead of high-sugar cookies. Provide water or low-sugar lemonade instead of coffee or soda.

Learning your loved one has prostate cancer can be traumatizing. Asking for help can also be very difficult and emotional.

Hospitality Idea #4: Have tissue readily available and, if someone cries, let them know their emotions are normal. Don't try to make them stop until they are ready.

Leading A Discussion at the Companions and Family Event

They saw your flier or responded to your invitation. So, now you are sitting in a group with companions and family members of prostate cancer patients. What now?

STEP BY STEP

1. Start the small group session by asking everyone introduce themselves. You may have done this as a large group earlier, but do it again. They may have been overwhelmed earlier.
2. Ask each person why they came to the event. What are they hoping to learn or change? There is no need to respond to their needs at this point. This allows each person to clarify their reason for attending and helps that group to best support one another during the meeting.
3. Share with the group that you will be leading a discussion based on a story from the book, ***Circles of Love Collection – Stories of Companions and Families Facing Prostate Cancer***. (You may want to have extra copies of the book available or photo copies of the story.)
4. Invite participants to spend a few minutes reading the story selected for discussion. If someone does not feel comfortable reading, encourage them to get additional refreshments while the others read the story. Note: Be sensitive to those who do not wish to read the story. They may find reading difficult for a variety of reasons. Assure them that you will summarize the story before the discussion and they can still find value in the discussion if they do not read the story.
5. After most people are finished reading the story, begin the discussion with a brief synopsis of the chapter, such as the key character names and their primary challenges/issues.
6. Use the discussion questions to initiate conversations in the group. Some people feel more comfortable talking about a ‘character’ in a story than about their situation. Encourage them to relate the story to their own life and consider their own response.

Things To Consider When Leading a Discussion With Companions and Family Members

WHAT IS PEER-TO-PEER SELF-HELP?

Your event is not a support group; rather it is a peer-to-peer self-help meeting. A self-help group is a voluntary gathering of people who share a common challenge - prostate cancer. By coming together, members share support and ideas on how to cope and live more productive and fulfilling lives. As companions and family members gather together they can help each other deal with problems, stress, hardship, pain, and find encouragement.

DO:

- ✓ Respect confidentiality and ask all participants to do the same.
- ✓ Refrain from giving advice unless this is asked for – let each participant find their own answer and be the expert about them self.
- ✓ Answer questions honestly using your own experience.
- ✓ Listen carefully to questions and statements to avoid giving more information than requested. Avoid overwhelming companions and family members.
- ✓ Share information about resources that you found helpful.
- ✓ When you are uncertain about what is being asked, don't hesitate to say "I don't know," and invite someone else respond.
- ✓ Respect all experiences, ideas and outlooks.
- ✓ One speaker at a time. There is much to be learned from listening.
- ✓ No side conversations please. Either share your ideas with the group or take time after the meeting to have one-on-one conversations.

AVOID:

- ✓ Do not give medical advice or encourage patients to make specific treatment choice or decisions about medical treatment. Speak only from your experience.

Wrapping Up Your Companions and Family Event

AFTER SMALL GROUP DISCUSSION

Before everyone leaves for the evening, gather your patients, companions and family members together again briefly before you adjourn. Ask a few simple questions:

- Did you find some comfort, information or some answers tonight?
- Do you want to participate in an event like this again? If people did not sign in at the beginning of the event, pass a tablet or sign-up sheet on which people can write their contact information.

REMIND THE GROUP

- Don't be ashamed or afraid of the way you feel. Others in your situation have felt the same way.
- If you overhear someone talking and what you hear scares you, ask them to explain what they just said. Don't assume that you heard everything and understood what it meant, ask for clarification and support.
- The way you behave cannot change the fact that someone has cancer or that your family is upset.
- Keep learning. There are many different ways to think and feel about having a loved one with cancer. Don't be afraid to ask for help.

WRAP IT UP

Share any announcements and thank people for attending. You did it! You provided a safe place for companions and family members of prostate cancer patients to learn, share and grow.

CONGRATULATIONS!



DIAGNOSIS



Diagnosis can be a very stressful and emotional time for the patient and those people who stand beside him. Days, weeks and even months later, diagnosis can feel like blur. Information overload is very common. Where do you find your support? How do you care for yourself as you care for your loved one?

Circles of Love Collection
Chapters 1-4



Jo Ann & Jerry
The Circles of Love Collection page 13

Discussion questions

1. Did (do) you have an "opening line" when explaining your partner's prostate cancer? How do the words sound to you?
2. What were your first thoughts upon hearing the news?
3. Was there a specific time when the diagnosis went from "his" disease to "our" disease? Did your feelings or questions change as you adopted a new perspective?
4. When you told your family and friends of the diagnosis, who was most helpful? How?
5. Did (do) you harbor any anger toward those living "normally," or seem to be enjoying life worry free? Who? In what way? What would be helpful to you?
6. How did you inform your children? What worked best for you? For them? What, if anything, would you do differently? How do you include them in the "our" disease?
7. What are some of the "gifts" you have received as a result of this experience?
8. Did you experience unmet needs early in the diagnosis experience? What are some of your unmet needs now?
9. How did you feel at your first Us TOO support group meeting?
10. Is there anything you would like to change for those who are new to such a group?

