



All of Me

Addressing Sexual Health in Patients Impacted by Cancer

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Preferred pronouns she/her/hers

www.aftercancer.co

www.allofmeiowa.org



After Cancer
Solutions for Sexual Health

Cancer and Its Side Effects

Cancer Treatments: Surgery - Radiation - Chemotherapy - Hormone

SIDE EFFECTS

Nerve Damage	Infertility
Loss of Limb	Fatigue
Hormone Changes	Hair Loss
Intercourse Inability	Pain
Weight Gain/Loss	Menopause Symptoms
Mucositis	Memory/Focus 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	

QUALITY OF LIFE

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

Hormonal: Medications, chemotherapy

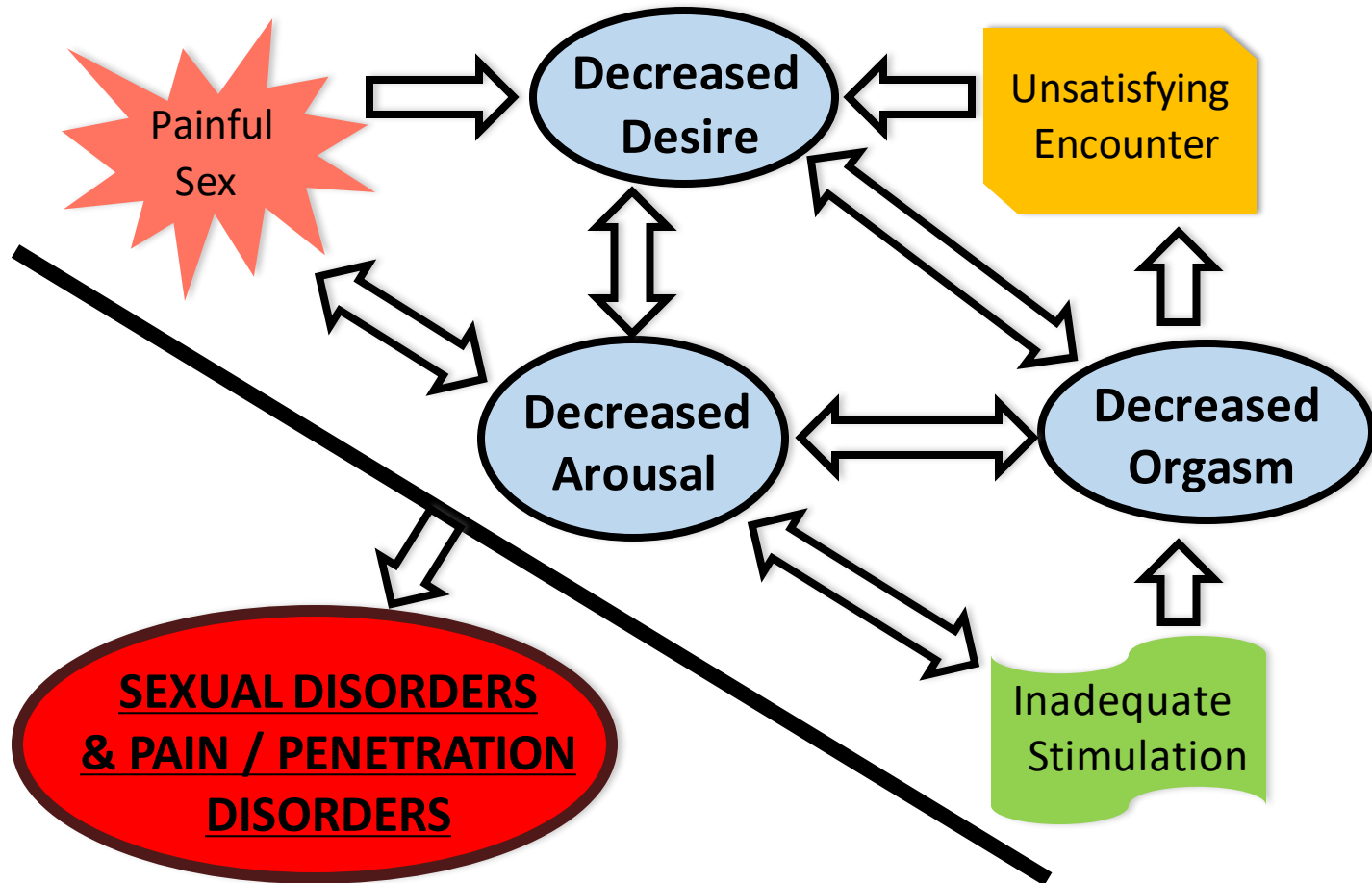
Psychological: Anxiety, depression, self-esteem, body image, gender perception

