# Let’s Talk About Sexual Health and Fertility Issues Faced by People With Cancer

A National Comprehensive Cancer Network forum examines how knowledge gaps, societal stigma and shifting policies can impact quality of life for people with cancer.

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The National Comprehensive Cancer Network (NCCN)—an alliance of leading cancer centers—hosted an oncology policy summit May 6 focused on how sexual and reproductive health can impact people with cancer before, during, and after treatment. Speakers covered a wide range of topics, within the context of gender and sex, intimacy, fertility and reproductive health, treatment side-effects, and the impact of a changing policy landscape in the wake of new laws and judicial decisions.

The summit began with an introduction from NCCN’s Chief Executive Officer, Crystal S. Denlinger, MD, who previously served for many years as Chair of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship. These evidence-based expert consensus recommendations feature best practices for addressing sexual health, fertility, hormone-related symptoms, and many other late and long-term effects from cancer. The clinician-facing NCCN Guidelines for Survivorship, as well as a patient- and caregiver-friendly format, are all available for free at NCCN.org or via the Virtual Library of NCCN Guidelines App.

Dr. Denlinger remarked: “We can’t overlook the importance of quality of life for people being treated for cancer and those in remission. High-quality cancer care means addressing any barriers preventing patients from living their best possible life. When it comes to sexual and reproductive health, lack of discussion can be a significant limitation. That is why we have brought together a diverse group of experts to take part in these delicate but important conversations.”

“Research strongly suggests that oncologists and other cancer clinicians receive little training on how to discuss sexual health and related concerns with their patients, to the detriment of their patients’ care and health outcomes,” added Jennifer Barsky Reese, PhD, FSBM, Associate Professor, Cancer Prevention and Control Program, Fox Chase Cancer Center. “It is so important that education about sexual and reproductive health be included into the training of cancer clinicians if these critical health issues are to be addressed in patients’ comprehensive cancer care.”

“No one should feel like they have to suffer just because they’ve been diagnosed with cancer,” agreed panelist Mindy Goldman, MD, UCSF Helen Diller Family Comprehensive Cancer Center, Member of the NCCN Guidelines Panel for Survivorship. “Early menopause is a seldom discussed, but frequent side-effect from cancer treatment. We have options to address the symptoms, but patients are often afraid to bring them up or don’t know who to talk to about them, and clinicians may also consider it to be a taboo topic. Patients seeking answers will often find themselves confused or relying on unvetted on-line material. We hope that by including recommendations on treatment for sexual function issues in the NCCN Guidelines, we can help people have the information they need to facilitate these necessary conversations with their care providers.”

Cecile Ferrando, MD, MPH, Professor of Obstetrics & Gynecology & Reproductive Sciences UC San Diego Department of OBGYN & Reproductive Sciences, gave a morning keynote address describing aspects of cancer care and how they fit within the context of the larger life experience of the patient.

According to Dr. Ferrando: “The cancer survivorship phase can be just as important as the treatment phase. Clinicians should know how to provide inclusive care that considers both one’s gender identity and sexuality in addition to the patient’s personal values and goals. This is why each individual patient story is so important.”

Two afternoon keynote speakers shared first-hand looks at the issue of reproductive health and fertility preservation for people undergoing cancer care.

“As someone who has fought for laws to protect fertility options for cancer patients, and founded Cervivor, Inc. to educate and empower cervical cancer patients and survivors, I believe sexual and reproductive health should be core aspects of cancer care,” said Tamika Felder, Chief Visionary, Cervivor, Inc. “It’s about quality of life and dignity. By sharing our stories, we can also reduce the stigma around cancers like cervical cancer. Policies must reflect this to ensure everyone gets the care they need and deserve.”

“Patient navigators help guide patients through the healthcare system and overcome barriers,” explained Kristin Smith, Fertility Preservation Program Manager, Robert H. Lurie Comprehensive Cancer Center of Northwestern University. “Fertility preservation navigators can help bridge the institutional and interdisciplinary boundaries that exist for patients who need expedited care.”

Speakers throughout the day spoke about the many obstacles that prevent access to fertility preservation in eligible patients.

“A lesser-discussed side effect of common cancer treatments is the high-likelihood of infertility,” said Tracy Weiss, Executive Director, The Chick Mission. “Despite this startling fact, very few insurance programs offer preservation support to cancer patients, which leads to a lack of access and equity. That’s where The Chick Mission steps in—we strive to give people options regarding a future family before cancer makes decisions for them. We also try to keep this conversation buzzing for the public at large. In the six years since our organization was founded, we have awarded grants to more than 500 patients, saving families more than six million dollars in total.”

Sean Kern, MD, a urologic oncologist with the Murtha Cancer Center, Uniformed Services University and Walter Reed National Military Medical Center treats cancer patients and is also a survivor himself.

Dr. Kern stated: “Adolescent and young adult cancer patients are a particularly vulnerable population when it comes to sexual health and infertility concerns. We can’t emphasize enough how important it is to be mindful of how to minimize and manage the late toxicities from cancer treatment. Patients should be counseled on the impact treatment may have on fertility and sexual health, so they can know their options and receive appropriate, multidisciplinary care.”

The panelists also examined how an unclear patchwork of state laws and regulations can impact patient access to appropriate, expert-recommended cancer care. They discussed potential “reproductive service deserts” and what care looks like in environments where doctors and patients may face medical decisions that could lead to possible criminal liability. Equity issues involving gender, race, location, and other factors were also highlighted.

Additional speakers included: Laila Agrawal, MD, Medical Oncologist, Norton Cancer Institute; Joyce Reinecke, JD, Executive Director, Alliance for Fertility Preservation; Scout, PhD, MA, Executive Director, National LGBT Cancer Network; Rebecca Spence, JD, MPH, Chief Ethics Counsel, American Society for Clinical Oncology (ASCO); and Ana Tergas, MD, Assistant Professor, Division of Gynecologic Oncology, Department of Surgery, City of Hope National Medical Center. The panel discussions were moderated by Clifford Goodman, PhD, and closing remarks were provided by Gary Weyhmuller, MBA, Chief Operating Officer, NCCN.

NCCN’s next policy summit will focus on Advancing Diversity, Equity, and Inclusion in the Cancer Workforce. That event will be taking place in Washington D.C. and online on Tuesday, September 10, 2024. Visit NCCN.org/summits to learn more.

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