Fall 2005 Update

Jo Ann happily reports that there are many things to celebrate for her family this year.

First, Jo Ann and Jerry celebrated the 29th anniversary of their marriage on September 11. More importantly, September marked the 5th year of Jerry's living with prostate cancer. "It is amazing," says Jo Ann, "and we are so very thankful!"

Over the past 5 years, Jo Ann and Jerry felt it very important to reclaim all of the aspects of the physical intimacy that has been so important to them throughout their relationship. After unsuccessful tries with many of the modalities available to treat erectile dysfunction, Jo Ann and Jerry decided upon a penile implant.

"It was a major decision", says Jerry. "In choosing the radical prostatectomy, we were concerned about the possible side effects, but decided that we would deal with whatever came along as a result of the treatment."

With the help of a urologist that Jerry felt comfortable with, the decision was made in March 2004 to have the implant. Jo Ann and Jerry are both extremely satisfied with the decision, and whenever asked, take the time to talk about it with others in large groups, or in smaller, more intimate settings.

"Ultimately," says Jo Ann, "our lives are more carefree now than they have ever been. We have a beautiful new perspective on what is important, and have found a freedom in that much-needed revelation. All of the time that we spend together is a gift, from the handling of daily mundane chores to whispering quietly to each other at night about all of the exotic places that we plan to see. The times that we are together, alone, or with our family, those times are precious to us, and we treasure them."

Margaret & Philip
The Circles of Love Collection page 24

Discussion questions

1. How are you with your partner "every step of the way?" Do you have someone besides your spouse who is with you every step of the way? Who?
2. Does your spouse/do you ask questions of your physicians? Keep abreast of new available treatments?
3. Are you able to keep/bring humor into your lives? How?
4. Have there been major attitude changes in your partner since his diagnosis? In you? Please share.
5. Does your partner/do you have a special hobby that is used as a kind of "therapy," e.g., music, photography, etc. Talk about that.
6. How has your role as a partner changed since the diagnosis of prostate cancer?
7. Are you willing to let others meet the needs of your partner? Who? How does that feel?
8. Some men and their spouse have become very active in new volunteer or vocational roles as a result of living with prostate cancer. Are there any ways in which you or your loved one have become active in some kind of service role? Are there aspects of Us TOO about which you would like more information?
9. Have your goals or plans changed as a result of prostate cancer? In what way? How does that feel?
10. Do you feel you and/or your spouse have discovered an unexpected inner strength within since the diagnosis of prostate cancer? Please explain.

Fall 2005 Update

(Philip) For us things are going very well. I am still "clear" of cancer (undetectable PSA). While the thought of the possibility of the cancer returning is always lurking in the back of my mind, faith and hope that the vaccination protocol will "work", is comforting, even if it eventually turns out other wise.

Participation in the USTOO support group at WRAMC and the Man-to-Man (ACS) group at NNMC have become a regular part of our lives. There is a lot of satisfaction in the potential of helping others. As time passes, the difficult aspects of this journey seem to fade, being thankful for each day trumps everything else. So many things have contributed to our (Margaret and I) well being, that it is hard to begin listing those things for which we are thankful. Among them are the friendships that have materialized through the treatment process and the years that have followed.

I imagine many, if not most, couples are concerned and apprehensive over the nature and quality of their intimate relations. It is important to know and recognize that this aspect of life will be different. But, it can and should be as beautiful and satisfying as before. Yes, it will take more effort and, yes, it will have it's ups and downs. Isn't that the way it is in all relationships?

Notes from the pathway

- Wives attend the support group meetings with your husband.
- Husbands invite and sincerely encourage your wife to attend, if not for you, for her and for the good of the group.
- Read the book, *The Loving Ain't Over* by Ralph and Barbara Alterowitz. It is a priceless book about intimacy after prostate cancer.

Jackie & John

The Circles of Love Collection page 30

Discussion questions

1. From whom do you receive your greatest support?
2. Who else do you need in your (or your partner's) support system? How do you invite them into your support system?
3. Are there folks in your support system who you feel are not supportive? What is the best way to deal with them?
4. Does your partner's physician include you in his/her conversations? What do you do if they do not?
5. If you are the primary researcher in the family, how do you feel about that role? Is your partner receptive to the information you share with him?
6. Did your partner discuss treatment possibilities with you? Were you part of the decision-making process?
7. What were (are) your greatest fears as a result of your partner's treatment?

Nancy

The Circles of Love Collection page 37

Discussion questions

1. Who makes up your “tiny village of support?” How are you connected?
2. Do you have any naysayers or fatalists in your “village?” If so, explain. Have you shared your concerns and feelings with that person?
3. Do you use the Internet to find prostate cancer information? How do you sort out the valid information from the questionable? What are your most helpful sites?
4. Have you made Us TOO International a part of your village? In what way is Us Too most helpful? Are there other ways Us TOO could assist you?
5. How do the challenges of an adult child caregiver compare to those of a spouse/companion caregiver?

