

This is Awkward... **Having Difficult Conversations about AYA Sexual Health**

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Speaker disclosure statement

- Stacy Whiteside has no industry relationships to disclose.

Objectives

- Recognize barriers to communicating with AYA patients about sexual health & identify strategies to overcome barriers using provided techniques
- Demonstrate knowledge of important sexual health topics pertinent to AYA with cancer or blood disorders
- Identify available resources for providers and patients regarding sexual health in AYAs with cancer or blood disorders
- Identify relevant religious, cultural, ethical and legal issues related to sexual health in AYAs with cancer

Poll Question #1

According to the Adolescent and School Health division of the CDC, what percentage of **high school students** have **ever** had intercourse?

a) 20%

b) 40%

c) 60%

d) 80%

Poll Question #2

What percentage of high school students are **currently** sexually active?

a) 29%

b) 38%

c) 52%

d) 65%

Poll Question #3

What percentage of high school students report they had sexual intercourse for the first time **before** 13 years of age?

- a) 9%
- b) 7%
- c) 4%
- d) 2%

Over Half of U.S. Teens Have Had Sexual Intercourse by Age 18, New Report Shows

For Immediate Release: June 22, 2017

- Among teen females aged 15-19, 42% had ever had sex
- Among teen males aged 15-19, 44% had ever had sex
- These percentages have gradually declined since 1988; when 51% of female and 60% of male teens reported having ever had sex
- In 2011-2015, nearly 3 in 10 teens (30% of female teens and 29% of male teens) had sexual intercourse at least once in the past three months
- Average age of sexual debut in US: 16

I know we are “pediatric” providers.... but like it or not... our patients are having sex.



Sexual activity of AYAs with cancer

- Limited studies
- 2008 & 2017 studies of 42 AYAs with cancer on treatment reported similar rates of sexual activity compared to non ill adolescents
- Rosenberg et al 2020 study of 92 AYAs with cancer ***ON therapy***:
 - 30% reported dating
 - 13% currently sexually active
 - 23% considering having sex
 - 18% reported having had oral, anal or vaginal sex
 - 75% reported inconsistent birth control use
 - 54% reported inconsistent condom use

Poll Question #4

How do you feel about addressing sexual health concerns with an AYA cancer patient?

- a) I'd rather have a root canal
- b) That's not my job
- c) I can power through it if I have to
- d) I feel very comfortable discussing this topic

Poll Question #5

What barriers to you have in your daily practice that prevent you from discussing sexual health with AYA patients?

- a) Time
- b) Lack of knowledge
- c) Discomfort
- d) Difficulty navigating parental presence

You are not alone...

- Less than 1/3 of nurses said they offered to discuss sexual concerns with a patient in the previous 12 months
- Only 61% of nurses thought it was appropriate to initiate the conversation with a patient even though 100% of nurses believed sexual concerns should be discussed
- 90% of nurses indicated that physicians had the primary responsibility for discussing sexual concerns

Provider barriers

- Lack of knowledge or experience
- Lack of resources or educational materials
- Low priority
- Parents
- Time
- Provider discomfort
- Lack of rapport or relationship



The AYA perspective

- 82% reported the need for information and counseling related to sexuality as **UNMET**
- 79% were not satisfied with the manner the information on intimacy and sexuality was provided (if it was AT ALL)
- 12% reported having a discussion within the first 6 months of treatment
- Barriers to communication with Health Care Provider about sexual health
 - Perceived provider discomfort
 - Lack of rapport with clinician
 - Discomfort initiating conversation
 - Presence of family members

FAIL

Sexual dysfunction

- Half of young adult survivors of childhood cancers struggle with at least one major sexual problem within 2 years of diagnosis
- 30% report two or more problems
- These issues negatively affect intimacy, romantic relationships, body image, and overall well being



