



Trauma and Cancer

Erin Sullivan Wagner (she/her)

<https://www.youtube.com/watch?v=GA1NP2NcFMc>



Financial Disclosure:

Executive Director- After Cancer, Inc, (501c3 organization)

www.aftercancer.co

www.allofmeiowa.org



My Cancer Story and Timeline

The Diagnosis - January

Anal Cancer

Active Treatment - February-March

5 weeks – Radiation and Chemotherapy

Follow-up appt – May-June

Colo-Rectal Surgeon / Medical Oncology

Referrals – July to September

Radiation Oncology / Vulvar Disease / Gynecology

Pelvic Floor Therapy / Sexual Health Clinic



What Went Wrong and When

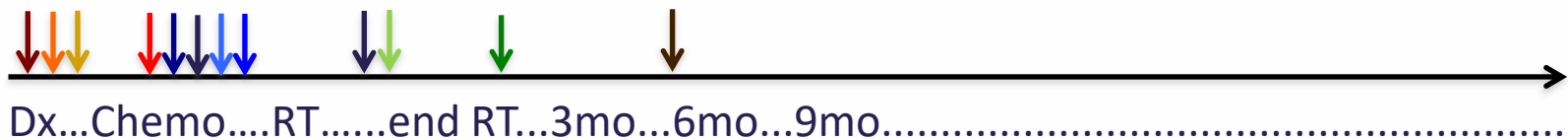


| | |
|---|---|
| <ul style="list-style-type: none">• Normalizing the conversation• Consent for treatment• Setting expectations• Refer to sex therapist, sexologist, or psychologist• Refer to physical therapist for ongoing dilator use support | <ul style="list-style-type: none">• Refer to gynecologist• Prescribe estrogen cream• Discuss systemic estrogen• Prescribe aqueous Lidocaine• Dilator instruction• Refer to gynecologist specializing in sexual health and cancer |
|---|---|

What happened to me:



What I wish had happened to me:



Cancer and its Side Effects

Cancer Treatments: Surgery - Radiation - Chemotherapy - Hormone

SIDE EFFECTS

| | |
|-----------------------|-----------------------|
| Nerve Damage | Infertility |
| Loss of Limb | Fatigue |
| Hormone Changes | Hair Loss |
| Pain | Peripheral Neuropathy |
| Weight Gain/Loss | Menopause Symptoms |
| Mucositis | Communication Issues |
| Lymphedema | Loss of Sex Organ |
| Urinary Incontinence | Gynecomastia |
| Erectile Dysfunction | Stenosis |
| Bowel Incontinence | Ostomy |
| Lymph Node Removal | Loss of Sensitivity |
| Pain with Ejaculation | Testicle Reduction |
| Decreased Stamina | Loss of Mobility |
| Loss of an Organ | Fibrosis |

QUALITY OF LIFE

Physical: Dysregulation of sexual cycle, restricted movement, ostomy, ED

Hormonal: Medications, chemotherapy

Psychological: Anxiety, depression, self-esteem, body image, gender perception

Relational: Communication, change in roles and expectations, sexual scripts

Social: Isolation, dependence

DECREASED DESIRE

ANXIETY RELATED TO CANCER
FATIGUE
CANCER RELATED STRESS
BODY IMAGE PROBLEMS
FEAR OF CANCER CONTAGIOUS/RECURRENCE
MEMORY AND CONCENTRATION PROBLEMS

UNSATISFYING ENCOUNTER

PARTNER ROLE/CHANGE CAREGIVING
PARTNER ROLE UNCERTAINTY
PARTNER FEAR OF HARMING
PARTNER STRESS
SEXUAL SCRIPT UNCERTAINTY
EXCESSIVE FOCUS ON
INTERCOURSE/ORGASM
UNRESOLVED RELATIONAL CONFLICT

DECREASED AROUSAL

DECREASED LUBRICATION
HORMONE CHANGE

DECREASED ORGASM

LOSS OF GENITAL SKIN SENSIVITY
GENITAL SKIN HYPERSENSITIVITY
PARTNER COMMUNICATION PROBLEMS
NUMBNESS
ANTIDEPRESSANT THERAPY EFFECT

SEXUAL DISORDERS and PAIN/PENETRATION DIFFICULTIES

PAINFUL SEX

NERVE DAMAGE
VULVOVAG ATROPHY
VAGINAL STENOSIS
INABILITY FOR PENETRATION
PAIN WITH GENITAL TOUCH
VULNERABILITY TO INFECTION
PELVIC FLOOR HYPERTONUS
VAGINISMUS

STIMULATION

DECREASED STAMINA
SKIN SENSITIVITY CHANGES
SEXUAL SCRIPT CHANGES
PARTNER SEXUAL DYSFUNCTION
PARTNER COMMUNICATION PROBLEMS