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

Social: Isolation, dependence



The Web of Female Sexual Dysfunction



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

DECREASED DESIRE

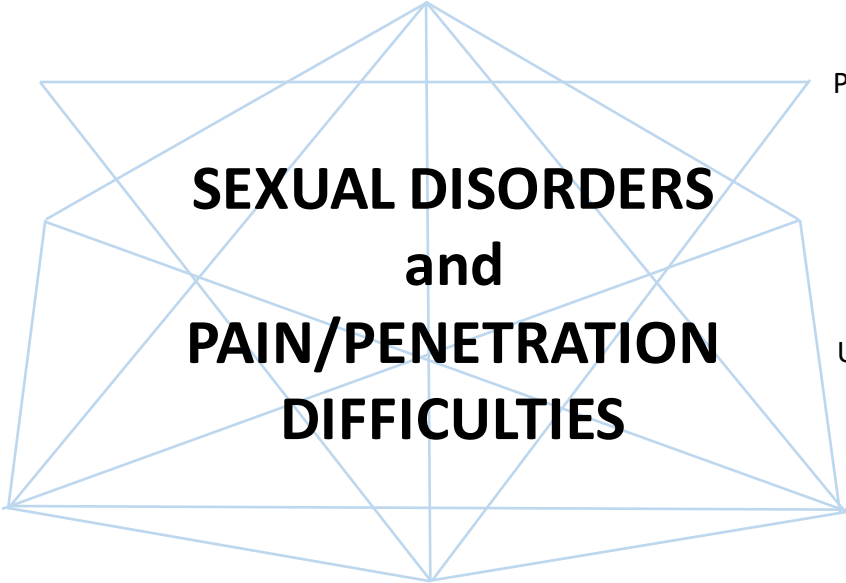
ANXIETY RELATED TO CANCER
FATIGUE
CANCER RELATED STRESS
BODY IMAGE PROBLEMS
FEAR OF CANCER CONTAGIOUS/RECURRENCE
MEMORY AND CONCENTRATION PROBLEMS

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

PAINFUL SEX

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



SEXUAL DISORDERS and PAIN/PENETRATION DIFFICULTIES

DECREASED AROUSAL

DECREASED LUBRICATION
HORMONE CHANGE

STIMULATION

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

DECREASED ORGASM

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

Why This Work is So Important

Changes in sexual health are some of the most prevalent and distressing side effects of cancer treatment—yet most patients with cancer may *never be asked about them*.

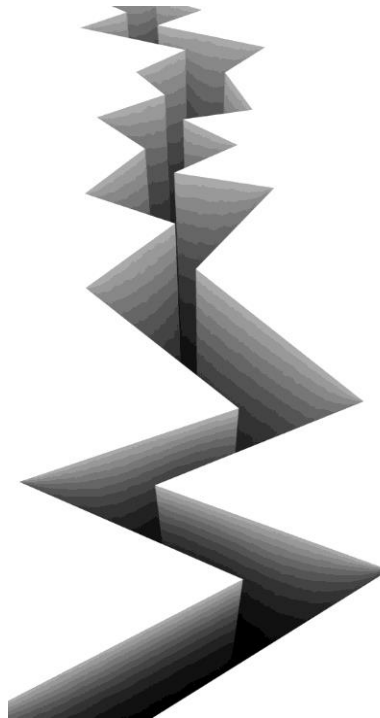
More than 50% of patients experience sexual health concerns –all cancer types

Less than 20% will have these concerns addressed

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

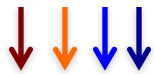
- Focused on fighting the disease
- Terminology/explanation of the problem
- Sexual issues not seen as medical issues
- Embarrassed for self and provider
- Fear of being negatively judged
- Believe a care team member will bring it up if appropriate
- Unsure of who to speak to on care team
- Not sexually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

The **All of Me** Project

Implementation Framework

- Normalize the Conversation
 - 30-second message
 - Messaging, signage in waiting areas
- Set Expectations
 - Patient brochure
 - Patient handouts
- Refer Patients Timely
 - Roadmap - list of internal and external resources to include APPs specialized in women's or men's health, gynecology, urology, PT/pelvic floor therapists, mental health therapists, sex therapists