Effect of cancer on desire

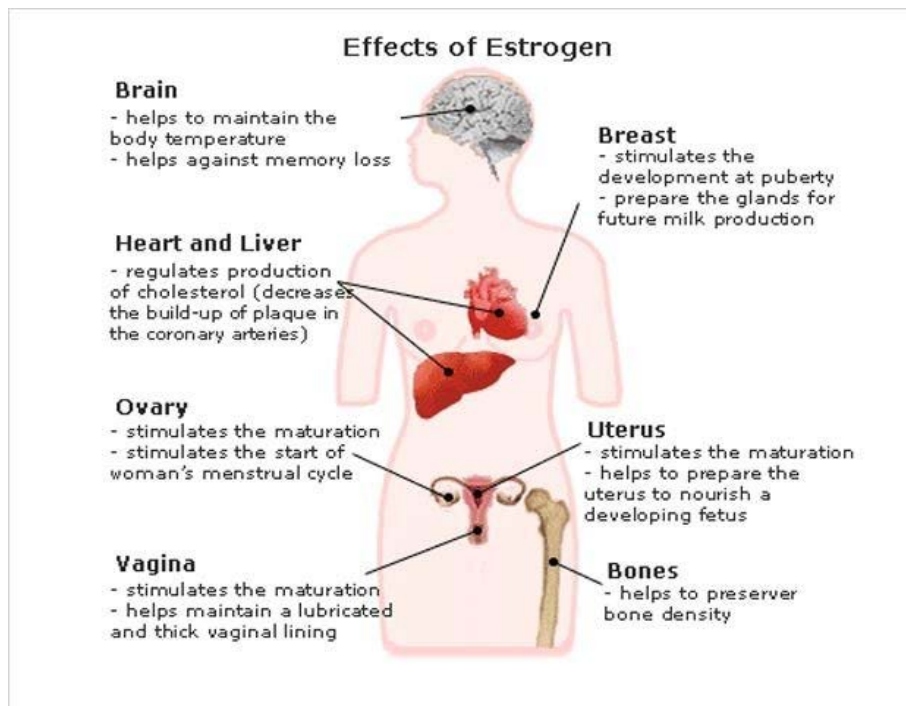
- 60% of AYA survivors reported sexual desire concerns and reduced frequency of sexual activity
- 62.5% cited loss of sexual interest
- 31.3% reported loss of interest due to feeling physically unwell during treatment
- Survivors reported loss of interest due to medications (28%), emotional fluctuations (28%), & body image concerns (50%)

Effect of cancer on arousal

- Mental and physical readiness for sexual activity
- Aksoy et al: 2/3 of male lymphoma patients reported some degree of erectile dysfunction after treatment
- 44% of female AYA cancer survivors reported it was “somewhat difficult” to become aroused
- 22% of female survivors reported it was “somewhat difficult” achieving adequate vaginal lubrication for sexual activity
- Lack of lubrication was primary sexual concern during treatment for females

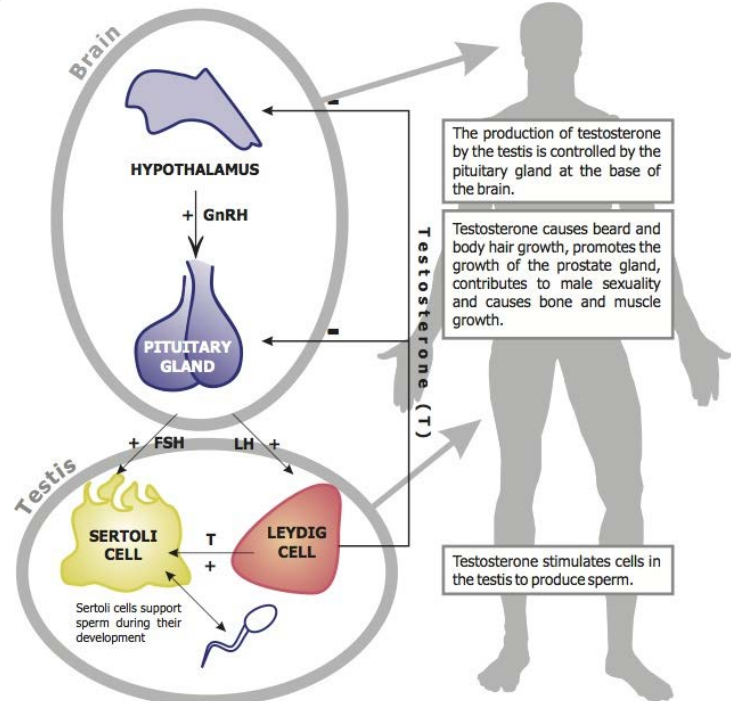
Female physiologic factors

- Premature menopause
 - Climacteric symptoms caused by loss of estrogen
 - Vasomotor symptoms including hot flashes/night sweats
- Vaginal dryness
- Low libido
- Pain



Male physiologic factors

- Erectile dysfunction
- Ejaculatory dysfunction
- Low libido
- Pain



<https://www.earthslab.com/physiology/hormonal-control-reproduction-males/>

Psychological Concerns

- Depression/anxiety
- Medications
- Sleep disorders
- Fatigue
- Impaired body image



22yo female with osteosarcoma

“I worry there are things that I can’t do, maybe like positions or things like that... My leg doesn’t get in the way a ton, but sometimes there are a lot of things that are harder because I can’t be as physical. And then there’s the emotional aspect where I just worry that he’s going to think it’s ugly or be grossed out or something by the scar...”

