

# Implementation Framework

After Cancer, Inc, through its work on the All of Me project developed an Implementation Framework for Sexual Health Care in Oncology.

This guide is written for health care providers and care teams who work with people who have cancer, who are being treated for cancer, or who are cancer survivors. Our work grew out of care needs identified by people impacted by cancer, focus groups with providers, a needs assessment, and listening to providers and care team members during six half-day workshops around Iowa over the past two years. It aims to be consistent with national guidance from the National Comprehensive Cancer Network and American Society of Clinical Oncology. Our work is also informed by the international approaches described in the textbook of the European Society of Sexual Medicine. The resulting framework has been validated during two statewide conferences attended by a total of 140 providers. Our target audience includes advanced practice professionals, oncology nurses, navigators, social workers, physical therapists, radiation therapists, and mental health therapists, as well as other members of the patient care team who interface with patients regarding treatment side effects.

The type of cancer, the treatment modality and the physical space where cancer care occurs does not limit the application of this framework – it should be utilized in the manner which best suits the patient's needs, the oncology care setting, or both. This framework and the associated tools are designed to improve sexual health care at any and every visit where cancer care occurs. The purpose of sexual health care in the oncology setting is to reduce patient uncertainty, confusion, anxiety and distress while improving sexual health outcomes. Reduction of patient apprehension is the responsibility of the cancer care team and essential for effective and efficient communication in the medical setting.

Sexual health outcomes after cancer will improve as the focus of cancer care shifts away from rehabilitation toward prevention. This shift is being driven by patient demand and is aided by patient-centered cancer conversations. Treatment decisions that reflect the integration of individual quality of life priorities and pertinent medical information have become the standard of care for prostate cancer, leading to efforts to mitigate surgical morbidity through sexual “pre-habilitation”. However, critical gaps in research and evidence currently exist at the intersection of oncology and sexual medicine as well as other related fields. When treatment-related loss of function after a medical intervention is likely or inevitable, the provider's responsibility to reduce harm is increased, not reduced. This obligation requires doing everything possible to nurture each patient's agency over their sexual health and to minimize negative outcomes by offering all ethical treatment choices.

## Normalize the Sexual Health Conversation

Sexual health care can be provided at every visit where quality of life and side effects are addressed. Many providers will be limited by time, physical environment and other work duties when striving to provide sexual health care in an oncology setting. Other providers will encounter patients in a setting with adequate time, privacy or even the opportunity to schedule dedicated appointments. Discussion of sexual health within oncology can be a short 30-second statement provided in a private or group setting, perhaps with other people impacted by cancer or family members present. Conversely, it may be a one-on-one conversation which spans multiple appointments. Every oncology visit where sexual health is addressed, no matter the location or length of time, will aid in normalizing the sexual health conversation and holding a space for patients to ask questions or bring up concerns at any follow up appointments.

- a. Create and deliver a 30-second message to normalize the conversation about sexual health and sexual health side effects. Supplemental Tool = Short Message Worksheet and Sample Messages
- b. Use this message at the first cancer care visit and every subsequent visit where QOL and/or side effects of cancer treatment are discussed.
  - i. Deliver your 30-second message about sexual health effects whether or not the individual is currently sexually active.
  - ii. Advise that there will be future opportunities to continue and expand the discussion of cancer and sexual health.
  - iii. Encourage questions about cancer and sexual health

## Set Expectations

The anticipated sexual health effects of the specific cancer type must be shared. Sexual health may be impacted as a result of anatomic changes or treatment side effects. The role of the provider is to be proactive in sharing information and guiding the person impacted by cancer in setting realistic expectations of altered sexual health and function. One way this may occur is in providing vocabulary that allows clear communication about physical, mental, and emotional changes. Information and resources can further support understanding and clarity.

Setting patient expectations occurs as part of your 30-second message related to sexual health and cancer. The specific side effects that impact sexual function and the sexual response cycle can be listed in your 30-second message.

1. State clearly that sexual health effects of cancer and cancer treatment side effects are expected
  - a. Individualize consideration of sexual health and function for each person impacted by cancer
  - b. Consider the intersection of sexual health and function with each the following as appropriate:
    - i. Effects of cancer type
    - ii. Effects of the disease and the specific cancer treatment
      1. Surgery (cancer-related and reconstructive)
      2. Chemotherapy
      3. Radiation
      4. Hormone therapy
      5. Other medications
    - iii. Direct and indirect impact(s) on sexual function
    - iv. Short-term and long-term impact(s) on sexual function
    - v. Individual and partner and/or intimate relationship(s)
    - vi. Supplemental Tool = Web of Sexual Dysfunction
2. Provide information related to sexual health side effects
  - a. Offer 'frequently asked questions' signage, wording and terminology to support formation of questions about sexual health and cancer
    - i. In the counseling space
    - ii. In other exam rooms
    - iii. In the waiting room
  - b. Offer individualized information to people impacted by cancer Patient Educational Handouts
3. Provide patient educational materials, related to common challenges for navigating intimacy, available for patients to take home at the end of the visit. (See list of handouts available for order on the After Cancer website)
4. Inform patients that appointments can be scheduled with a Provider in their clinic to further discuss the impact of cancer treatment on their sexual, answer questions, and evaluate and address concerns.

## Refer Patients Timely

Care team members may need to refer a patient to a Provider in their clinic to answer their questions or concerns, or to evaluate patients for possible issues impacting their sexual health.

Providers may receive sexual health questions and concerns they are unable to address. Identifying the referral resources available is the beginning of forming a diverse network to support sexual health for people impacted by cancer. A variety of resources including specialists in various fields, websites, books, and articles can contribute to the sexual health discussion. These resources can assist with refining the patient's ability to ask questions, communicate concerns, adjust expectations, set personal goals, and accept change or loss.

1. Identify internal & external referral resources

- i. Subject matter experts who have experience addressing sexual health issues with people impacted by cancer
    - ii. Any person who regularly interfaces with people impacted by cancer in addressing quality of life effects caused by cancer or its treatment
  - b. Create a Referral Roadmap
    - ii. Individual needs – current, known, and future/anticipated
    - iii. Current referral resources
      - 1. Internal: already exist within the cancer center or health system
      - 2. External: local, regional, and national
    - iv. Supplemental Tool = Current Roadmap to Referrals
  - c. Contact current referral resources
  - d. Evaluate and update the referral process on a regular basis
2. Offer existing information in various formats
- a. Provide written, take-home information about both internal and external referral resources
  - b. Provide information individuals can share with their partner(s) to enhance communication about sexual health (i.e. body image issues, fatigue, etc.)
  - c. Display and provide hard copies of internal and external sexual health resources which individuals may take home without asking the provider (locations may include the waiting room, counseling spaces and/or exam rooms)
  - d. Support groups may exist locally, nationally and internationally as well as on the internet through organization websites and social media
  - e. Resources including books, articles and other written materials are available on the websites above









