

# Friends-for-life

A Research Study For Men with Prostate Cancer

Support Partner Training Manual

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# Training Protocol

The purpose of the training session is to explain the goals of the study and the protocols to meet 8 times during 60 days. Long-term survivor participants will learn how to become support partners through discussion and role-play. Signs and symptoms of a major depressive episode will be presented and discussion will include when and how to notify the Principal Investigator. The scope of the study (sharing thoughts, feelings, and emotions) will be reinforced. Hence, when asked about medical advice (e.g., “what would you do in this situation?”), support partners will be directed to address this type of concern by assisting subjects to write down their questions to be asked of their physician so not forgotten during the next medical appointment. The Principal Investigator, Dr. Weber, will carry out the training of support partners. The content will be organized according to purpose, skills required, topics of discussion and ending the research study relationship.

## Training Session Objectives

1. Delineate the responsibilities of the support partner’s role in the dyadic intervention study.
2. Delineate past experiences related to radical prostatectomy and diagnosis of prostate cancer.
3. Integrate situations from past experiences related to prostate cancer and prostatectomy into the dyadic intervention with men with recent radical prostatectomy.

## Teaching Format

Lecture, discussion, and role-play will be used to talk about the purpose of the study, common experiences for the man with prostate cancer after radical prostatectomy, and to illustrate strategies for effective communication.

## Skills

### Active Listening

The Investigator will talk about effective listening skills and how important they are to the success of the intervention. Discussion will then be directed by the section in the training pamphlet “Friends, Romans, Countrymen, lend me your ears....” The group will talk about verbal as well as non-verbal queues. What is left unsaid is often as important as what is said. Role-play will be used to develop these skills. Two such scenarios are included.

Effective listening is both attentive as well as reflective. Accepting others for who they are is mirrored in the manner they are approached. Physical components to active listening include face-to-face interaction, open posture, direct eye contact, remaining relaxed, and creating a relaxed environment. Emphasizing what has been said through reflective paraphrasing and focusing on a goal directed conversation that validates a genuine interest in others and what they have to say. The following two scenarios will be use to illustrate features of active listening skills.

### Role Play Scenarios

Scenario #1 - During the first scenario, the long-term survivor participants will be divided into pairs. One member from each pair will be instructed to talk for 10 minutes about an important event that occurred in his life. The other member of the pairs will be instructed to be inattentive, interrupt the conversation, act bored, and not to make eye contact with his partner. When the time has lapsed, the men sharing their important event will be asked, “What

happened?” and “how did you feel?”. The exercise will be repeated with the partners switching roles. Those who were telling their stories would now listen with undivided attention, face the storyteller, make eye contact, and take an interest in what is being said. When the 10 minutes has lapsed, once again the storyteller will be asked to explain what the experience felt like.

Scenario #2 - During this exercise, the long-term survivor participants will be paired with one man talking about his favorite hobby. The partner will be instructed to listen attentively as described above. The listener will be instructed to paraphrase what the storyteller has said. When the 10-minute time has lapsed, the storyteller will be asked about the accuracy of the paraphrase version of the story.

After the role-play, long-term survivors will practice recording their reactions in a log.

### **Topics for Discussion**

Protocols - The study requires the partners to meet eight times over a sixty-day period. Once a week may be a convenient time interval. Strategies the long-term survivors can use in setting up meetings will be discussed. In the event a dyad is unable to meet as planned, the long-term survivors will be instructed to contact the Investigator. Events that may interfere with meetings will be discussed (include inclement weather, doctor appointments, and personal obligations).

Conversation (See Appendix \*\*\* for a copy of the pamphlet) - During the dyadic meetings, certain topics maybe but are important to others that have been diagnosed with prostate cancer. Possible topics to consider will be discussed. One topic that may be difficult to discuss is erectile dysfunction. Role-play will be used so the long-term survivors can discuss how they would handle this sensitive issue. The thoughts, experiences, and feelings about prostate cancer and treatment will be elicited and role-play will be used to assist the long-term survivors in responding to these. The long-term survivors will also practice summarizing these in a log. It is important that the discussion along with the duration of each meeting, thoughts, feelings, and emotions are described in the log so the topic can be evaluated for inclusion in future research studies.