24yo male with rhabdomyosarcoma

“I am definitely more sensitive during any intimacy. It is easy to cause me pain through what would otherwise be a normal act. Specifically my remaining testicle is really sensitive.”

21yo male with lymphoma

“If a day goes by and I have to think about my medical past at all I find it almost impossible to become sexually aroused because I can’t relax enough from those thoughts to get to that point.”

Gonadal Functioning and Perceptions of Infertility Risk Among Adult Survivors of Childhood Cancer: A Report From the St Jude Lifetime Cohort Study

Vicky Lehmann, PhD¹; Wassim Chemaitilly, MD¹; Lu Lu, MS¹; Daniel M. Green, MD¹; William H. Kutteh, MD, PhD^{1,2}; Tara M. Brinkman, PhD¹; Deo Kumar Srivastava, PhD¹; Leslie L. Robison, PhD¹; Melissa M. Hudson, MD¹; and James L. Klosky, PhD¹

- More than half of male survivors were classified as having impaired gonadal function
 - 70% accurately perceived themselves at increased risk
 - 19.7% overestimated their risk
 - 16.3% underestimated their risk
 - 23.4% of females were classified as infertile
 - 78.4% considered themselves at increased risk for infertility
 - Almost half of females **overestimated** their risk
 - Survivors with impaired fertility who perceive themselves at no increased risk are prone to emotional difficulties, distress, and relationship problems
-

Other implications

- Female patients tend to overestimate their risk of infertility resulting in lower use of contraceptives
- Women who survive cancer are 3x more likely to have an unintended pregnancy compared to the general population



**We know this is a significant issue...
what do we do about it???**



SCOTT BRADSHAW

The BASIC PROBLEM



I CAN SEE YOU,
I CAN HEAR YOU,

YET I CANNOT
COMPREHEND ANYTHING
YOU SAY OR DO.



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"Of course I know how to communicate without a phone. I have an app for that!"



"I SPEAK SIX DIFFERENT LANGUAGES FLUENTLY BUT I DON'T UNDERSTAND MY TEENAGER DAUGHTER."



NATIONWIDE CHILDREN'S

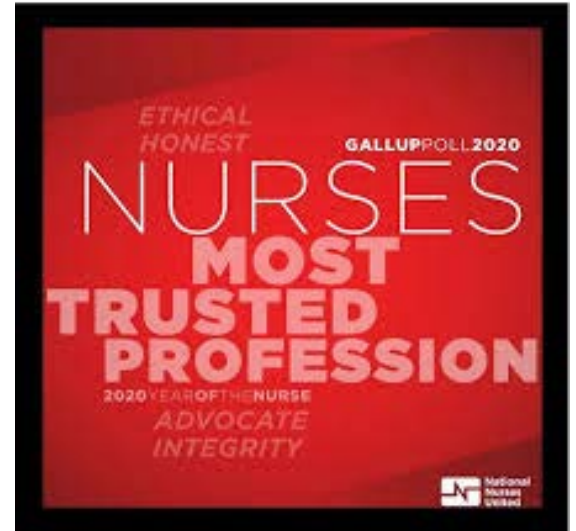
When your child needs a hospital, everything matters.

Nurses are positioned to fill the gap

- AYAs prefer discussing sexual health with nurse practitioners 61.8% vs physicians 41.8%
- Nurses have established rapport & relationships with patients

“It’s the sort of thing that actually afterward people have questions you know, days, weeks, months down the line. And inevitably it falls under nursing...”

“We have a very different relationship with patients than the doctors do. I think it almost comes up more easily in conversations with us.”