**As of April 4, 2004, Prostate Pointers became part of the
Us TOO International Prostate Cancer Education & Support Network family,
and can be found at www.ustoo.org*



TREATMENT & RECOVERY



Treatment can be a long and challenging process. Simply becoming aware of treatment options then making a decision can be overwhelming in itself. What is your role in treatment decisions and in his course of treatment?

*Circles of Love Collection
Chapters 5-8*



Jackie & Jim

The Circles of Love Collection page 45

Discussion questions

1. Prostate cancer is a couple's disease. Do you agree or disagree? Discuss.
2. In the story, the question arises, "if our sex life is taken away, what is life like?" How did/do you answer that question? Would your answer be different today than it was at the time of diagnosis? If so, in what way?
3. Did/do you keep some feelings hidden from your partner?
4. Does your partner receive support other than from you, such as from the children and/or immediately family? In what ways? How do you feel about this?
5. Did/do you go through periods of asking "what if?" If so, what are the specific questions you ponder? Do you discuss them with your partner?
6. Has/does your partner take part in any clinical trials? Discuss your feelings about this?
7. Did/does your partner express his fears with you? You with him? What are some of those fears?
8. Did/do you use a holistic approach to treatment? What does that mean for you? What are your greatest challenges in this area? Is your doctor supportive of including alternative treatments in your partner's health regime?
9. Do you see a difference between being "healed" and being "cured?" Explain.
10. What are the major factors in living life to the fullest from day to day?
11. Have you discussed end-of-life issues? Made specific plans? Discussed and prepared necessary documents?

Fall 2005 Update

(Jackie) We are continuing on our journey with prostate cancer into the fourteenth year. At the moment Jim's PSA is negligible; he is using intermittent hormone therapy and has been off the last treatment with Lupron for three months. Now we watch for the monthly PSA report. Every day is a gift. We have decided to continue to live fully with an awareness of what is happening, but without being consumed by it. We are deeply grateful to have found this balance.

Notes from the Pathway

1. (Jim) I have found it incredibly useful to attend as many of the monthly Us TOO prostate cancer support groups as possible. This keeps me up to date with what is happening, and it gives me the chance to report where I am on my journey. And of course it is most valuable to help support those who come to the cancer support group with a new diagnosis. This is one of those win-win situations where everyone benefits.
2. (Jim) Now that I am in my 70's, we have decided to move into a retirement community with continuous care. I have no idea where my journey with prostate cancer will take me, but there is a definite sense of relief to know that if I need it, assisted living and skilled care are available in the community where I reside. Both my partner and I will be in the same residential community in independent living for now, fully available to each other even if we need additional care levels. And our kids won't have to worry about making decisions for us if we are incapable of that at some point in the future. The research is also interesting in this regard; in retirement communities with continuous care, the need for skilled care is a considerably shorter time period than the average.

Christie & Clark
The Circles of Love Collection page 55

Discussion questions

1. Did you know anything about prostate cancer before your partner's diagnosis?
What was your first understanding upon learning of the diagnosis?
2. Did you understand the terms and implications of incontinence and impotency?
3. Was one of you a talker while the other went within? What problems did that cause, if any? How did you overcome them?
4. Have you discussed "quality of life" issues? Discuss.
5. Do you think you've grown closer as a couple or do you feel like there is a new third party (prostate cancer) in your relationship?
6. Healthy communication is an important component in any relationship. This is especially true if there are health challenges to face. Do you agree?
7. Do you believe your communications have declined, improved, or stayed the same? Discuss.

Rebecca & David
The Circles of Love Collection page 62

Discussion questions

1. How do you deal with a doctor that you feel is arrogant or full of himself?
2. Did your doctor suggest possible alternatives to his/her specialty (e.g., a surgeon suggesting seed implants or radiation, etc.)
3. Did you feel pressured into making a decision quickly? Discuss.
4. Did/do you have a tendency to micro-manage your partner's health care? (Keep track of medical information, become obsessive about diet, etc.) How does that feel? Do you feel the need to relax around these issues?
5. Do you ever feel "crazy?" Explain.
6. How much does the bed-side manner from your partner's physician mean to you?
7. How does your partner's doctor deal with intimacy-related questions from you and/or your partner?
8. Do/Did you ever feel inadequate in caring for him after surgery? What would have been helpful to you in this regard?
9. Who can you call on for logistical or respite assistance?
10. Other than diet, did you and/or your partner make significant life changes?
11. Are there topics you and your partner find too uncomfortable or are unable to discuss?
12. If dealing with erectile dysfunction, what has been most/least helpful to you?
13. Has prostate cancer ever led you into some kind of therapy? Discuss how you made the decision to seek therapy. Was therapy helpful to you?
14. If you are experiencing health challenges of your own, how do you make sure your needs are met?

Fall 2005 Update

(Rebecca) Cancer and intimacy issues are far removed from our thoughts at most times now. David's PSA results continue to come back below detectible levels. Intimacy issues, which were a major problem for some time, have been permanently solved since the implant surgery.

Notes from the pathway

If we could go back and redo it all, knowing what we know now...

