

**Life After Cancer:
A Manual for Psychotherapy Groups
for Women who have Experienced Gynecological Cancer**



Nature's beauty, not just her functioning organs,
is the essence of sexuality...
if you want to know what sex is,
think long and hard about a flower,
especially its beauty and its appeal to the senses.
Then think about all of nature
and your own place in it.
Whatever makes a flower glow with enchantment
is the essence of your own sexuality.
--Thomas Moore

Phillipa Ann Redlich Caldwell, M.A.

Rebecca Skye Caldwell, Ph.D.

Mary Ann Aposhian, Ph.D.

Stanford University

For more information: Rebecca@caldwellphd.com

This manual serves as a guide for health care professionals who plan to facilitate support groups for women who have experienced gynecological cancer. The primary intention of the support group is to provide these women with an opportunity to share their experiences and to voice their concerns within a compassionate and supportive environment. The group provides a forum in which the women can feel free to discuss issues such as communication with partners, friends, and family members, feelings of loss or isolation, and/or the desire to feel effective and productive in life. It is a place for them to bring their concerns about coping with the changes in body shape and with the residual effects of chemotherapy and radiation on their desire to be intimate and to participate in things that they find enjoyable. For some the physical changes are minimal. However, diagnosis of gynecological cancer is potentially detrimental to a women's inner concept of self. These groups are an opportunity to honor their transformed bodies and minds after experiencing the changes associated with having had cancer. Ideally, the group intervention provides these women with opportunities to mourn their old sexual identities and to create new ones. As facilitator, your goal is to create an environment in which they can re-identify with their sexuality after experiencing traumatic stresses associated with having had cancer.

The support group intervention outlined in this manual was used in a pilot study at Stanford in the Department of Psychiatry. The results of the study suggested that this group intervention achieved its main objective to treat sexual dysfunction as well as mood disturbance. This outcome article by Caldwell, Classen, Lagana', McGarvey, Baum, Duenke, & Koopman is entitled "Changes in sexual functioning and mood among women treated for gynecological cancer who receive group therapy: A pilot study." It will be published in Journal of Clinical Psychology in Medical Settings in the November 2003 issue.

The purpose, the fundamental components, and the specific interventions of this support group are outlined in the following pages. If you would be interested running a group in the future, it is our hope that this information will provide you with some insight.

Purpose of the group:

- ❖ **Create supportive atmosphere where women would feel comfortable to be vulnerable and share information and to help one another.**
- ❖ **To re-introduce sexuality into the women's lives**
 - ❖ To allow them to become comfortable with their bodies after cancer
 - ❖ To introduce ways of enhancing their sexual function now including education about such aids as lubricants, stages of recovery and ability to have sex, the influence of the mind on sex-imagery etc.
 - ❖ To mourn the loss of the old body image
 - ❖ To consider cultural and personal issues that have influenced their sexuality and that may now be inhibiting their current abilities to become sexual. (Guilt over an abortion, “women shouldn’t be interested in sex after menopause,” “women don’t have sexual needs”)

Fundamental Components of Group Intervention:

The group process includes the four components:

- (1) bonding of group members**
- (2) expression of emotions**
- (3) experiencing of a variety of pleasurable activities**
- (4) exploration of sexual scripts learned from their cultural backgrounds and from their personal childhood experiences in their family of origin**

While the components one and two are present in most support group interventions for women who are living with a cancer diagnosis, components three and four are unique to this intervention. The premise of the *third* element is based on the philosophy articulated by Masters and Johnson (1966) that an essential prerequisite for sexual activity is an ability to seek and tolerate pleasure. The women in the group are asked to pursue activities that they find enjoyable. The choices of pleasurable activities includes such activities as attending music concerts and taking bubble baths. Women are encouraged to note any resistance to doing something pleasurable for themselves and to describe any feelings they had during the experience. This is a difficult exercise for most of the women. It brings up issues of self worth. The thought of

pursuing pleasurable activities reminds them of the pain and the discomfort they have been experiencing. This exercise illuminates some of the issues that may be inhibiting them from fully living their lives. This neutral exercise proved to be empowering for the women who were willing to do it and observe themselves in the process.