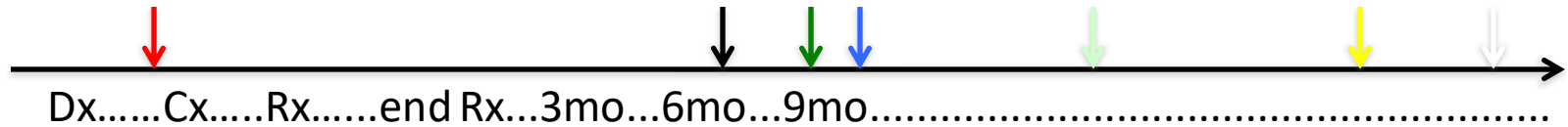
What Went Wrong and When



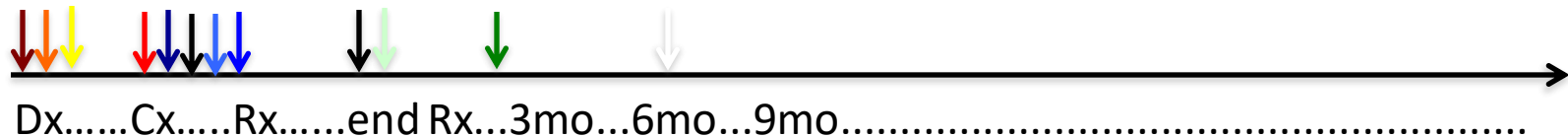
- Normalizing the conversation
- Consent for treatment
- Setting expectations
- Refer to sex therapist, sexologist, or psychologist
- Refer to physical therapist for ongoing dilator use support

- 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



It All Starts With a Simple 30-SECOND MESSAGE

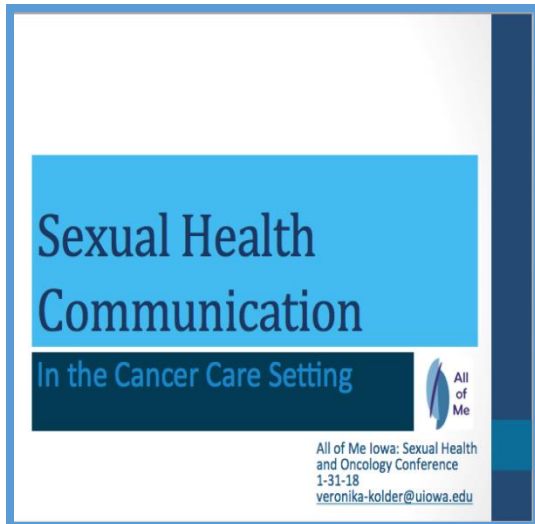
A short, introductory 30-second message to patients about sexual health side effects as a result of cancer or its treatment

There are six components of the 30-second message:

1. Side effects impacting sexual health are **common and expected**
2. Sexual health is an important **quality of life issue** for most people
3. Tell **your care team** about treatment-related sexual problems
4. Support and **resources are available**
5. Studies show early treatment of sexual health problems may lead to better outcomes; **sooner is better than later**
6. You **may not care now**, but life is long, and you may care later

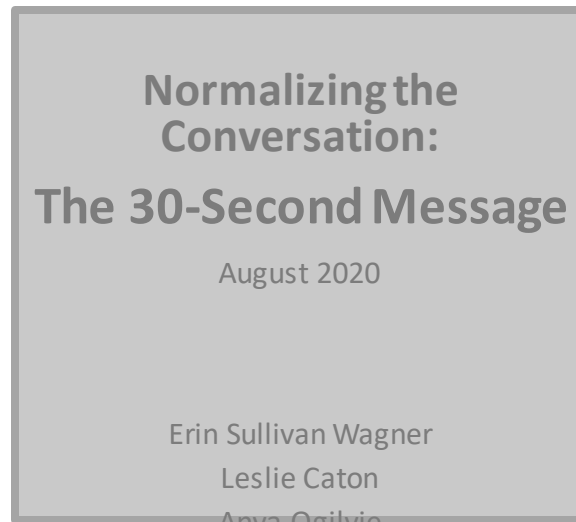
Provider videos “Normalizing the Conversation”