Adapted from Phillips. Am Fam Physician 2000;62(1):127-36
Designed by Dr. Sarah Shaffer, DO

www.aftercancer.co

www.allofmeiowa.org



After Cancer
Solutions for Sexual Health

Communication Gap

Providers

- Clinics overburdened/lack of time
- Lack of expertise, knowledge, and training
- Embarrassed for self or patient
- Assumptions- sexual orientation marital status, age, religion
- Patients are not alone/ privacy concerns
- Patients will request help if needed
- Sexual health side effects will be discussed by another provider
- Lack of a referral network
- Lack of support mandating care



Patients

- Focused on fighting the disease
- Terminology/explanation of the problem
- Sexual issues not seen as medical issues
- Embarrassed for self and provider
- Fear of being negatively judged
- Believe a care team member will bring it up if appropriate
- Unsure of who to speak to on care team
- Not sexually active/unaware of current changes
- “Perfect patient” syndrome



Implementation Framework Addressing Sexual Health

Normalize the Conversation / Set Patient Expectations / Refer timely

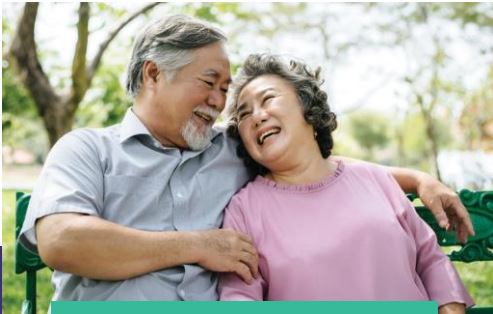
- **Workshops - 30-Second Patient Message**
- **Accredited Course- Sexual Health Specialist online course**
- **Library of Educational handouts for patients**
- **Provider Resources-**
 - Needs Assessment
 - Referral Roadmap- common referral specialties information to refer patients timely
 - Engaging LGBTQ+ People in Their Healthcare
 - Waiting area and exam room signage for patients
 - Access to “How to Become a Sexual Health Champion”- www.Allofmeiowa.org

Library of Educational Handouts

- Sexual Health and Cancer **Patient Brochure** (English/Spanish versions)
- **Hormonal and Non-Hormonal** Clinical Considerations
- Slide Into **Lubricants**
- The Miracle of **Pelvic Floor Therapy**
- Practical Suggestions for Tackling **Low Libido**
- **Anal Intimacy**
- Intimacy After an **Ostomy**
- **Fertility** Considerations After a Cancer Diagnosis
- Minimize and Treat **Androgen Deprivation Therapy**
- **Lymphedema**
- **Penile Rehab** Using a Vacuum Erection Device
- **Dating** During and After Cancer
- **Living Your Best Life** After Cancer
- **Adolescent and Young Adult (AYA)** Concerns
- **The Web** of Sexual Dysfunction
- Altered **Body Image**
- **Rewriting** Sexual Scripts
- For the **Partner** of the Patient
- **Sensate Focus** Exercises
- **Hot Flashes**

What you Need to Know

- It is common to experience side effects that impact your sexual functioning.
- Sexual health is important for quality of life for most people.
- You are not alone, and there are resources to help.
- Tell a member or your patient care team about any changes you experience.
- Though you may not care about this right now, we know early detection of sexual side effects will increase the likelihood of resolving any problems.



Resources

Sexual health care can involve many aspects of your well-being, including physical, mental, emotional, and spiritual health. Here are some resources and support to consider:

- Counseling
- Sex Therapy
- Social Work
- Physical Therapy
- Ostomy Care
- Gynecology
- Urology
- Support Groups

Scan Here for
More Information



After Cancer
Solutions for Sexual Health

YOUR SEXUAL HEALTH AND CANCER



Contact Us

Erin Sullivan Wagner



319.594.5933



“When they first told me I had cancer, sex was the last thing on my mind. But now I wonder, could getting help sooner have made a difference?”

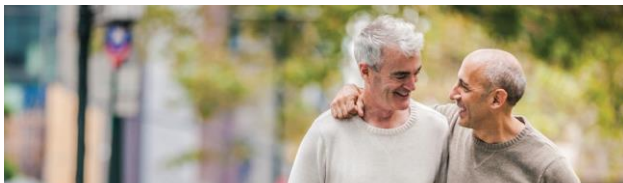


Intimacy -Physical Or Emotional

Do you know the difference and why it matters?

We may not all think of intimacy the same way, though we all want to feel an attachment or closeness to others. Physical intimacy is commonly referred to as sexual intimacy, while emotional intimacy is described to be something totally different... but is it?

Emotional intimacy is all about our emotional connection and attachment with others. It is a special connection at a deep level but requires no physical contact. Emotional intimacy can be enhanced by physical touch, but it can also be the motivator for sexual desire.