Intimacy vs. Sexuality - Discussion about sexuality will begin with the information in the training pamphlet about “No Shirt, No Shoes, No Service or When all Else Fails, Read the Directions.” Intimacy, orgasm, how lovers perceive men after radical prostatectomy may be a difficult issue to talk about but are central concerns to these men. When prostatectomy results in erectile dysfunction, some men shift their relationship with their wife from one that focused on sexuality to one that focuses on intimacy. Role-play will be used along with discussion to identify characteristics necessary for an intimate relationship and how the long-term survivors will talk about the topic with subjects.

Incontinence will be addressed in a similar manner as Intimacy and Sexuality. The section of the training pamphlet about “Where have all the bathrooms gone?” or “Void where prohibited” will be the starting point to the discussion. Role-play will be used to highlight possible ways to talk about these sensitive but necessary topics. After role-play, the long-term survivors will practice recording in the logs.

Untoward Reactions - During the intervention, subjects may begin to have feelings that are emotionally overwhelming. These feelings can be both positive as well as negative. Positive feelings are those that bring about a sense of relief and peace of mind from the dyadic relationship. The definition of clinical depression by the American Psychiatric Association will be used as the guidelines for this study for negative feelings. They include suicidal ideation, ongoing inability to sleep or always sleeping, extended grief, raging anger, and inability to sit still and carry on conversation.<sup>1</sup> Discussion will include the importance of understanding that emotional reactions are not necessarily directed at the long-term survivors but rather in response to situations. Role-play will be used to produce situations where clinical depression symptoms are present. These negative feelings are more than can be relieved by the support of a good friend, and long-term survivors are to contact the Investigator without delay, so subject's can be referred to their physician for professional counseling. After having a chance to record their reactions in logs, the long-term survivors will discuss the role-play events as they unfolded. This will enable the long-term survivors to discuss untoward reactions and to discover if they correctly identified them in the log. Discussion will include reporting the events to the Investigator both in the log and by telephone.

### **Ending the Research Study Relationship**

Discussion about how to end the dyads will be started by introducing the training pamphlet section "I never say goodbye." Long-term survivors will be encouraged to talk about the feelings they might expect associated with ending a meaningful relationship. While it is not the intent of this study to encourage the men to stay in touch with each other after the intervention period, that is their decision and recording that desire will be included in the log.

### **Reference**

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-IV. 4th ed. Washington, DC: R.R. Donnelley & Sons Company, 1994.

## Support Partner Training Pamphlet Possible Topics of Discussion

The purpose of this research study is to determine the effects of two men, who have endured a common experience (radical prostatectomy), sharing their thoughts, feelings and emotions. Since each dyad is expected to share a unique experience, you may talk about other topics that are equally important to those that appear here. However, the list below is divided into topic areas that others have described as important.

### **“Friends, Romans, Countrymen, lend me your ears....”**

Something to keep in mind during the dyadic meetings... remember how you felt when you were first diagnosed? Were there times when you just wanted to talk and have someone listen, someone who understood what you were going through and knew what you were feeling? Active listening is just as important as talking sometimes, but you have to be the judge of what is right with your partner.

To begin, session one is a time to get acquainted with each other. This will most likely be the most awkward of all the meetings, it is a time of discovery that “I’m not alone, others have the same fears and concerns as I do.” That is why this session is titled:

### **“Getting by with a little help from my friends”**

- Introductions
- Share commonalities including hobbies and interests. Prostate cancer is not the only thing you have in common.
- Signs and symptoms - how did you first know something was wrong? How did it make you feel?
- Share your concerns (other men that have been in the same situation have said they felt...)
  - loss of control
  - fear of my own mortality
  - I’m not the man I used to be
- Set up a time to meet again

Session two may be a time when you remember back to the decisions that had to be made about treatment options. You may have felt that this was a time of confusion and perhaps anger and “I feel like I am the only one that ever had to make this decision.” The title of session two is:

### **“I’d rather be in Philadelphia”**

- Treatment Decisions
  - The choices I have made. Was I right?
  - Share how to handle the side effects.

- What did you think about? Was there any confusion?
- Set a time to meet again

In session three, information about treatment and side effects that accompany the treatment may be occurring. Perhaps you remember worrying about your “manhood”, sexuality, impotence and intimacy at this point. How will spousal partner look at me? Session three has two titles that may be an indication of the concerns and feelings at this point.

**“No Shirt, No Shoes, No Service”**

*or*

**“When all else fails, read the directions”**

This may be a difficult subject to start talking about, however, it has been described by others that have gone through the prostate cancer experience.