Communication



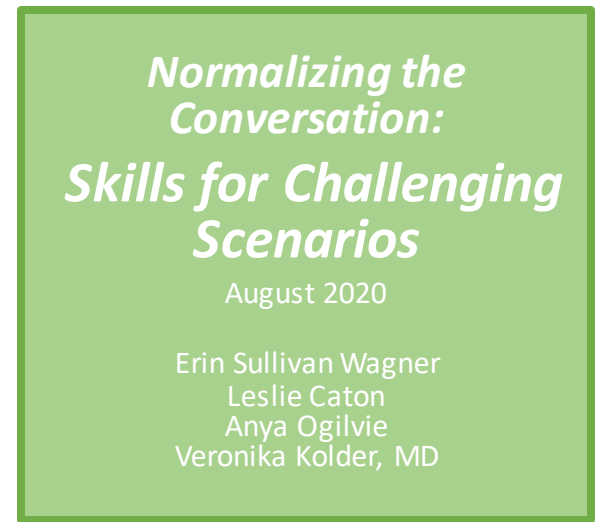
<https://allofmeiowa.org>

30-Second message

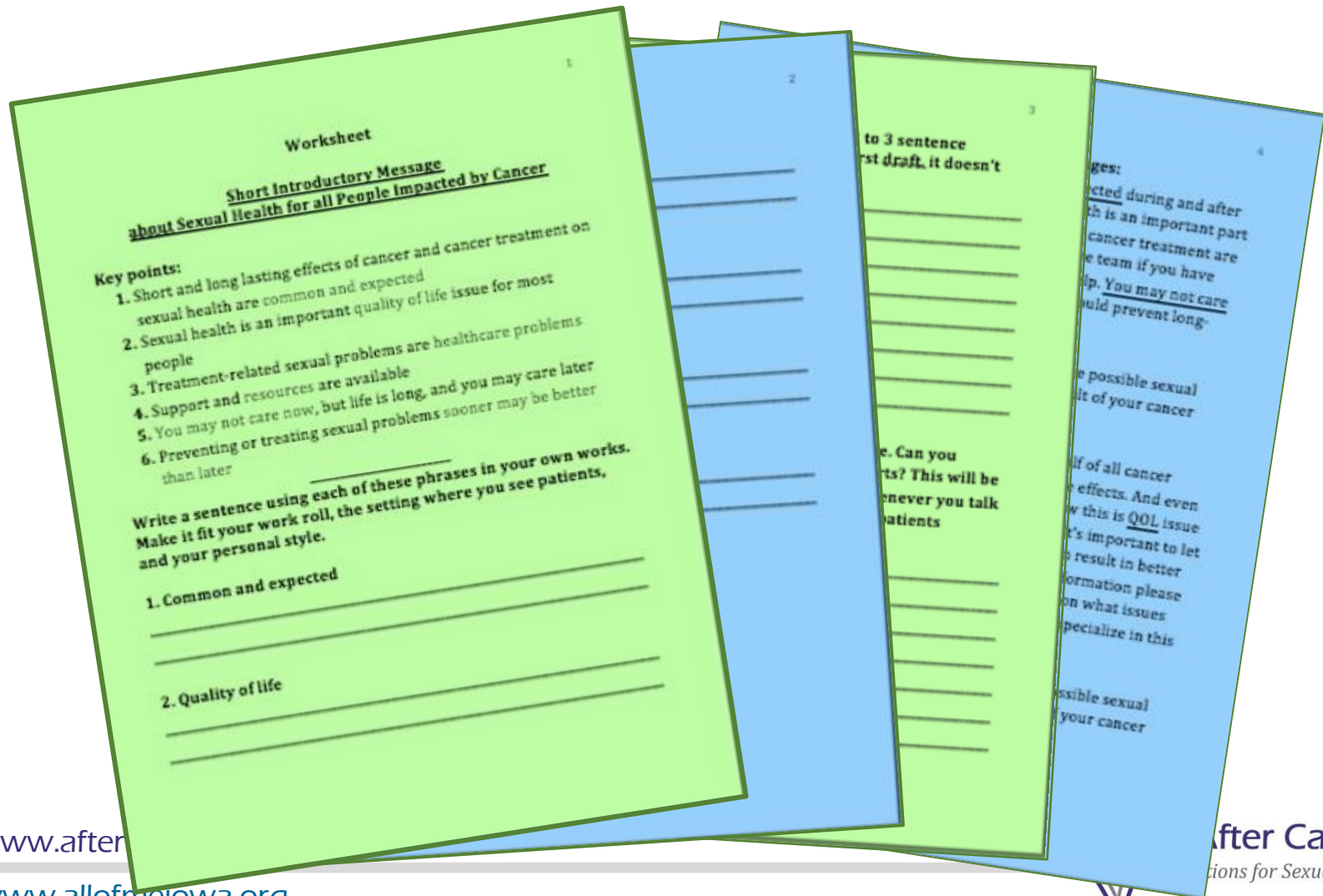


<https://allofmeiowa.org/pilot-programs/st-anthonys/>

Challenging scenarios



30-Second message worksheet



Trifold patient brochure

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, but emotional intimacy is described to be something totally different... or 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.