A *fourth* component of the group therapy intervention is to explore the women's sexual scripts learned from their cultural backgrounds and from their personal childhood experiences in their family of origin. They are asked to consider how they conceptualized sexuality and themselves as women. This gives the women opportunities to identify and reconsider psychological barriers to experiencing their sexuality more fully. The group intervention encourages women to share old sexual beliefs, prejudices, and fears that have reemerged in response to their cancer diagnosis and treatment. By exploring these historical influences as a group, women find opportunities to help one another. For example, one woman's story of an early abortion helped another participant to process the grief and guilt of her own experience of childlessness and to consider the possibility of adoption. These *four components* are designed to create an opportunity for the women to rebuild a new sexual identity that is inclusive of their experience of gynecological cancer.

The norms of the group intervention encourage women to openly discuss their pain and suffering associated with their recent experiences with cancer and sexuality. The efforts to help women to feel comfortable expressing their feelings about losses of areas of the body and of sexual functioning are accompanied by discussions of mortality and life priorities as well. The expression of anger and negative emotions appear to be helpful to women in creating new perspectives and skills supporting their sexual functioning.

Specific Interventions:

1. Welcome Feminine Sexuality into the Room

- **Create a setting for an intimate group.**
 - This includes arranging the chairs for the group in an intimate circle, consideration of lighting, noise, and interruptions.
 - Bring fresh flowers, one rose, or other emblems of a feminine nature (a beautiful shell). Place these on a table beside the circle.
- **Begin with a meditation to relax and center the group.**

- These groups bond and will gossip and talk as they enter. Indicate that the group is now beginning with the meditation.
- Include imagery about pleasure, sensuality, enjoyment of nature and life.
- **Present a homework exercise during the first group: Ask each of the women to do something for herself—to pleasure herself in any way that she would enjoy.**
 - This activity (or purchase) must be for her alone to enjoy, not for the benefit of her family or friends or mate or to accommodate a rule or custom (e.g., to buy flowers for herself -- not because company is coming over, to take a bath with candles and bubbles for fun -- not to relax to have sex for her husband's needs, or to purchase a symphony or a dance performance of her choice). The point of this exercise is to enjoy herself and to feel good about that.
 - Throughout the groups, ask how this was for the women. There is much resistance to this task. Some take quite a few weeks to do it.
- **To re-awaken women's sexuality, reawaken and introduce *sensuality*.**
 - See Jean Shinoda Bolen's book, *The Goddess in Every Woman*. See Venus's realm and place in women's lives. This is the doorway back into sexuality for many women—feeling attractive -- alive in their bodies after having decorated themselves or having a pleasurable experience (bath, massage). This is the gateway or threshold which the women have a hard time crossing. Many feel worthless because of the ways they have been treated or due to the maiming surgery. Re-awaken this sense of femininity and pleasure and aliveness.
 - **Talk about how women have been sensual or sexual in the past, how they are doing it now, or what their fantasies of this might be. When someone has an example, amplify it.** Talk about what it was like to go to the nudist camp, flirt with the grocery clerk, take a bath with candles, wear leopard, have an affair etc. Ask women to share instances of this happening now no matter how small. Wearing a new pair of ear rings and meeting a man's gaze is a big step here.
- **Mirror achievements, show delight, share excitement and model acceptance.** No *shoulds* here please. Attitudes to model: “be kind and caring to oneself, patient with progress, and curious about what new development may happen”. Model an attitude of pleasure in life and sexuality.

Discussion the subject of sex and pleasure will bring up thoughts of former suffering and fears of death. To address these, see below.

2. Mourning the loss of the old body image

- **Allow digressions into the anger. Many women feel betrayed by doctors, boyfriends, and family.** This is part of the mourning process. When they can express these feelings, they will be able to express joy and sex as well. Passion has many faces.
- **Explore the way sex was before.** How free or restricted did the women feel? What were some good sexual experiences. This type of sharing gets sex into the room; it also is a way for women to begin sharing sexual information. Women do not usually share this socially.
- **Allow feelings of loss** about reduced sexual drive, capacity to have kids, fears of not living to be a grandmother, fears of never having a partner again, never feeling like a woman again.
- **Explore sexual, gynecological histories**—This was extremely important for one woman who had had an abortion just before getting cancer. There was guilt and anger about this as she had felt forced by her husband to get the abortion. They had only been married a short time. Group members can share their *experiences to normalize old sexual wounds, guilt, and misconceptions*. In this case, another group member had had the same experience and had worked through it by adopting a child. The impact of this type of sharing and modeling is at the core of this group's ability to help these women. The woman completely changed her life after hearing the adaptive story and left her cancer (which had occurred 10 years before) behind her to create a new life.