- Sexuality vs intimacy - What is it like to talk about what you are feeling with your spouse?
- Will I be able to achieve an erection?
- Is orgasm still possible?
- What will my lover think of me?
- Set a time to meet again

Perhaps the side effects are beginning to happen or there is concern about the possibility of side effects starting, like incontinence. Others have reported concerns to be, “How can I travel away from home for fear of needing a bathroom? Session four is titled:

**“Where have all the bathrooms gone?”**

*or*

**“Void where prohibited”**

- Urinary difficulties
  - What is it like and how did I feel after using the bathroom and there was leakage?
  - How does it feel to have to use absorbent material in my underwear?
  - Should I worry when traveling “will I soil the bed?”
  - What kind of life is this?
- Set a time to meet again

While thoughts and feelings may occur for each person in a different order, session four may be the time to talk about the emotions that accompany the social aspect of having a diagnosis of and being treated for prostate cancer. Perhaps at first diagnosis, my friends and family initially rallied to my side only to now return to other responsibilities in life. Others have had family and friends offer advice when not requested. Meeting number four is called:

**“With friends like these, who needs enemas?”**

- Social Support
  - Why doesn't anyone understand what I am going through?
  - I feel like I am a burden.
  - Don't they know I have cancer!?
- Set a time to meet again

Session five may be the time to talk about the down feelings other men with prostate cancer have described. With the possibility that it may be easy to become sedentary and feel like the world is caving-in, meeting five is called:

**“Moss never grows on a rolling stone”**

- Depression
  - What keeps me going?
  - Why me?
- Set a time to meet again

Thinking back, was there a time that you thought to yourself that you did not “have it in you” to win this battle with prostate cancer? Believing in you is more than half the battle. Seeing the accomplishments of others may help men not unlike you believe that they too can survive and return to successful aging. Session six may be the time to stop thinking:

**“Better you than me....”**

- What made you think “I can beat this disease.”
- Set a time to meet again

Is there life after a diagnosis of prostate cancer? Is there quality to that life? Session seven may address the fears of what will my life be like after prostate cancer?

**“Life, Liberty, and the Pursuit of Happiness”**

What do these things mean to me?

- Life Satisfaction
- Quality of Life
- Emotional well-being
- Successful aging

Session eight wraps things up. You may have found a new friend, or you may not. What is important is that you may have helped another man not unlike yourself by sharing your feelings and emotions that only you were capable of doing. Having gone through the experience of prostate cancer, only you have had that experience. If you decide, certainly stay in touch with your dyadic partner. You have shared some very intimate thoughts with each other.

**“I never say Goodbye”**

**Thank you for participating in this study. The information you have provided will help others diagnosed with prostate cancer, like you, in the future.**

## II. Support partner inclusion/exclusion criteria

1) I was diagnosed with prostate cancer in 2000 or before

Yes  No

2) I have signed a release of medical information so Dr. Weber can obtain my PSA levels for the past year

Yes  No

3) I am 50 years old or older

Yes  No

4) I want to participate

Yes  No

EXAMPLE

## I. Introduction

Bryan Weber is an assistant professor, who lives in Gainesville and works as a researcher for the University of Florida College of Nursing and The Institute on Aging. His area of nursing research is aimed at improving the quality of life for men diagnosed with prostate cancer. The present study is being conducted with men in the North Central Florida area who have been recently diagnosed with prostate cancer and who have had a radical prostatectomy. This group of men was selected since they have to cope with cancer and the side effects of treatment that include incontinence and erectile dysfunction.

The purpose of this research study is to test an intervention that will provide support and improve a man's personal beliefs of his capabilities to survive prostate cancer and deal with the side effects of treatment. The information received from this study will assist health care professionals to know more about the needs of men with prostate cancer and how health care can be tailored to a man's specific needs while improving his quality of life.

### III. Objectives and Definition

#### Definition

Dyad -

Pair-wise matching (treatment and race) and time-limited interactions (60 days) of two strangers who share a common “lived experience.” (prostate cancer). The relationship is expected to generate behaviors that pre-existing relationships would not produce or satisfy, thereby producing a synergistic effect unique to the dyad. The relationship is entered voluntarily.

Synergy -

Working together for a combined action.

#### Objectives

1. Responsibilities
  - a. meet 8 times during 60 days
  - b. refrain from referring subjects to support groups during the study period
  - c. complete a dyadic log after each meeting
  - d. know the signs and symptoms of depression and report any suspect behaviors to Dr. Weber
  - e. know how to contact Dr. Weber
2. I will be able to present personal experiences related to prostate cancer and radical prostatectomy during the training session
3. I will be able to come up with ideas and suggestions of how personal experiences can be shared with other men who are recently diagnosed with prostate cancer.