SEXUAL SCRIPTS

Sexual scripts are the very personal ways we express intimacy and love. It is the how, what, when, where and why of your sexual relationship with your partner. Cancer can influence how we think about ourselves as sexual beings and our sexual scripts may need to change. Treatment can cause physical changes, affect how we feel about our bodies, or change our desire for sex. Spontaneity may not be possible for a while. Communicating with your partner about the changes you experience is a first step in rewriting your sexual scripts and feeling confident about being intimate with your partner again.



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.

- (In alphabetical order)
- Counseling
 - Gynecology
 - Ostomy Care
 - Physical Therapy
 - Sex Therapy
 - Social Work
 - Spiritual
 - Support Groups



Iowa Cancer Consortium

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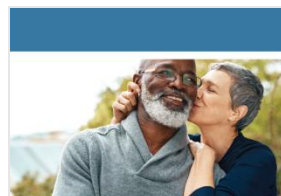


YOUR SEXUAL HEALTH AND CANCER

“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?”

AllOfMelowa.org

Providing resources and educational programs for health care providers and patients



ABOUT All of Me

All of Me- Prioritizing Sexual Health for Iowans impacted by Cancer is a project originally funded by the Iowa Cancer Consortium.

Its aim is to improve quality of life by empowering patients and providers to address sexual health from the time of diagnosis through survivorship. Whether you have a partner or not, when you are an active participant in treatment choices that affect your sexual health, negative impacts of cancer and its treatment can be anticipated and addressed. You have the information you need to be in charge.

WHAT YOU NEED TO KNOW

- Sexual health is important for quality of life for most people
- Short and long lasting effects of cancer and cancer treatment on sexual health are common
- You don't need to face problems alone, support and resources are available
- Tell your care team about treatment-related problems
- Prevention and early treatment of sexual problems may lead to better outcomes; sooner may be better than later
- You may not care now, but life is long, and you may care later



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COMMON PROBLEMS

Changes in energy level, body image, confidence and relationship roles may be experienced by anyone who has been impacted by cancer.

Other problems may be specific to males or females.

- Males may experience problems with erection, ejaculation or pain during sex / pain with sex.
- Females may experience vaginal dryness, decreased lubrication, changes in orgasm or pain during / pain with sex.

Some of these problems resolve after treatment has ended, while others may be long lasting or permanent.

Cancer therapy/treatment often has an effect on relationships causing partners to have their own needs for information and support.



QUESTIONS FOR YOUR DOCTOR



- How will my cancer therapy and/or medications affect my sex life?
- Is it safe for me and my partner to have sex during cancer treatment?
- What can I do before, during or after my cancer treatment to lessen the negative impact on my sexual functioning?
- What can my partner expect from the long term side effects of my cancer treatment?
- What sexual health changes should I bring to the attention of my medical care team?
- What resources are available to address sexual health changes and the impact on my intimate relationships?

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www.allofmeiowa.org

www.allofmeiowa.org, resources for providers



After Cancer
Solutions for Sexual Health

Signage for waiting areas- table tents

CANCER OR ITS TREATMENT MAY CAUSE SEXUAL HEALTH ISSUES –

It's common and expected to experience sexual health side effects as a result of your cancer or its treatment. Some side effects are temporary and others can be persistent and long lasting.

These issues are health care issues and we want you to bring them to our attention immediately.

WE HAVE RESOURCES TO HELP!

Though you may not care about your sexual health right now, studies show addressing these issues sooner vs later increase the chances of having them resolved.

If a member of your care team hasn't addressed the possible impact your cancer or its treatment will have on your sexual health, please ask me any of the following:

1. How will my specific treatment/therapy impact my sexual health?
2. What are the common side effects of my specific treatment?
3. When will sexual health side effects begin and how will they last?
4. Is there anything I can do to lessen the severity of the side effects?
5. Are there alternative treatments that could preserve my sexual health?
6. Is there anything I should be doing or reading to prepare me for the potential side effects?



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www:allofmeiowa.org, resources for providers



After Cancer
Solutions for Sexual Health

3"x 3" Provider pocket card

FRONT

BACK





All of Me

PRIORITIZING SEXUAL HEALTH

Sex is what you are born with. Depends on chromosomes, reproductive organs, and physical anatomy: male, female, intersex.

Gender is how you identify yourself. A personal sense of maleness or femaleness: man, woman, gender-queer, or something else.