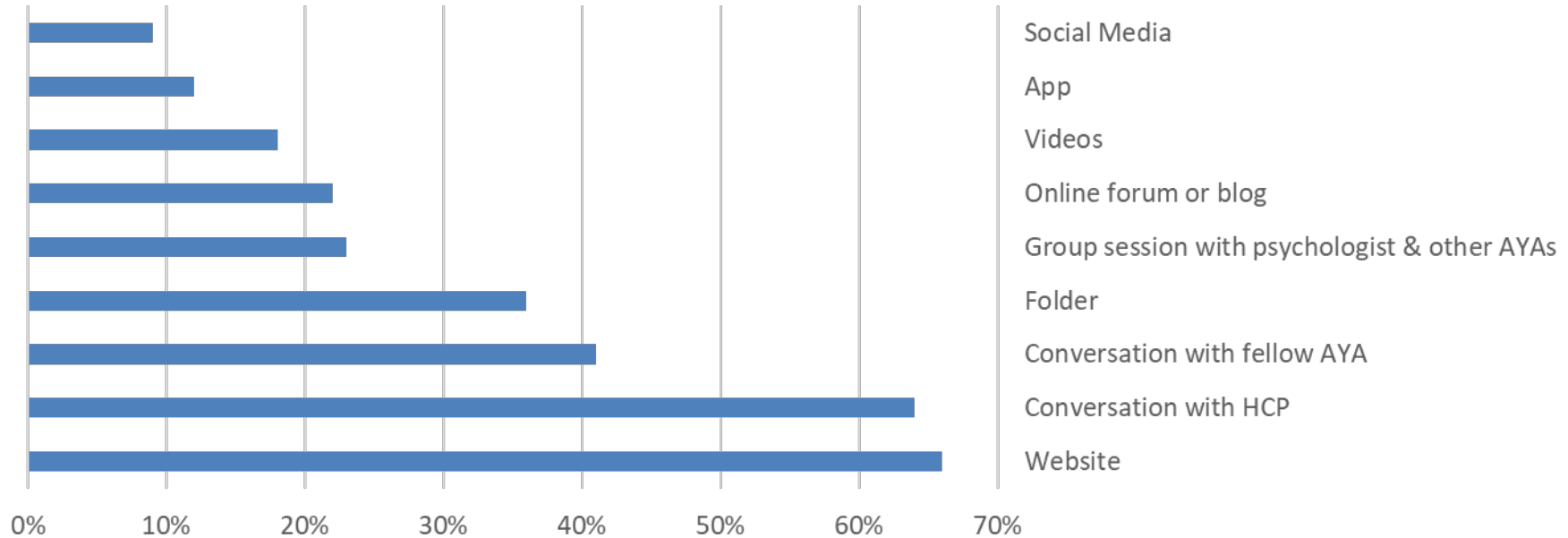
Poll Question #6

How do AYAs prefer to receive sexual health information?

- a) From other AYAs
- b) Social media
- c) From their parents
- d) Website

What AYAs tell us

Best way for providing information to AYAs



AYA Sexual Health Toolkit



Clinical tools

- PROMIS (Patient-Reported Outcomes Measurement Information System)
 - PROMIS SexFS v2.0 measures a range of sexual activities, symptoms, functioning, and evaluation of experiences over the past 30 days
 - Male & female version, brief version
 - Validated measurement used for research studies
- FSFI (Female Sexual Function Index)
 - 19 questions measures a range of sexual activities, symptoms, functioning, and evaluation of experiences over the past 30 days
 - It was developed for the specific purpose of assessing domains of sexual functioning (e.g. sexual arousal, orgasm, satisfaction, pain) in clinical trials

Promis Scale v2.0: Satisfaction with Sex Life

- In the past 30 days, how satisfied have you been with your sex life?
- In the past 30 days, how much pleasure has your sex life given you?
- In the past 30 days, how often have you thought your sex life is wonderful?
- In the past 30 days how satisfied have you been with your sexual relationship(s)?
- In the past 30 days, when you have had sexual activity, how much have you enjoyed it?
- Not at all/a little bit/somewhat/quite a bit/very

Limitations

- Many tools are not validated for under 18
- Needs to be administered by someone familiar with tool and scoring
- Can be useful for a basic screen to alert provider that a referral is needed