## IV. What do I need to know as a Support Partner?

### Active Listening

Effective listening skills are important to the success of this intervention. Sometimes it is what is not said that is important. Silence is often uncomfortable but provides your partner with time to think about an answer to a question. It also provides time to think about how to ask a question. Some important things to remember are face-to-face interaction, open posture, direct eye contact, remaining relaxed, and creating a relaxed environment. Emphasizing what has been said through restating and focusing on your partner's conversation makes him aware that you have a genuine interest in what he has to say.

### Role Play Scenarios

Scenario #1 - During the first scenario, the long-term survivor participants will be divided into pairs. One member from each pair will be instructed to talk for 10 minutes about an important event that occurred in his life. The other member of the pairs will be instructed to be inattentive, interrupt the conversation, act bored, and not to make eye contact with his partner. When the time has elapsed, the men sharing their important event will be asked, "What happened?" and "How did they feel?" The exercise will be repeated with the partners switching roles. Those who were telling their stories will now listen with undivided attention, face the storyteller, make eye contact, and take an interest in what is being said. When the 10 minutes has elapsed, once again the storyteller will be asked to explain what the experience felt like.

Scenario #2 - During this exercise, the long-term survivor participants will again be divided into pairs, One member from each pair will talk about his favorite

hobby. The partner will be instructed to listen attentively as described above. The listener will be instructed to paraphrase what the storyteller has said. When the 10-minute time has elapsed, the storyteller will be asked about the accuracy of the paraphrased version of the story.

Practice recording your reactions in a log.

Topics of Discussion

## V. Protocols

1. What is Confidentiality?
2. How often should I meet with each man I am paired?
3. What should we do if my partner and I are not able to meet face-to-face?
4. Where can I get more gift certificates?
5. When should I complete the dyadic log?
6. What are some signs and symptoms of depression?
7. How can I contact Dr. Weber?
8. What will I talk about with my partner?

## *Important facts*

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1. According to the American Cancer Society, more than 198,000 men will be diagnosed with prostate cancer this year. That means that every 3 minutes a man will be diagnosed with prostate cancer. He will have to deal with the emotional consequences of the disease and its treatment.
2. Women outnumber men at cancer support groups, 3 to 1.
3. Only 13% of men, who have a need for a support group, attend one.

**FRIENDS-FOR-LIFE IS AN INNOVATIVE ALTERNATIVE TO SUPPORT GROUPS.**

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Support groups are effective at meeting the psychological reaction to the diagnosis and treatment side effects of cancer. But if men don't participate in groups, they do not benefit from the group experience.

Alternative strategies need to be developed that will meet the emotional needs of those men who need support as they deal with the consequences of prostate cancer and its treatment.

**Friends-for-Life** is a research study testing the effects of one-to-one support that may be a more acceptable means of support for men who have prostate cancer when compared to support groups.

## **FRIENDS-FOR-LIFE**

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## **A RESEARCH STUDY FOR MEN WITH PROSTATE CANCER**

**Bryan A. Weber, RN, PhD**

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PO Box 100197, HSC  
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(352) 392-3371

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Funding provided by:

The National Institutes of Health

The National Cancer Institute



**UNIVERSITY OF  
FLORIDA**

## WHAT IS THE STUDY ABOUT?

1. The purpose of the study is to test an innovative intervention designed to improve the lives of men who have prostate cancer.
2. Study participants will be randomly assigned to either a control group or an intervention group. Those in the control group will receive usual and customary care only. Those in the intervention group will receive usual and customary care and will be paired with another man (support partner) who was diagnosed with prostate cancer 3 or more years ago.
3. Those randomly assigned to the intervention group will meet 8 times during 8 weeks one-to-one with their partner to discuss the feelings and concerns that are unique to having prostate cancer.
4. Study participants will be asked to answer questionnaires at the beginning, half way through and at the end of the 60-day study period. The questions will be about the support received from others, feelings about various areas of life, and matters that concern quality of life.

### WHO IS CONDUCTING THE STUDY?

Bryan Weber, PhD, RN, is the Principal Investigator of the study. Dr. Weber is an Assistant Professor in the Department of Adult and Elderly Nursing in the College of Nursing at the University of Florida.