Your 30-second message should include the following 6 components:

<p>Common and Expected Quality of Life Healthcare Issue</p>	<p>Sooner vs. Later You may not care Now Resources</p>
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SETTING EXPECTATIONS

Patients may need anticipatory guidance related to:

- Anatomy*
- Hormones*
- Specific Treatment*
- Relationships, sexual scrip*
- Types of Sexual Problems*
- Body Image/Self Esteem*
- Medication Effects*
- Therapy Side Effect*

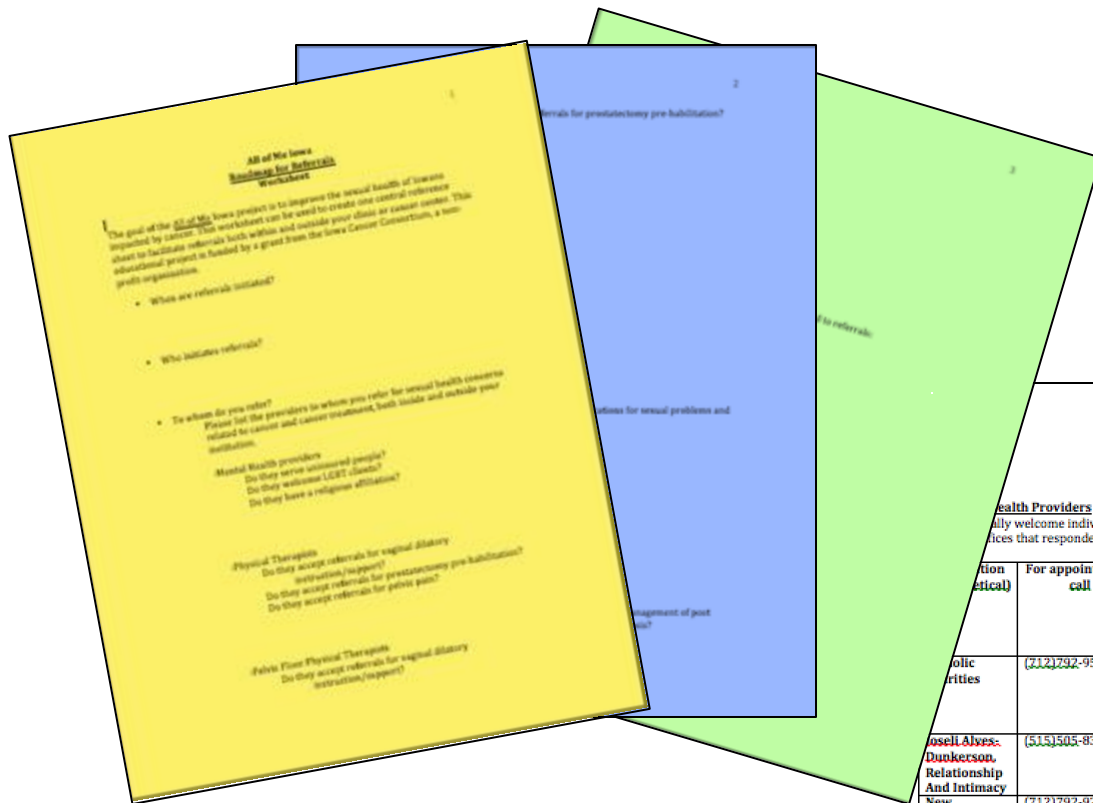
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Roadmap for referrals worksheet