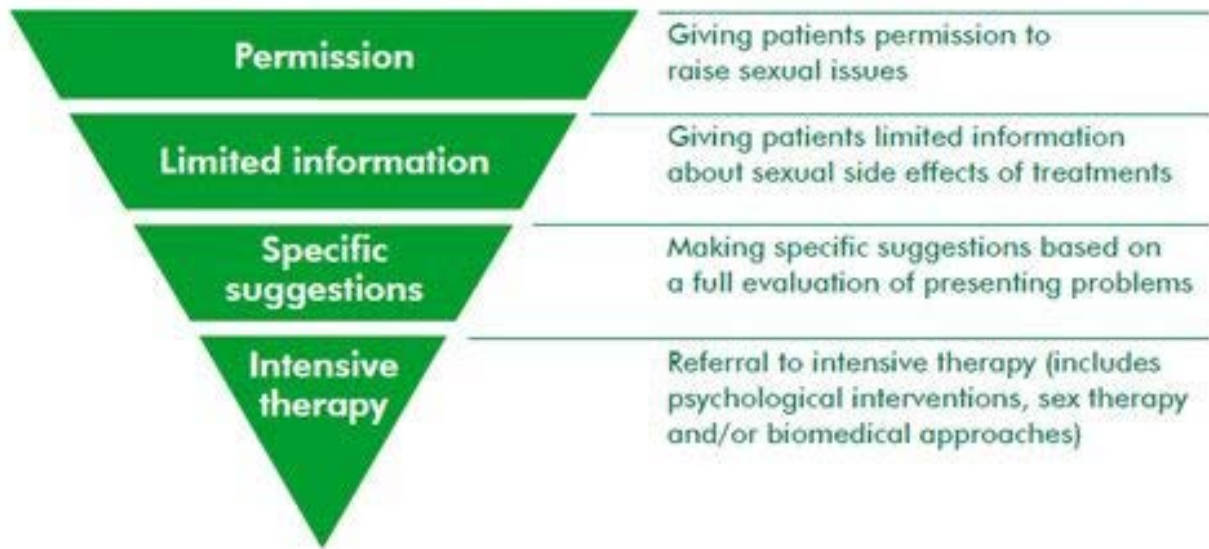
Communication tools



NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.

An oldie but a goodie...

PLISSIT Model of Addressing Sexual Functioning (Annon, 1974)



PLISSIT

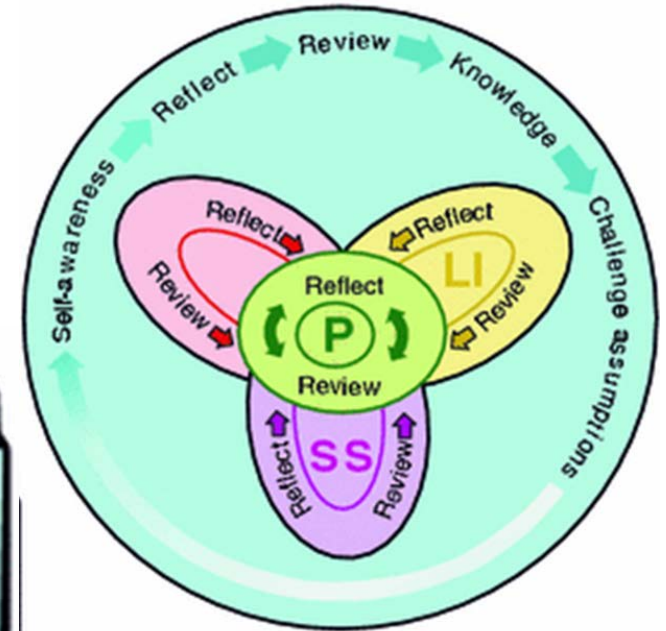
- Developed in 1974
- Originally created to address sexual health needs in individuals with an acquired disability
- Modified in 2006 to Ex-PLISSIT
- Key features of Ex-PLISSIT model include
 - explicit permission-giving as a core feature of each of the other stages
 - requirement to review all interactions with patients
 - incorporation of reflection as a means of increasing self-awareness by challenging assumptions

Ex PLISSIT

- **P**ermission at every stage & every visit
 - Assessment
- **L**imited **I**nformation
 - Education
 - Written information
- **S**pecific **S**uggestions
 - Counseling
- **I**ntensive **T**herapy
 - Referrals

| KEY | |
|-----|----------------------|
| P | Permission giving |
| LI | Limited Information |
| SS | Specific Suggestions |
| IT | Intensive Therapy |

The Extended PLISSIT Model



The 5 A's Model

- Ask
 - Validation
 - Advise
 - Brief opportunity to advise to problem can be addressed
 - Assess
 - Ask functional questions in matter of fact manner
 - Assist
 - Provide education, information, and resources
 - Arrange Follow up
-



Carter et al 2016

AIDED Approach

- **Assess** understanding or knowledge
- **Introduce** the topic
- **Describe** potential impact
- **Explain**
- **Discuss**

TABLE 2. An AIDED Approach to Talking With Your Patients About Their Fertility*

| Central Components | Sample Probes/Talking Points |
|---|--|
| Assess patient's general understanding of their diagnosis and its potential impact on fertility as well as current and future desires to have a child. | "Has anyone discussed how your cancer treatment may affect your ability to have children?" |
| | "I would like to discuss how your cancer treatment might affect your ability to have children. I'd like to understand your perspective so that we can discuss potential options." |
| | "I know this is something you may not be thinking about right now, but do you think you may want to have (more) children in the future?" |
| Introduce the topic of fertility and why you are discussing this topic. | "I would like to talk with you about these issues. Is this something you would like to hear about?" |
| | "Is there someone you would like to have with you when we talk about this?" |
| | "Before I begin, tell me what you have already been told about the possible effect of treatment on your fertility." |
| Describe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biologic and nonbiological parenting options. | "Risk(s) of infertility with patients depends on the disease type and planned treatment(s)." |
| | "The recommended treatment involves freezing fertilized eggs/your eggs/your sperm. Can I describe those to you now?" |
| Explain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists. | "The process for freezing an embryo/your eggs takes 2.5 to 3 weeks. When patients are interested in these options, we refer them to a specialist." |
| | "The process for freezing your sperm takes a week to 10 days, and men usually give three separate specimens with 2 to 5 days between collections. When patients are interested in this option, we refer them to a specialist." |
| Discuss and provide patients with information and offer support to facilitate decisions about fertility preservation. | "This can be a difficult decision. There is no "right" decision, and we will support you whatever you decide. The goal is to provide all the information you need to make the best decision for yourself based on what you know and need right now." |

Abbreviation: AYA, adolescent and young adult.