Initial treatment: We would have opted for seed implants plus external beam radiation, even in the face of the "get it the heck out of me RIGHT NOW" mentality. Our understanding is that the numbers for this are as good as those for Radical Prostatectomy, but with far fewer treatment injuries.

Intimacy issues: I think that most couples would be well served by seeking couples therapy beginning at the time of diagnosis, and continuing until treatment and treatment injuries (impotence in particular) have been resolved. Most men, even those who are normally good communicators, have a tendency to clam up and retreat to their virtual caves when survival and potency issues are suddenly sprung on them. Having a trained professional can be vital to keeping lines of communication and connection between partners strong and vital.

The Howard Family
The Circles of Love Collection page 76

Discussion questions

1. Sometimes prostate cancer patients and their partners will say they've gained a great deal from their cancer experience. Can you relate to that?
2. What members of your nuclear/extended family are/were most committed to you and your partner in the recovery process? How?
3. Has (is) your partner participated in a prostate cancer study? How do you feel about that?
4. If you are African American, are you aware of how crucial it is for African American men to have a PSA and digital rectal exam by the age of 40? Do you share this information with African American men you know?
5. Why do they call prostate cancer a couple's disease?
6. How do you get support from your children and other family members?
7. How do you give support to your children and other family members?
8. How was the decision for treatment made? Who was involved in making that decision? Who had the greatest influence on the decision?
9. Have you ever expressed your gratitude to your health care professionals?
10. What were/are your best experiences in being your partner's caregiver?
11. What were/are your greatest challenges in being your partner's caregiver?
12. Has your family been redefined in any way as a result of prostate cancer?
13. How has this experience changed you?
14. What lessons have you learned?
15. Where is your focus right now?

Fall 2005 Update:

(Kenneth) Doris and I are doing quite well. We had a wonderful summer vacationing in Paris and London. We returned home for the wedding celebration of our daughter Dorcus, which was held on our 43rd wedding anniversary. We continue to take one day at a time, remembering that every day is a gift from God and we are thankful. We stay vigilant, as October 10th is the anniversary date of my surgery. I continue to attend monthly prostate support group meetings, and have regular check ups. We continue to share our experiences with others hoping something we say may relieve some of their anxiety.



LIVING WITH PROSTATE CANCER



Every patient hopes for recovery. Sometimes complete recovery is not possible. How do you return to “normal” in the face of chronic disease? Has “normal” changed? Has your relationship changed? Your outlook? Your hopes? When does hopeful living return?

*Circles of Love Collection
Chapters 9-12*



Maureen & Jim
The Circles of Love Collection page 88

Discussion questions

1. Did your loved one experience any symptoms prior to the diagnosis? Discuss.
2. What have you and your family found to be important as you strive to achieve or maintain a spiritual and mental balance?
3. Has the expression of sexual intimacy changed for you and your loved during the various phases of your journey? In what ways?
4. What methods have you found effective in keeping open communication regarding issues of intimacy?
5. Have you or your loved one experienced any hesitancy in sharing the diagnosis with family members? With friends? With employers or work colleagues?
6. What was your family's experience in "doctor shopping"? Did your journey include a second or even third opinion while evaluating treatment options?
7. As a spouse/companion, have you ever felt a lack of compassion or sensitivity from medical caregivers? How did that make you feel? Did you seek active ways to address or overcome this?
8. How does your family deal with the issues of death and dying? Is there anyone that you were comfortable with in discussing the possibility of your future without your loved one?
9. What impact has prostate cancer had on your views of, and relationships with, other couples that you might socialize with?
10. In what ways has living with prostate cancer changed your relationship with your loved one? In what ways is your life more fulfilling? Are there things in the past that you long for or miss?

Fall 2005 Update

(Maureen) When the original article was written, Jim was on intermittent hormone treatment. Since that time, he took a break from the treatment, but has been back on it for the past eight or nine months. The treatment consists of Casodex, Lupron and Avodart. He expects to take another break, beginning in January.

Jim has also been on Zometa, an infusion, every 28 days, that controls bone cancer. He's had these transfusions for about two years. They continue even when he is on break from hormone treatment.

That's the update on the physiology of cancer. Mentally and spiritually, he couldn't be better. Many of you know that he has been the Chairman of the Board of Directors for Us TOO International for the past year. He absolutely thrives in this role. I've always said Jim is the poster boy for prostate cancer, since he has been a survivor for more than 17 years. His attitude, as well as being very selective with his health care providers, has played a major role in his health status.

Jim is a firm believer in holistic healing and does not separate body, mind or spirit. He makes sure that his care givers work from the same perspective.

His energy certainly has not declined. I remember about six years ago when Jim first started hormone treatment the doctors warned him that his energy level might be reduced. I could only laugh and say, "Wow, then maybe he'll be like the rest of us human beings." Well, not true. He still has more energy than anyone I've ever met. Again, I am sure his incredible positive attitude is the key.

Happily, his attitude seems to rub off on me. How can you be with someone who is positive all the time and not pick up on it? While we are very aware that Jim carries a very serious disease in his physical body, it does not define who he is. Who he **really** is

is demonstrated in his caring and sharing with other men and their families who have prostate cancer. It shows up when he "whoops it up" with our grandchildren. He exhibits his true self as he hugs our family and friends and as he holds my hand on our daily walks.