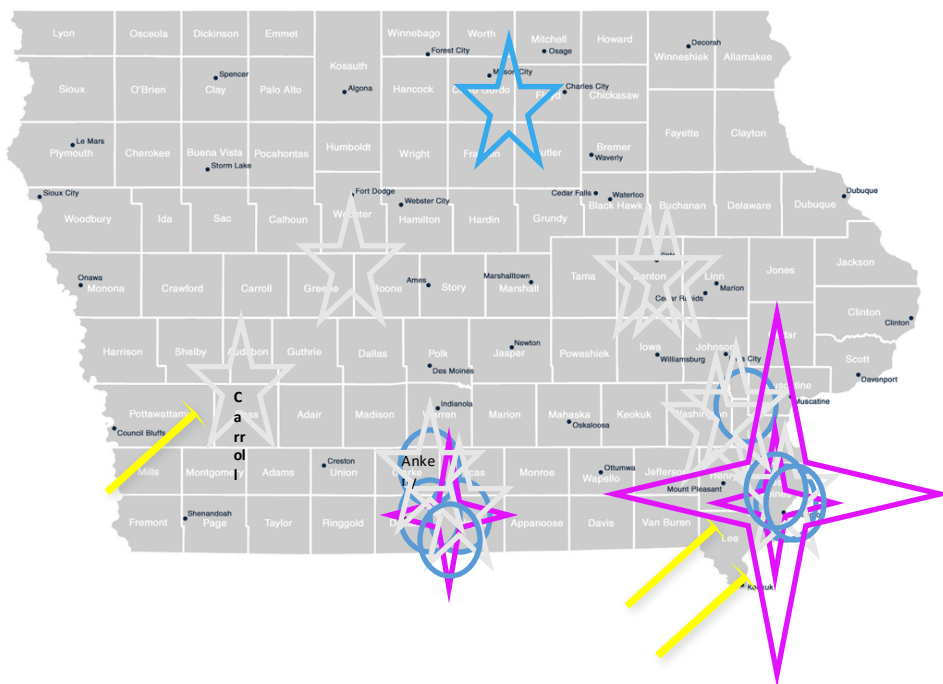
St. Anthony Sexual Health and Cancer
Roadmap for Referrals
4/2021
Jessica ~~Borkowski~~, BSN, RN, OCN

Health Providers
We warmly welcome individuals and couples with sexual health problems who have been impacted by cancer. Offices that responded to our calls are listed.

(Location/Category)	For appointments call	Contact info	Accepts insurance ?	Serve uninsured ?	Welcome LGBTQ clients: Official non-discrimination policy/word of mouth?	Religious affiliation ?	Notes
Polycystic Ovaries	(712)292-9597	MS, LMSW: Tina Zanders	Welcome donations; low-cost; Sliding fee scale	Y	Y	Y	Non-Catholics welcome. Offices in Carroll, Storm Lake, Eggt, Dodge, Spencer, Algona, Sioux City.
Joseli Alves, Dunkerson, Relationship And Intimacy	(515)505-8313	Joseli Alves, Dunkerson, LMFT, Certified Sex Therapist			Y	N	
New Opportunities	(712)292-9266	Head RN: Vicki Steffes , SW: Paula Klocke , ARNP: Anise Lindner , ARNP: Carol Klocke	Y	Y	Y	N	Also have offices in surrounding counties.
Plaines Area Mental Health	(712)292-2991	Clinical Supervisor: Glenna Nockels , LISW	Y	Y	Y	N	Telehealth counseling available.

The All of Me Project

Work Completed Across Iowa From 2016 to 2021



10 grand rounds and awareness raising lectures, 2014-2016

9 half-day accredited workshops with 2 facilitators and 2 simulated patients, 2017-2019

2 abstract presentations, Scientific Network Female Sexual Health & Cancer Network, UC Davis Sacramento, and Duke University, Raleigh NC - 2017-2018

3 all-day conferences on sexual health and cancer, 2018-2021

2 completed pilot programs, 2020-2021

Welcome to The All of Me Project



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Results

30 providers expressed interest in receiving educational materials.
Of these:

- 24 completed the pre-pilot survey
- 11 completed both the pre- and post-pilot survey

The 24 respondents who completed the pre-pilot survey were grouped by profession:

- Oncology Nurse (6)
- Social Worker/Mental Health (5)
- Physical Therapist (4)
- PharmD/RPh (3)
- ARNP/PA (2)
- One each: Administrator, Occupational Therapist, Speech Therapist, Radiation Dosimetrist

Results - Perception of importance

Not at all important	Slightly important	Moderately important	Very important	Extremely important
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Pre-Pilot

19 of 24 respondents (79%) indicated that both providing **information about sexual health** to patients with cancer was very or extremely important, and providing **information about the potential sexual side effects** of cancer treatment was very or extremely important

Post-Pilot

All respondents (11 of 11) indicated that both providing information about sexual health and the potential sexual side effects of cancer treatment was very or extremely important ($p < .05$)*

* Wilcoxon signed rank test showed significant increase pre to post importance, $p < .05$

Results – Pre-Pilot Confidence (N=24)

Not at all confident	Slightly confident	Moderately confident	Very confident	Extremely confident
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Rate your confidence in:	% moderately, very, or extremely confident	n
Giving a short introductory message about sexual health and cancer	25%	6/24
Knowing what that message should include	21%	5/24
Knowing when to bring up the topic	33%	8/24
Knowledge of sexual health side effects	38%	9/24
Setting expectations about the impact on their sexual functioning and intimate relationships	13%	3/24
Knowing when to refer patients	25%	6/24
Knowing where to refer patients	21%	5/24