*Communication tips adapted from Vadaparampil et al.⁴⁴ Detailed scripts and additional information are available for female patients, male patients, and post-treatment survivors.

*TABLE 2. An AIDED Approach to Talking With Your Patients About Their Fertility**

Published in: Giselle K. Perez; John M. Salsman; Kaitlyn Fladeboe; Anne C. Kirchhoff; Elyse R. Park; Abby R. Rosenberg; *American Society of Clinical Oncology Educational Book* 40e171-e185.

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Additional tips for success

- Use simple dignified words
- Start with least sensitive topics first
- Ask open-ended questions
- NORMALIZE
- Stay nonjudgmental
- Practice

Know your HOT buttons

- Knowing your own issues in advance will help you be calm in difficult situations
- Be open
 - You may be the only person the patient brings up this topic to. Your responses may affect whether or not the patient feels safe bringing it up again
- Don't forget to *LISTEN*



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Conversation starters

- *Many patients I have cared for have shared that they are concerned about how cancer can affect their relationships and sex life... is this something you have thought about?*
- *It's common for teens to feel that cancer has affected their romantic relationships and sense of intimacy. Has this been true for you?*
- *I want to make sure I am giving you the best care that I can and all the information you need to stay healthy? Is there anything about your sexuality or sex life that would be important for me to know?*
- *I want you to know that this conversation will be confidential, which means that I won't tell anyone else what you tell me.*

TABLE 3. Discussing Sexual Health

| Central Components | Sample Probes/Talking Points |
|--|--|
| Initiating conversations | <p data-bbox="537 85 1619 139">“I’d like to ask you some questions about your sexual health. Is that okay? You don’t have to answer any questions that you don’t want to.”</p> <p data-bbox="537 150 1619 238">“If it is okay with you, I’d like to share some information with you about how [cancer/treatment] may affect your sexual health. Even if this doesn’t feel relevant for you right now, it might be helpful information for you to have for the future.”</p> |
| Asking and eliciting important questions | <p data-bbox="537 248 1619 336">“It is important for me to know what is important to you. This includes your personal life like sex and intimacy. How would you describe your sexual orientation? Are you attracted to men, women, both, or neither? What about your gender identity? Do you identify as a man, woman, or non-binary?”</p> <p data-bbox="537 347 1619 401">“Sometimes young people with cancer feel like they don’t get enough information from their doctors/nurses about their sexual health, and I want to make sure I’m giving you all the information you need. What else would you like to know?”</p> <p data-bbox="537 412 1619 467">“It’s common for teens and young adults to feel that cancer has affected their sense of intimacy or romantic relationships. Has this been true for you?”</p> |
| Normalizing and validating | <p data-bbox="537 478 1619 565">“Talking about sex and gender can feel awkward, and I confess I may not use or say the right words. I invite you to correct me or help me so that I can take better care of you.” Always ask how your patient would like to be referred to and their preferred language.</p> <p data-bbox="537 576 1619 663">“Many young people with cancer experience concerns with their sexual functioning. Often, they don’t realize that these issues can be related to their treatment, and in some cases, there are things we can do to help. We are here to answer any of your questions about what might be related to your cancer treatment.”</p> <p data-bbox="537 674 1619 729">“Sometimes teens and young adults with cancer are curious about how their cancer treatment can affect their sexual health but don’t feel comfortable asking. Would it help if I share some information about it?”</p> |
| Creating a safe space | <p data-bbox="537 740 1619 827">“I want to make sure I am giving you the best care I can and all the information you need to stay healthy. Is there anything about your sexuality or sex life that I haven’t asked about but you think it would be important for me to know?”</p> <p data-bbox="537 838 1619 893">To an adolescent: “I’d like to talk to you about your sexual health. I want you to know that this conversation will be confidential, which means that I won’t tell anyone else what you tell me.”</p> <p data-bbox="537 904 1619 958">To a parent: “As part of his/her cancer care, we routinely have conversations with your son/daughter about their sexual health. What should I know about how you have discussed this in your family so far?”</p> <p data-bbox="537 969 1619 1016">“Sometimes teens and young adults feel more comfortable discussing their sexual health with a clinician of their same gender. Is that something you would prefer?”</p> |