Yes, to me, Jim is the poster boy. I see the expression of relief and hope on the faces of men and their partners when they learn how long he has led a productive, happy life while being treated for prostate cancer.

As for me, I am along for this ride of a lifetime. I knew it would always be exciting. I suspected that each challenge would be an opportunity in his eyes. He has taught me so much, and we continue to learn from and for each other. We learn from others who are facing similar situations. We share their lessons, their love, their humor and their healing, in body, mind and spirit. We are optimistic about the future. We strive to make each day one of absolute quality. We take nothing for granted. We are grateful for friends and family and hope we can return even a portion of all that we receive.

That is our today. It is our tomorrow. Our complete trust lies in the Spirit of God. We joyfully accept all the good God has for us, one day at a time.

Billy & Ed

The Circles of Love Collection page 96

Discussion questions

1. Did you ever hesitate (especially early in the diagnosis) putting in your “two cents worth,” such as your opinions, feelings etc.?
2. Did/do you write down your questions you have and take them when you accompany your partner to doctor appointments?
3. Did/do you discuss responses by his doctor?
4. Do you think your being gay makes your situation different from a heterosexual couple? If so, in what ways?
5. What do you want other couples to understand to be supportive of you?
6. As a gay partner, what were/are your greatest fears?
7. How did/do you reassure your partner of your commitment to him?
8. How do you live with the always-possible reoccurrence?
9. Have you ever felt, like there are so many people caring for your partner, yet you feel so alone with no one is caring for you? Discuss.
10. What have you learned about yourself from this prostate cancer experience?
11. What new strengths do you think you have found through this experience?
Explain.
12. Have you or your partner ever experienced the question asked by Billy and Ed:
“Now you’ve done what you were supposed to do. When are you going to do what you **want** to do? What is YOUR answer?”
13. What gifts can you give yourself and your partner?

Fall 2005 Update

(Billy) Both of us are doing very well. After six years of partnership, we are joining our lives and buying a condo together in a completely restored 1922 apartment building. Life still holds many challenges, but as our realtor pointed out when my house went on the market, if you have love for each other, you have everything you need.

Notes from the Pathway

Talk about your feelings, including your fears, with each other using "I" statements.

Remember that the prostate cancer survivor lives with the disease every single day, even if he is "cured."

Don't waste time and energy on unimportant things or doing anything that makes you feel bad or angry.

Take time to enjoy the natural beauty around you every day.

Don't put off things that you want to do. Do them now.

Eat a prostate healthy diet and exercise regularly.

If you don't have a pet, get one if you can or volunteer at the Humane Society. Petting a dog or cat lowers your blood pressure almost instantly. If you have room for a dolphin or horse, so much the better.

Cynthia & Luke
The Circles of Love Collection page 107

Discussion questions

1. How has prostate cancer changed your life? Your plans for life?
2. Did you influence your partner to have the physical exam that led to the prostate cancer diagnosis? How do you feel about that?
3. Did you have to keep the prostate cancer diagnosis “secret” for a time? Why? How did it feel?
4. Did/does your partner rely on you to be his health-secretary, making appointments, keeping records, doing research, etc?
5. How does your partner’s doctor respond to you?
6. Would you like your partner to take more responsibility for his health care?
7. What changes, if any, have you made in your own lifestyle or health care as a result of your partner’s health challenge?
8. Do you feel you received enough information from the doctor before prostate cancer treatment?
9. Did your doctor discuss incontinence and/or impotency with you and your partner?
10. If your partner is incontinent, how can you be supportive of him?
11. If your partner is impotent, have you redefined intimacy?
12. Are you able to discuss these (and other) side effects comfortably with each other? With the doctor?
13. Are sex and intimacy the same? Discuss. What alternatives have you and your partner discussed or discovered?

14. Does the topic of sexual intimacy come up with your partner, friends, etc? How do you feel about that?
15. Do you feel your partner is doing what he can to improve his health? If not, how does that make you feel?
16. How do you deal with frustration and anger?
17. How does your partner deal with frustration and anger?
18. How do you share feelings of frustration and anger with each other?
19. Do you ever feel disloyal when sharing your sadness, or feeling sad, angry, grief for loss of normalcy or loss of your dreams?

Fall 2005 Update

(Cynthia) Counseling helped us get past the worst of our fears: his fear of me leaving; and my fear of him not loving me. The biggest problem for us I think is that we cannot seem to get the scheduling right. If he isn't "moved" to pay that special kind of attention to me, I need him to find a way to schedule it. We can't seem to get on track and stay there.

Notes from the Pathway

I cannot offer words of advice. I haven't found any for myself, except maybe ask for what you need and get over your sensitivity about initiating loving? I don't begin to know how to do it. We do begin and end every day telling each other "I love you." It means ever so much more than sex but it doesn't really replace that special intimacy.