3. Interventions to develop a new Sexual Self

- **Educate about lubricants and stages of recovery. Do not assume that either of these topics have been addressed by doctors who have treated these women.** Women need real information and facts. Bring pictures of the insides of our bodies. One woman could not picture how sex could occur with stitches in her vagina. The lining of the vagina takes time to thicken after chemo. Women become frightened after having one bad sexual experience. As a therapist, network with women who have had cancer to find out the latest lubricants and ask doctors for facts. Docs don't talk enough to patients about this.

- **Sex is in the mind!** Educate about the use of tools for excitement such as imagery, readings from books, D H Lawrence *Lady Chatterly's Lover*, is good acceptable one for a beginning. Ask women to find passages they like. Films also excite us. Talk about this and explore the mental components of sex.
- **Challenge preconceptions that a sexual self is no longer possible.** Allow group members to show one another how it would be possible. Challenge negative perceptions very gently and with curiosity. “Is that really true? I wonder if that is so?”
- **Ask for examples of how women have found to pleasure themselves *with or without a partner*;** and, *with or without* vaginal sex.
- **Introduce sexual ideas from other cultures** that are not so focused on the sexual organs— Talk about an article from a French magazine about the beauty of a woman’s back. In Japan, the neck is a sexual area. Any area (feet, hands) can be sexual. Just talking about sexuality in this way can help women re-evaluate their sexual potential and begin to value their whole bodies as sexual and become interested in this subject.

4. Interventions to create a Supportive group

- **Maintain a safe atmosphere.** Intervene if members attack one another or become too intrusive. Your principal job is to keep them coming to group for 12 weeks to talk a little about sex each week and see if that re-wakens their interest in it. Keep this group safe and welcoming. Build trust so they can be vulnerable.
- **Be empathic internally as well as externally:**
 - *Matching* is a technique of going to a place within yourself that contains the same emotion as the group member is exhibiting. Feelings of betrayal, abandonment, or loss are human emotions that we all share. This is an unspoken intervention.
 - Model acceptance, tolerance by verbally mirroring each group member’s expressions and concerns.
- **Deflect attention from yourself** to give group members a chance to help one another. Guide but share the position of expert with other members. Discourage transference and encourage camaraderie.
- **Guide the group,** allowing some divergence will enable the group members to bond. If a topic is pressing for a member, she may need to express it to the group in order to bond. If a

quiet member finally speaks up, listen even if it seems off topic. It may be her way in to join the group. This is tricky. Watch for intensity of emotional expression. Remember passion has many faces.

- **Sense the temperature of the group.** Intervene before the group does if a member is too far off track or speaking for too long. There is a big difference between distracting the group and really working.
- Remind the group of its purpose. Make a process comment noting the amount of time the group has spent with the specific topic. Check in with the group to confirm their intended focus.

Countertransference Issues:

- **Have fun.** This is a wonderful group: intimate, ready to move, ready to bond. Don't be afraid of this group. It will touch you deeply and you will get more than you give.
- **Most therapists are afraid to talk about sex with women who were facing death. This fear is not valid.** This group provides a great forum for the women to mourn the past and enjoy the present. By making the group about sex, you (1) put them in a position where they want to talk about past pain and process it (to avoid the work on sex and also break the rules) and (2) you also give them a way out of the pain by helping them to develop a new relationship with their aliveness and feminine sexuality.

Reintroducing Sexuality into the Women's Lives: Group Syllabus for Women who have Experienced Gynecological Cancer

❖ First Session

- *Principle: Building Bonds & Hope: A Sense of Belonging*
 - Informed Consent, Confidentiality
 - Introductions: What brought you to this group called, "Sexuality & Women with Gynecological Cancer," and what do you hope to get out of it?
 - Phone numbers

Patients' Homework: Call 2 people from the group and try to connect.

Therapists' Homework: Sexual Scripting

Goal—To begin to help draw connections for people concerning sexuality, emotions, family, friends, body image, spirituality, and physical limitations.

❖ Second Session

- *Principle: Expressing Emotions*
 - Discussion about feelings of cancer survival are brought to the surface, such as: anger, frustration, fear, survivor's guilt, anxiety, sadness, and happiness.