A word about confidentiality

- Laws vary by state
- Tell adolescents you will keep discussions private
- Review instances when you are required to share confidential information
- Offer to share together if necessary



PEOPLE YOUNGER THAN 18 MAY CONSENT TO:

| STATE | <u>CONTR ACCEPTI VE SERVIC ES</u> | <u>STI SERVI CES</u> | <u>PRE NATA L CAR E</u> | <u>ADOPTI ON</u> | <u>MEDICAL CARE FOR MINOR'S CHILD</u> | <u>ABORTION SERVICES</u> |
|-------------------|---|------------------------------|---|----------------------|---|------------------------------|
| Alabama | All† | All* | All | All | All | Parental Consent |
| Alaska | All | All | All | | All | ▼ (Parental Notice) |
| Arizona | All | All | | All | | Parental Consent |
| Arkansas | All | All* | All | | All | Parental Consent |
| California | All | All | All | All | | ▼ (Parental Consent) |
| Colorado | All | All | All | All | All | Parental Notice |
| Connecticut | Some | All | | Legal counsel | All | All |
| Delaware | All* | All* | All* | All | All | Parental Notice‡ |
| Dist. of Columbia | All | All | All | All | All | All |
| Florida | Some | All | All | | All | Parental Consent and |

<https://www.guttmacher.org/state-policy/explore/overview-minors-consent-law>

Highlights

- The Guttmacher Institute is a research and policy organization committed to advancing sexual and reproductive health rights in the US and globally
- Many states permit all or some people younger than 18 to obtain contraceptive, prenatal and STI services without parental involvement.
 - 27 states allow all individuals to consent for contraception
 - 19 allows only certain individuals under 18 to consent for contraception
 - 4 states have no explicit policy or case law
- For laws related to HIV, other STI services, pregnancy care, adoption or medical care for a child, state laws apply to all individuals age 12-17.
 - 39 states & DC allow all individuals regardless of age to consent to STI & HIV services
 - 18 states allow, but do not require, a provider to inform a young person's parents that he or she is seeking or receiving STI services when deemed in patient's best interest

Dealing with parents

- Make it routine care to provide time for AYAs to be alone with their providers
- Assure parents you are all part of one team
- Know confidentiality boundaries
- Follow up with parents in broad terms

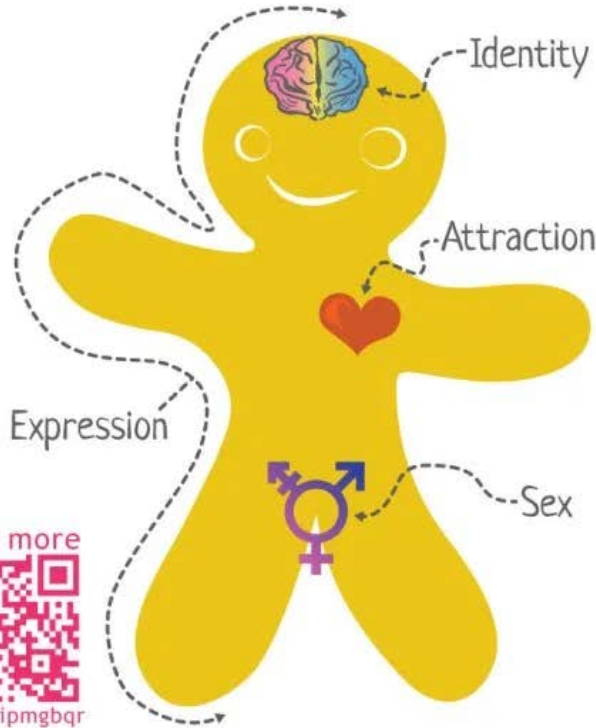


Special populations

- 500,000 to 1 million adults in the US are cancer survivors and identify as sexual and gender minorities
- Sexual/gender minority (SGM) refers to individuals who identify with a diverse array of sexual orientations and gender identities including lesbian, gay, bisexual, transgender, as well as queer/questioning & intersex
- Understudied
- Higher levels of mental distress than heterosexual patients