Anne & Frank

The Circles of Love Collection page 116

Discussion questions

1. When you married, saying “in sickness and in health,” did you have any idea what it meant?
2. Have you ever changed doctors, or wanted to change doctors, because you felt you were not getting what you needed from him/her?
3. How did you learn of your partner’s prostate cancer? Did you feel the time, place and method was appropriate, considering the severity of the news?
4. Did/do you understand the medical language used by the doctors? Do you ask for clarification when you don’t understand something?
5. Did both of you discuss treatment options?
6. When was the first time you heard your partner say, “I have cancer?” When did you first say, “My partner has cancer?” What did that feel like?
7. How often do you hear success stories?
8. How often do you hear doom-and-gloom stories?
9. What do you feel at “check-up” times?
10. Is prostate cancer at the forefront of your life? Has it moved into the background?
11. How has prostate cancer impacted your outlook on life?
12. Do you feel you can get on with your life? If not, why not? If so, how are you doing this?

Fall 2005 Update

(Anne) Frank and I are at the eight and one-half year mark in our prostate cancer journey. Specifically, it is eight and one-half years since Frank's treatment with radioactive iodine seeds. We have faced the challenges of impotence (right from the start) and incontinence, which reared its head only within the past year.

We have never lost our sense of intimacy, which, to our way of thinking, occurs in the mind and the heart more than in the body. We have always been able to talk frankly and sensitively to one another. As for sex, we use Viagra with moderate success and find innovate ways to give pleasure to one another.

As we age, a number of medical problems have complicated our lives, but we do our best to accommodate them and not let them interfere any more than necessary. We try to be realistic about the uncertainty of the future while, at the same time, living in the present.

Notes from the Pathway

If we could give advice to any couple starting down this long road of prostate cancer it would be to keep the lines of communication open. Share your fears and concerns with each other, and don't either of you build a wall around yourself. This is a life-long chronic disease that affects both of you, and it's easier if faced together.



ADVANCED DISEASE



Sometimes recovery is not possible and the cancer progresses. Sadly, for some, thoughts of recovery turn to questions of palliative care and hospice. How do you respond to these decisions and make peace with the potential outcome?

*Circles of Love Collection
Chapters 13-16*



Wendy & Bill

The Circles of Love Collection page 125

Discussion questions

1. Did the diagnosis of prostate cancer open a whole new world for you? In what ways?
2. In what ways do you feel you and your partner are different from other couples experiencing prostate cancer (e.g., younger, poorer, richer, more or less education, gay etc.) Do you think this impacts you in any way?
3. Where are your “safe places” for expressing your feelings? Your “unsafe places?”
4. Are there ways you can help yourself by helping others? Have there been other experiences in your life when you were able to do this?
5. How would you describe your outlook on life on a good day? On a bad day?
6. Would you describe your outlook on life generally as optimistic or pessimistic?
7. Have your interests changed? If so, how?
8. How do you define “quality of life?” Is your definition the same as your partner’s definition? How does it feel to answer this question?
9. Do you have a spiritual component to your life? Has it changed since the cancer diagnosis?
10. Can you and your partner “just be together?” What does that mean for you?
11. What have/can you do – just for yourself and as a couple – that has nothing to do with prostate cancer?

Fall 2005 Update

(Wendy) After we were interviewed for the **Circles of Love Collection**, our oldest son joined the Army and was stationed at Fort Benning, GA for his basic combat training. Bill and I were able to drive to Georgia to attend his graduation with the help of a local church group who gathered funds to give to us for the trip. He has since moved to Fort Gordon, GA and is enjoying military life.

When we returned from the trip, our oldest dog Molly had disappeared and we have not been able to find her. This was a difficult loss for us but we have recently welcomed a new pup into our lives and she is helping us see the world through puppy's eyes.

A few weeks ago we found out that Bill had five new spots in his bones and spine so he is currently undergoing radiation treatments and will resume chemo when he is finished with radiation. We both remain upbeat and see this as merely a bump in the road as we have plans to wade through drifts of snow in the woods of Maine this winter as we have for the past two years.

Notes from the Pathway

For those dealing with advanced disease I would suggest finding a therapist who has had experience working with people whose lives have been affected by chronic/long-term illness. There are so many things that come at you as this disease progresses and no matter how strong or grounded one may feel, every one needs a safe place to vent and to process the changes, twists and turns that come with advancing disease.

Don't dwell on time frames or on what might happen in the future. Take life one day at a time, in some cases one hour at a time or one minute at a time. If you can get up, put both feet on the ground each day this is something to celebrate. All any of us have is today and beyond that we just don't know what will happen.

Barb & Bill

The Circles of Love Collection page 134

Discussion questions

1. Did you experience the prostate cancer diagnosis as a complete surprise?
Explain.
2. Did either of you experience a period of denial? If so, what brought it into focus and led you to acceptance?
3. Were you satisfied with the way you (both of you) were treated and informed? If so, what was helpful? If not, what would you change?
4. How do you feel about the statement, “Knowledge is Power?”
5. How did/does your partner feel about your participation in his health care? Do you think he wants more/less? Have you discussed your participation with him?
6. Have you ever given yourself a “pity party?” Discuss. Then what?
7. Did your doctor ever tell you there was “no hope” or give you a specific diagnosis of the number of months your partner could expect to survive? If so, what was your reaction? What advice would you give to others who receive this message?
8. How did/do you deal with the good intentions of family and friends that you do not find helpful.
9. Have you ever needed time alone, or respite, from well-intentioned family or friends? How did/can you request this?
10. What were/are the greatest benefits you received from a peer-to-peer self-help chapter?
11. Do you read, ask questions, and discuss prostate related material with your partner?