### DOES MY DOCTOR KNOW ABOUT THE STUDY?

Yes. Your physician has given Dr. Weber permission to contact the men in his/her practice to ask if you want to participate in the study.

### WHAT WILL THE STUDY COST ME?

Nothing. In fact, you will be paid for your time and effort.

### HOW MUCH TIME IS INVOLVED?

All study participants will be asked to answer questions over the telephone. These telephone calls will take approximately 40-minutes each. If you are randomly assigned to the control group, you will be paid \$5 for each telephone call. If you are randomly assigned to the intervention group, you will also be asked to meet 8 times during 8 weeks with your support partner. The meetings will take place at a location convenient to you like Starbucks Coffee or another place with a relaxed atmosphere where you can sit and talk. The amount of time you spend talking is completely up to you, and *the coffee is on us!*

If you are randomly assigned to the control group, you will be asked to spend

approximately 40 minutes answering a questionnaire 3 times during the study (beginning, after 4 weeks, and after 8 weeks). The questionnaire will be asked over the telephone. You will be paid \$5.00 for completing each of the questionnaires.

### WHAT ARE THE BENEFITS OF PARTICIPATING?

We are not sure about the benefit of participating that is why we are doing the study. Whether you are in the control group or the intervention group, the information you give us is important.

The results of the study will provide health care professionals important information about caring for men with prostate cancer.

### WHAT HAPPENS IF I WANT TO STOP THE STUDY?

Nothing. You are free to stop at any time, and that decision will not affect the care you now receive.

### WHAT IF I HAVE MORE QUESTIONS BEFORE DECIDING TO PARTICIPATE?

Call Bryan Weber, PhD, RN at (352) 392-3371 at the College of Nursing at the University of Florida. Dr. Weber will be glad to answer all of your questions before you make your decision.

### HOW DO I SIGN UP?

Call Bryan Weber, RN, PhD at (352) 392-3371 at the College of Nursing at the University of Florida.

Friends-for-Life  
Support Partner Training Session  
July 26, 1999  
March 6, 2000  
May 11, 2000  
December 2001

**Criteria for Identifying Depression** (DSM-IV)

1. Depressed mood most of the day, nearly every day, as indicated by either subjective report (person says they feel sad or empty) or by observation by others (person is tearful).
2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly everyday (either stated by the person or observed by others).
3. Significant weight loss when not dieting or weight gains, or decreases or increases in appetite nearly every day.
4. Insomnia or hypersomnia nearly every day.
5. Physical agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy nearly every day.
7. Feelings of worthlessness or excessive or inappropriate guilt nearly every day.
8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

# Friends-for-Life

Your Name \_\_\_\_\_

Subject ID number (to be filled in by Dr. Weber) \_\_\_\_\_

## Dyadic Intervention Log

At the conclusion of each meeting with your dyadic partner, please record the following information in the space below.

1. When did you meet (date)? \_\_\_\_\_

2. How long did you meet (hours)? \_\_\_\_\_

3. Did you notice any signs or symptoms of severe clinical depression in you partner? They include his talking about hurting or killing himself, not being able to sleep or sleeping all the time, uncontrollable anger, uncontrollable crying, and not being able to sit still and carry on a conversation. If you notice or suspect any of these or have any other concerns, be sure to record them here and call Dr. Weber **immediately** at **352-222-0359 (cell phone), 352-392-3371/ 265-0680 Ext. 86999 (office), 352-376-3210 (home), or page him at 352-374-0133.**

Yes \_\_\_\_\_

I suspect my partner has these symptoms based on the following information

No \_\_\_\_\_

My partner does not have any of these symptoms and I do not suspect any other problems.

4. What did you talk about? You may use another sheet of paper if needed.



# UNIVERSITY OF FLORIDA

\_\_\_\_\_  
(Date)

Dear Doctor \_\_\_\_\_

I am participating in a research study at the University of Florida. Medical record information is needed for data analysis. Please furnish the researcher with my 3 most recent Prostate Specific Antigen (PSA) levels.

Thank you.

\_\_\_\_\_  
(Patient name & medical record number)

\_\_\_\_\_  
(Patient Signature)

\_\_\_\_\_  
(Street Address)

\_\_\_\_\_  
(City, State, Zip)

\_\_\_\_\_  
(Date of Birth)

Please mail the requested information to:

Bryan Weber, ARNP, PhD  
University of Florida  
PO Box 100197  
Gainesville, Florida 32610-0197

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