Common Problems

- Changes in energy level, body image, confidence, and relationship roles may be experienced by anyone who has been impacted by cancer.
- Problems may be specific to penetrative sex, erection, ejaculation, vaginal dryness, inability to orgasm, or pain during sex. Other concerns are related to feeling less attractive, a loss of desire, or periods of extreme fatigue.
- Some problems resolve after treatment, while others may be persistent and long lasting.
- Relationships are often affected by cancer treatment, causing partners to have their own need for information and support.

Sexual Scripts

Cancer treatment can influence how we think and feel about ourselves as sexual beings. Your sexual script is the way you and your partner express intimacy and affection to one another. Your script is what you do to transition from a non-sexual interaction to a sexual one.

It may be difficult to follow the same script after treatment. Your desire may be different, and physical changes impact your ability to have sex the same way as before.

Communicating with a partner about these changes is a first step to figuring out how to rewrite your sexual script and be comfortable and confident about intimacy again.



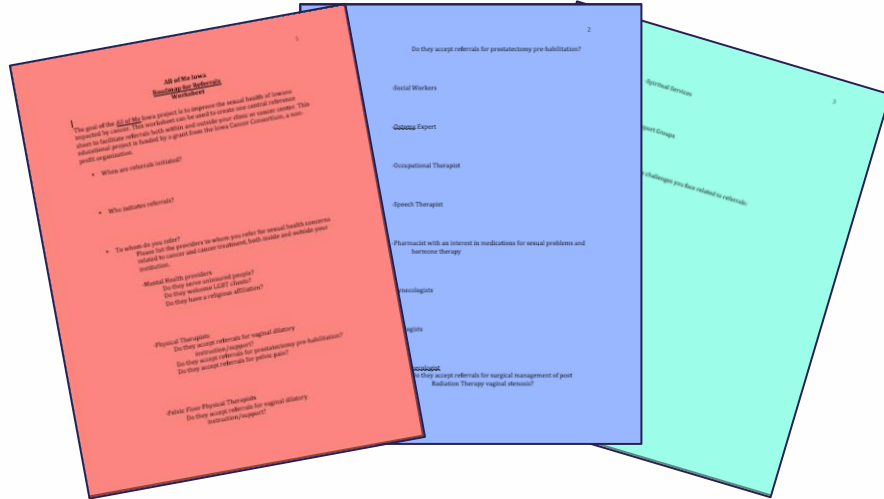
Questions for Your Doctor

- How will my cancer therapy affect my sex life?
- Is it safe for me and my partner to have sex during my treatment?
- What can I do before, during, or after my treatment to lessen the negative on my sexual functioning?
- What can my partner expect from the sexual health side effects?
- What changes should I be watching for?
- What resources are available to address the changes my intimate relationships?
- What have other patients, undergoing the same treatment found helpful for sexual side effects?

About After Cancer

Our goal is to empower patients and provide educational resources for patient care teams on addressing sexual side effects from diagnosis through survivorship. We provide solutions for sexual health so you have the information you need to be in charge.

Referral Roadmap / Needs Assessment



**St. Anthony Sexual Health and Cancer
Roadmap for Referrals**
4/2021
Jessica Borowski, MSN, RN, OCN

Mental Health Providers
-Specifically welcome individuals and couples with sexual health problems who have been impacted by cancer.
-Only offices that responded to our calls are listed.

| Organization (alphabetical) | For appointments call | Contact info | Accepts insurance ? | Serve uninsured ? | Welcome LGBTQ clients: Official non-discrimination policy/word of mouth? | Religious affiliation ? | Notes |
|---|-----------------------|--|--|-------------------|--|-------------------------|--|
| Catholic Charities | (314) 232-9597 | MS, LMSW: Tina Zanders | Welcome donations; low-cost; Sliding fee scale | Y | Y | Y | Non-Catholics welcome. Offices in Carroll, Storm Lake, Earl, Dodge, Spencer, Algona, Sioux City. |
| Joseli Albers, Dunkerson, Relationship And Intimacy | (515) 505-8313 | Joseli Albers, Dunkerson, LMFT, Certified Sex Therapist. | | | Y | N | |
| New Opportunities | (314) 232-9266 | Head RN: Vicki Stedler SW: Paula Kioske ARNP: Anne Idemier ARNP: Carol Kioske | Y | Y | Y | N | Also have offices in surrounding counties. |
| Plaines Area Mental Health | (314) 232-2991 | Clinical Supervisor: Glenna Nockels, LISW | Y | Y | Y | N | Telehealth counseling available. |

Needs Assessment-

<https://docs.google.com/forms/d/18QhV1WwvrjZsujCLNmUs1pZy0QptmRDglzpLHYWFd eY/edit>

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