12. Have you discussed unmet goals or dreams with your loved one? Can you make some of these things happen now?
13. Do you find that prostate cancer consumes your life? If so, how? Are you able to find balance in your life? If so, how?
14. What has happened to your own personal goals? Discuss.
15. How do you connect body, mind and Spirit?
16. Do faith and prayer play a role in your life? Discuss. How do you develop/use your spiritual life to assist you with this prostate cancer experience?
17. What, if anything, do you strive to keep “normal” in your life?
18. Barbara and Bill discuss their decision to “choose” what they do and how they feel. What does that mean to you?

Fall 2005 Update

(Barb) Bill and I are so glad we made the decision to sell our business and spend time together. Bill often says "Glad we took that trip when we did because I don't think that I could do it now."

This summer has been quite challenging. Bill is now androgen independent and was hospitalized twice in June for spinal pain with follow up radiation and chemotherapy to alleviate pain and slow down his cancer. We spent almost all of August either sick at home or in the hospital with complications from treatments, such as a colon perforation which fortunately did not require surgery.

Notes from the Pathway

(Barb) In hindsight, we believe that our life choices have served us well. In this illness, we are limited by Bill's fatigue and not feeling well, but are reminded to seize the moment. We go and do when Bill feels well and treasure every good moment.

We now are fully aware that at his disease stage, treatment is an art and not a science. Treatment options are limited and no one has a crystal ball as to how each person will respond and what complications will arise. We continue to be grateful to be working with M.D. Anderson, but now, more than ever, we have to be knowledgeable and participate with our doctors in evaluating and making treatment choices.

We continue to live in faith and the "power of now."

Michele

The Circles of Love Collection page 146

Discussion questions

1. How would you describe your care-giving responsibilities?
2. Are you're the primary care giver?
3. How did you learn to give the care you give?
4. What advice do you have for someone who suddenly finds himself or herself a primary caregiver?
5. What are YOUR greatest needs as a primary care-giver?
6. How do other family members participate in the prostate cancer patient's health care?
7. Are there other family members who choose not to participate in caregiving? How does that make you feel? How do you respond to them?
8. If you are working outside the home, how is your job affected by your added responsibility?
9. What are the patient's doctor's attitudes toward you? Discuss.
10. Have you, or do you need to, become more assertive in any way? Explain.
11. Are you a "warrior" when it comes to dealing with prostate cancer?
12. How has (is) this experience with prostate cancer changed how you look at life in general and/or specific relationships?
13. Can you move beyond your feelings of fear and sadness to become proactive with your companion or family member's illness?
14. How do you stay "in the present," and not get caught up in the "what ifs?"

Fall 2005 Update

(Michele) Right now we are in what I call the "remission honeymoon period". Dad's PSA is down to 2 (last weeks tests), and it continues to fall. He feels physically better, has gained some weight, and, even though he still uses the walker, he feels stronger. He packs some good speed with it. Over the last few months he has been going out more. I remember back in May, Mummy had commented on how she missed going out to dinner. Daddy promised her that, at the end of that month (May), they would go out. For Father's Day, which coincided with my sister's birthday, we all went out to dinner the first time in almost nine months. I had a birthday party in July, and I was so concerned about Dad's ability to make it up the two flights of stairs to the townhouse. He did it amazingly well. Then came our double wedding anniversaries in August, two days apart. We all went out to dinner to a restaurant that we had been going to since we were children. We had a blast, just like the good ole' days. These past months have been very happy times. We are cherishing them and hoping that we will keep him in remission for as long as possible.

Notes from the Pathway

Do your research. Arm yourself with knowledge.

Don't be afraid to ask questions and challenge your doctors. If you are not satisfied with their approach, don't be afraid to find another doctor.

Take each moment as a blessing. Keep a positive attitude. Acknowledge fears, but resolve to keep positive.

Carrie

The Circles of Love Collection page 152

Discussion questions

1. How have you used the Internet to help you learn about, or communicating about, prostate cancer?
2. Does your partner continue the health changes he made after the original diagnosis of prostate cancer (diet, exercise, etc)?
3. What do you do to support him in maintaining those changes?
4. Have you ever had, or do you have, the feeling, “I don’t want to know any more?” Discuss.
5. From where does your partner get the most support? From where do you get your support?
6. Have you ever discussed end-of-life issues with your partner? What questions do you have in this regard?
7. Do you ever laugh? Discuss.
8. Do you keep a journal? Discuss.
9. Does your partner keep a medical journal? Discuss.