Homework: Continue to call people. Try to give yourself two pleasurable elements each day and notice your feelings surrounding the pleasure. Pleasurable examples can include the sensual (taking a long bath, getting a massage, rubbing warm oil on body, eating a cookie, lying in the sun, or giving yourself a manicure/pedicure) and the abstract (going to a museum, arranging flowers, lighting a candle). If possible, try to pick one abstract pleasure and one sensual pleasure together. For example, taking a both while candles are lit.

Goal—To begin to untangle the complex knots of survival, suffering from cancer, and sexual desire.

❖ Third Session

- *Principle: Detoxifying Dying and ReLiving Pleasure & Love, De-Emphasizing Survival for Survival's Sake*
 - Sexual Myths: the helpful and not helpful; spirituality and religion; visualizations & relaxation techniques
 - Erotic Experiences & Erotic Fantasy
 - Beginning of sexual techniques: sensate focus, start-stop, letting yourself be "superficial" after Cancer Survival

Homework: Continue to call people. Try one sex exercise, notice, and possibly write about your feelings. Written material will not have to be discussed or shown to anyone. Expect some emotionally uncomfortable feelings.

Goal—The goal is no goal during "sex" or pleasure and to begin to uncover feelings of loss, frustration, and fear.

❖ Fourth Session

- *Principle: Taking Time: Especially in feeling sensual & sexual pleasure; Sensate Focus*
 - Continuation of discussion of sex exercises and the difficult task of "superficial," "simple," or "sensual" pleasure after survival of intense life/death struggle.

Homework: Continue to connect with people. Try one more sex exercise, and try to notice feelings about it.

Goal—To continue to try to seek pleasure and sensuality and to notice feelings of survival's guilt/fear/rage.

❖ Fifth Session

- *Principle: Fortifying Families-- Insight into Sexual Inhibitions of Nuclear Families; Sexual Issues with Partner before/during/after cancer; Sexual Issues with Sex*
 - Sexual Scripting: cultural scenarios, interpersonal scripts, intrapsychic scripts

Homework: None

Goal—To begin to understand how layers or circles of culture/self/relationships and experience of cancer has affected sexuality.

❖ Sixth Session

- *Principle: Dealing with Doctors: What Your Doctor Didn't Tell You*
 - Information: replens, atrophy, fungal infections, hormonal panel, physical exercise, meditation & prayer; erotic exercises; rage

Homework: Try to do one exercise from the information list, and call someone from the group and talk about it.

Goal—To begin to feel a sense of control and new sexual identity.

❖ Seventh Session

- *Principle: Pleasure & Pain: Expecting pain and hoping for healing*
 - Discussion of pain (vaginal, abdominal, & emotional) and phantom feelings

Homework: None

Goal—To continue to allow physical, emotional, and spiritual pain in order to gain pleasure.

❖ Eighth Session

- *Principles: Compounding Factors in--Pleasure & Pain and Taking Time*
 - Discussion about avoidance, fear, abandonment, limitations, anxiety

Homework: Continue to try a sexual technique and/or erotic fantasy.

Goal—To continue to let pleasure back into your life.

❖ Ninth Session

- *Principles: Compounding Factors in Taking Time & Dealing with Doctors*
 - Discussion about feelings of: helplessness, anger, embarrassment, shame

Homework: Fantasize about getting mad at a doctor.

Goal—To allow feelings of assertion and aggression to surface; to begin to relax into pleasure.

❖ Tenth Session

- *Principles: Complex Patterns in Sexual Scripting: Combining Principles of Fortifying Families, ReLiving, & Taking Time*

- More discussion about circles of culture/interpersonal/intrapsychic/cancer.

Homework: Sexual Scripting.

Goal—To continue to allow sensuality & sexuality into your life.

❖ Eleventh Session

- *Principle: Detoxifying Dying; Pleasure & Pain*

- Discussion of termination of the group & emotional factors of abandonment, grief, fear, anger.

- Feedback of group members to one another.

Homework: Try to call two people from the group.

Goal—To reconnect with selves and others knowing group is ending.

❖ Twelfth Session

- *Principle: Building Bonds & Hope; Expressing Emotions*

- Continuation of feedback.

- Closure.

- Where to Now?