Results – Comparison of Pre- and Post-Pilot Confidence (N=11)

Not at all confident	Slightly confident	Moderately confident	Very confident	Extremely confident
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Rate your confidence in:	Pre %	n	Post %	n	p- value*
Giving a short introductory message about sexual health and cancer	36%	4/11	100%	11/11	.003
Knowing what that message should include	36%	4/11	100%	11/11	.003
Knowing when to bring up the topic	45%	5/11	91%	10/11	.005
Knowledge of sexual health side effects	36%	4/11	91%	10/11	.007
Setting expectations about sexual functioning and intimate relationships	18%	2/11	91%	10/11	.008
Knowing when to refer patients	35%	4/11	100%	11/11	.003
Knowing where to refer patients	27%	3/11	100%	11/11	.003

*Wilcoxon signed rank test showed significant increase pre to post confidence

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Conclusions-Urology UIHC Pilot

- The All of Me sexual health care training improved provider confidence and feasibility in delivering the “30 second message” about sexual health and cancer
- Confidence of APPs in knowing what the 30 second message should include saw the largest improvement after training (27% to 100%)
- Baseline confidence and post-training confidence for nurses/MAs was lower than the APP group (20% baseline up to 50% post-training)

Conclusions

All of Me

To our knowledge, this is the largest group of Iowa cancer care providers ever surveyed about their perception of the importance of, and confidence in, providing sexual health care.

Results suggest implementation of sexual health care for Iowans impacted by cancer may be entering a new phase in which providers are aware of, and acknowledge the importance of, such care but may not yet have the confidence needed to act.

The improvement in respondent confidence after this educational program lends support to All of Me project plans for converting this material to an On-Demand platform.

Communication Aids & Patient Handouts

Website Resources

- 30-second message worksheet
- Patient brochures and new patient folders placed in waiting areas. Can also be used as a communication aide when giving the 30-second message
- Provider pocket card cheat sheet for professionals, with 30-second message and common side effects
- Table tents listing patient questions related to sexual health, to be placed in waiting areas
- Patient handouts in addition to the brochure, in English and Spanish
- Non-hormonal ways to reduce effects of menopause and cancer treatment on the vulva and vagina
- Dilators, vaginal moisturizers, and collision barriers
- Minimize and treat androgen deprivation therapy (ADT) side effects
- Penile rehabilitation using vacuum erection device (VED)

All of Me

Quick Introduction to Provider Resources

Erin Sullivan-Wagner, Patient Advocate

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Solutions for Sexual Health

Provider Resources

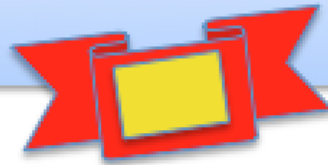
**Read
Supporting
Evidence**



**Become a
Sexual Health
Champion**



**Create a
Center of
Excellence**



**Celebrate
with us!**



Read the Evidence



Articles

Published Guidelines

Top Programs & Websites

All of Me
Conference Presentations





Become a Sexual Health Champion

Listen to Erin's Story

Empower Yourself

Find Tools

Maximize your Impact

Recognize National & International Guidance

Sample State-of-the-Art Articles & Presentations

Listen to *All of Me* Research Results

Watch Roll-plays

Make a Difference

Start Net-working

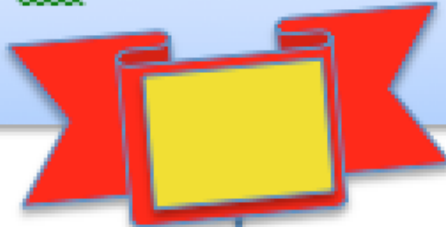
Learn about Common Effects & Treatment

Explore Best Practices

View 2021 *All of Me* Conference Presentations



Create a Center of Excellence



● Host a Workshop

▲ Plan an Educational Program

◆ Collaborate for Long-term Excellence



Learning Workshops and Online Educational Series



Normalize the Conversation Session - Your 30-second message (90 Minutes)

Normalize the Conversation Workshop - National guidance, patient stories, create and practice your 30-second message in oncology role play scenarios with simulated patients, video presentations, how and when to use the patient brochure, developing a referral roadmap (4 hours)

All of Me Educational Series – Comprehensive 8-week program containing evidence-based learning modules that address normalizing the sexual health conversation with challenging scenarios, setting patient expectations, evaluating and treating the patient, and referring to other specialists as needed. Self-study, live-stream featured speakers, weekly Q&A sessions, and a 'Build and Sustain' module (8 weeks)

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Solutions for Sexual Health