**As of April 4, 2004, Prostate Pointers became part of the
Us TOO International Prostate Cancer Education & Support Network family,
and can be found at www.ustoo.org*



***RESOURCES FOR
COMPANIONS &
FAMILIES***



THE CIRCLES OF LOVE COMPANIONS & FAMILIES CARE KIT

*Produced by Us TOO International.
Supported by an educational grant from Abbott Oncology.*

The Circles of Love Companions & Families Care Kit includes some of the finest materials available for companion and family member support. It is not only an exceptional resource tool, it is also a cost-effective way to add these valuable materials to your resource library. Purchasing these materials separately would cost a great deal more than the discounted Care Kit price. Care kits are also available to Us TOO chapter leaders at a further-discounted price.*

Circles of Love Companions & Families Care Kit includes:

- *What You Need to Know about Prostate Cancer* (from NCI)
- *Resource and Referral Guide* (from NCI)
- *Intimacy with Impotence: The Couple's Guide to Better Sex After Prostate Disease*, by Ralph and Barbara Alterowitz
- *The Circles of Love Collection: Stories of Companions and Family Members Facing Prostate Cancer.*
- *Circles of Love Music CD*

*Available at:
www.ustoo.org
To order by phone call
630-795-1002*

**Note: Chapter leader discounts do not apply to online orders.
If you are a chapter leader, please call Us TOO directly to place your order.*

TIPS AND TOOLS FOR COMPANIONS AND FAMILIES

1. Caregiver self-care is just as critical as care for the patient. You can provide better care when you care for yourself.
2. Reach out for help from family, friends, Us TOO chapters, your church and your community. You need not walk this path alone.
3. Remember to exercise regularly, eat a balanced diet and get enough sleep. These activities not only improve your health but your mental and emotional well-being as well.
4. Offer to go to doctor appointments with your loved one, ask questions and take notes. You and your loved one are a team. Talk openly with your loved one about his condition and concerns.
5. Educate yourself on the latest treatment options, medications, and life-style suggestions.

YOU MATTER TOO.

YOUR EXPERIENCE OF PROSTATE CANCER IS REAL.

YOU NEED AND DESERVE CARE AND SUPPORT TOO.

ATTITUDE IS EVERYTHING

It is commonly believed that a person's attitude impacts their experience of life. Someone who is pessimistic and sees life as gloomy will have a very different experience each day than someone who is optimistic and sees life as a grand adventure.

This is not simply 'Pollyanna' thinking. The body has very real responses to our thoughts. Based on your view point, the body creates or reduces chemicals associated with stress, improving or harming immune function, and countless other bodily functions accordingly. Although acute stress can enhance immune function, chronic stress has the opposite effect and can be detrimental to your health if not addressed.

As caregivers, we often spend a great deal of time focused on HIS health. The companion or/and family members' health can also be impacted by his diagnosis. Your health and well-being, psychological and physical, can directly impact his health. The healthier you are, the better equipped you can be to care for him.

Here are ten tips for reducing stress, creating better health and perhaps reframing your experience of prostate cancer:

1. Avoid violent movies, books, television programs. Go on a "news fast" by not reading the paper, listening to the radio or watching the news on TV for a week. Then try extending this for a longer period of time. Instead, read uplifting books and watch positive programs.
2. Associate with calm people.
3. Practice forgiveness and understanding, starting with your self.
4. Release any grudges. Rectify any existing relationship problems.
5. Appreciate nature. Slow down and smell the roses.
6. Tell yourself you love and appreciate yourself. Learn to mean it. If you can't, get help understanding why.

7. Tell others you love them.
8. Find a purpose in life. Volunteer. Do something good for others.
9. Practice saying positive affirmations daily.
10. Make a list every day of ten things you are truly grateful for in your life.
Acknowledge the negative but focus on the positive.

Sources:

1. Love, Medicine and Miracles: Lessons Learned about Self-Healing from a Surgeon's Experience with Exceptional Patients, Bernie S. Siegel, Harper Paperbacks; Reissue edition (June 6, 1990)
2. Smart Medicine for a Healthy Prostate - Natural and Conventional Therapies, Mark W. McClure, M.D., (NY: Avery Publishing Group, 2001)

FINDING SUPPORT FOR YOU

Peer support, either in-person self-help chapters or online discussion communities, can help patients and their loved ones offer and receive helpful advice and tips on how to get through treatment, recovery, and ongoing issues. A supportive group of people provide a forum for patients and their families to share stories, ask questions, and share the emotions of this challenging experience.

Benefits of participating in a peer-to-peer self-help program include:

- Preventing isolation
- Sharing experiences and exchanging information
- Lending and receiving support, encouragement, and hope
- Enhancing self-esteem
- Providing a cost-effective method of aiding cancer treatment.

Besides the immediate emotional benefits of self-help chapters or online communities, studies have shown that patients and loved ones who participate tend to live longer than those who do not.

Looking for an Us TOO peer-to-peer self-help chapter in your areas or an online discussion group?

- Visit the Us TOO website at www.ustoo.org.
- You may also contact Us TOO headquarters at 1-800-80-US TOO (800-808-7866) - in the Chicago area (630) 795-1002 - 9am - 4:30pm CT.
- Find online discussion & support: www.ustoo.org/Prostate_Pointers.asp