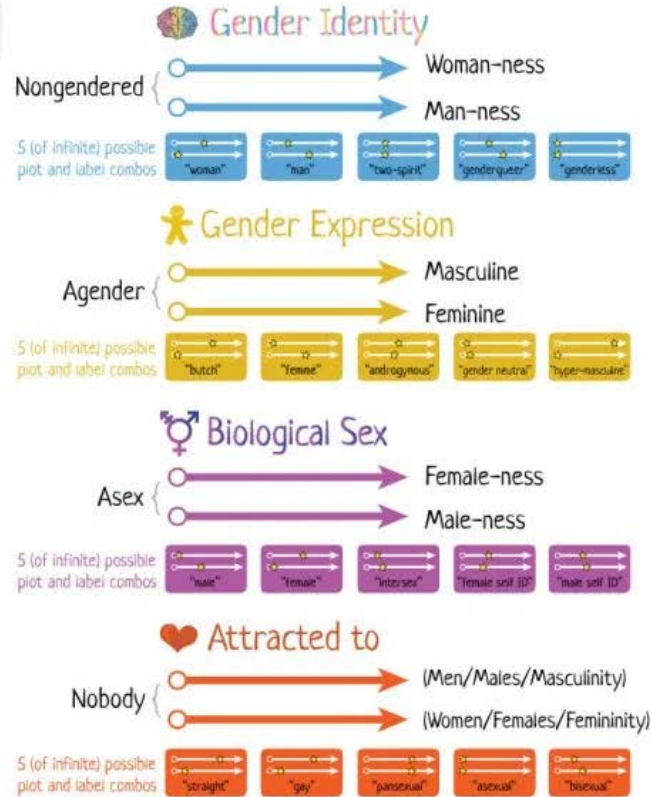
The Genderbread Person v2.0 by its pronounced METROsexual ^{comer}

Gender is one of those things everyone thinks they understand, but most people don't. Like *Inception*. Gender isn't binary. It's not either/or. In many cases it's both/and. A bit of this, a dash of that. This tasty little guide is meant to be an appetizer for understanding. It's okay if you're hungry for more.



read more

bit.ly/ipmgbqr



<https://socialworkhelper.com/wp-content/uploads/2013/07/Genderbread-2.1.pdf>

Improving care of SGM

- Education
 - Unique physiologic and psychologic needs
- Use inclusive language & materials
- Treat patients and partners with respect
- Create a safe environment
- Develop a referral network for at risk patients





Influence of Religion and Culture

- Ask about religious or cultural views that may impact care
 - Contraception
 - Sexuality
 - Marriage
 - Procreation
- Does the patient have the same viewpoint as their parents?
- Who is the family decision maker?

Palliative care

- Sexual health & intimacy is an important quality of life issue
- Patients in terminal phase of life value intimate relationships
- Health care providers less likely to bring up topic or never brought it up at all

Where to find help

- **Scarleteen:** This website provides a wealth of information for teens and young adults about sexuality, sex, and relationships, as well as advice and support, and even a safer sex shop. www.scarleteen.com/
- **Safe Teens:** Teenagers can use this youth-friendly website to find information on teen pregnancy, STDs, safe sex, relationships, and LGBTQ issues. www.safeteens.org/
- **American Sexual Health Association:** This associations provides a wealth of resources on sexual health for both men and women, and specific resources directed at teens and young adults. www.ashasexualhealth.org/sexual-health/teens-and-young-adults/
- **Amaze:** AMAZE harnesses the power of digital media to provide **young adolescents** around the globe with medically accurate, age-appropriate, affirming, and honest sex education <https://amaze.org/>

Additional help

- **Leukemia & Lymphoma Society:** Cancer specific information on sexuality and intimacy <https://www.lls.org/managing-your-cancer/sexuality-and-intimacy>
- **American Association of Sexuality Educators, Counselors, and therapists:** <https://www.aasect.org/>
- **Sex, Etc.:** Created for teens, by teens, this website provides accurate and honest information to improve teen sexual health, as well as various ways for adolescents to get involved in various campaigns around sexual and reproductive health <http://sexetc.org/>
- **Gay and Lesbian Medical Association:** Ensuring health equity for LGBTQ individuals <http://www.glma.org/>

The bottom line

- You do NOT need to be an expert in sexual health
- You DO need to be an expert in listening and following up



Key takeaways

- AYA cancer patients & survivors are having/thinking about sex
- AYA cancer survivors frequently experience sexual dysfunction
- AYA cancer patients want to talk about it but don't want to bring it up
- Health care providers are inept at talking about sex
- Nurses are uniquely positioned to fill this gap
- BRING IT UP and then LISTEN



Poll Question #7

How do you feel about addressing sexual health concerns with an AYA cancer patient *now*?

- a) I'd still rather have a root canal
- b) It's my job so I will give it a shot
- c) I will power through it because I recognize how important it is to my patients
- d) I feel better about discussing this topic after this talk 😊



My sincere thanks to the APHON conference planning committee for making it possible to continue our annual conference in spite of unprecedented challenges

Thank you to the Fertility & Reproductive Health team at Nationwide Children's for their support & dedication

Thank you to my kids for being my reason for everything



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