



After Cancer
Solutions for Sexual Health

Trauma and Cancer

Erin Sullivan Wagner (she/her)

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

www.aftercancer.co

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

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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

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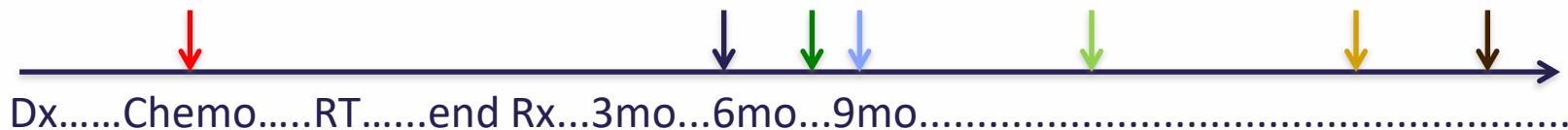


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What Went Wrong and When

<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
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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

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

SEXUAL DISORDERS and PAIN/PENETRATION DIFFICULTIES

DECREASED ORGASM

LOSS OF GENITAL SKIN SENSIVITY

GENITAL SKIN HYPERSENSITIVITY

PARTNER COMMUNICATION PROBLEMS

NUMBNESS

ANTIDEPRESSANT THERAPY EFFECT

Adapted from Phillips. Am Fam Physician 2000;62(1):127-36

Designed by Dr. Sarah Shaffer, DO

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UNSATISFYING ENCOUNTER

PARTNER ROLE/CHANGE CAREGIVING

PARTNER ROLE UNCERTAINTY

PARTNER FEAR OF HARMING

PARTNER STRESS

SEXUAL SCRIP UNCERTAINTY

EXCESSIVE FOCUS ON

INTERCOURSE/ORGASM

UNRESOLVED RELATIONAL CONFLICT

DECREASED AROUSAL

DECREASED LUBRICATION

HORMONE CHANGE



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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

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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**

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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



Contact Us

Erin Sullivan Wagner



319.594.5933



YOUR SEXUAL HEALTH AND CANCER



“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.



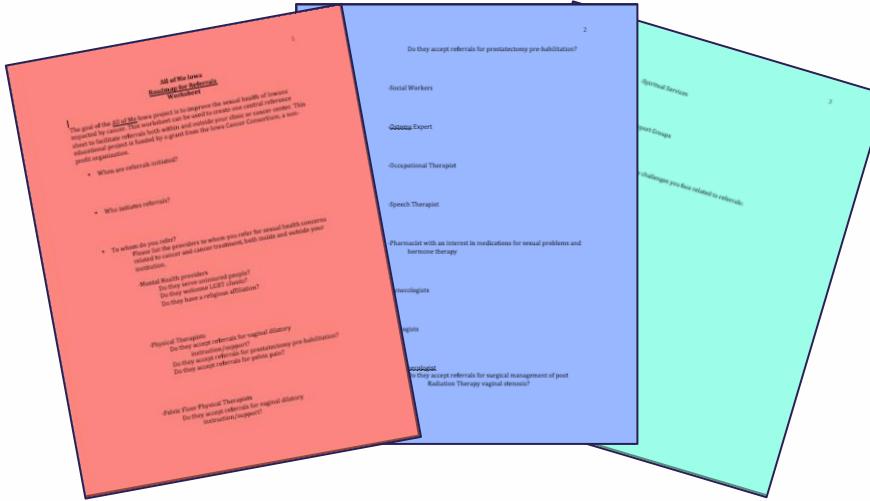
Questions for Your Doctor

- 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 Buckowski, BSN, 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	(712)752-9597	MS, LMSW: Tina Zanders	Welcome donations; low-cost; Sliding fee scale	Y	Y	Y	Y	Non-Catholics welcome. Offices in Carroll, Storm Lake, Fort Dodge, Spencer, Algona, Sioux City.
Joseli Alves-Dankerson, Relationship And Intimacy	(515)305-8313	Joseli Alves-Dankerson, LMFT, Certified Sex Therapist			Y		N	
New Opportunities	(712)752-9266	Head RN: Vicki Stelle, SW: Paula Klocke, ARNP: Anise Irmler, ARNP: Carol Klocke	Y	Y	Y		N	Also have offices in surrounding counties.
Plaines Area Mental Health	(712)752-2991	Clinical Supervisor: Glenna Nocketz, LISW	Y	Y	Y		N	Telehealth counseling available.

Needs Assessment-

<https://docs.google.com/forms/d/18QhV1WwvrjZsujCLNmUs1pZy0QptmRDglzpLHYWFdeY/edit>

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