

Sharing Personal Stories to Encourage Open Conversations Within Families About Hereditary Breast and Ovarian Cancer



An Instructional Guide Healthcare Providers,
for Screening Digital Stories

Produced by StoryCenter, in collaboration with the National Association of Chronic Disease Directors and the Centers for Disease Control and Prevention

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ABOUT THE PROJECT

There is a growing need for the healthcare sector to support family conversations about histories of cancer in the family, genetic counseling, and testing for cancer risk. In response to this need, the [National Association of Chronic Disease Directors](#), with funding from the Centers for Disease Control and Prevention's [Bring Your Brave Campaign](#), collaborated with [StoryCenter](#) on a [hereditary breast and ovarian cancer storytelling project](#).

The stories featured in this guide were created in online digital storytelling workshops facilitated by StoryCenter. They are intended to encourage open and honest family conversations about breast cancer risks and family history of cancer, and then urge people to talk to their healthcare providers about options for genetic testing. The hope is that the stories will inspire young women to learn their risk for breast and ovarian cancer, talk with their provider about their risk, and live a healthy lifestyle. The stories can also help providers support family discussions on known or unknown family history, health behaviors associated with risk, and cancer prevention strategies. The collection of stories from this project can be found [here](#).

Our special thanks go to the courageous storytellers whose work is featured here. Their openness to documenting their lived experience with breast and ovarian cancer represents a critical contribution to reproductive health promotion efforts.

TERMS OF USE

These materials can be used by healthcare providers to lead conversations with patients and at-risk family members and individuals. Additionally, the digital stories and associated materials can be integrated into medical school curricula to promote and cultivate empathetic care. We invite you to share the stories, *as long as you follow the instructions presented in this guide*. **Please refrain from screening or selling stories for commercial gain.**

DISCUSSION QUESTIONS

Below are tools for providers to use in leading discussions about the stories, including general discussion questions that may be useful with all of the stories, as well as a short summary, a list of key issues addressed, and specific questions that aim to bring out details and encourage more thoughtful discussion, for each individual story.

General Discussion Questions for All Stories

1. How did the story make you feel? Describe the parts of the story (audio and visual) that especially moved you, and talk about why. Take time to relate the feelings that came up in watching the story, to your own experiences– for example, if the story reminded you of painful, frustrating, or joyful events in your life.

2. From watching the story, what did you learn about:

- The people in it
- The place where it happened
- Genetic risk for breast and ovarian cancer
- Your own story of cancer

3. Has risk for hereditary breast or ovarian cancer (HBOC) been discussed in your family?

If YES:

- Who initiated the conversation and how?
- How did it go? Do you wish it had been done differently? How so?
- What makes these conversations difficult in your family? What has made them easier?

IF NO:

- Why not?
- How would you approach initiating this conversation in your family?

HEREDITARY BREAST AND OVARIAN CANCER STORIES: Content Summaries, Images, and Discussion Questions

The collection of stories from this project can be found [here](#). The stories are presented in alphabetical order below.

APRIL: Sister Stories

When April was 27, her oldest sister died from breast cancer. Later, April's second sister passed away before her 40th birthday. When April's third sister was diagnosed with breast cancer at 41, she was proactive with her treatment, and despite a second cancer diagnosis, is a 20+ year survivor. April could not find any record of a family history of breast and ovarian cancer before her oldest sister's diagnosis but wonders if this is because no one had ever talked about it. Now, members of her family communicate proactively about their risk and encourage the younger generations to get genetic testing.



Key Issues

- Stigma surrounding the topic of “women’s cancers” and reluctance within Black communities to seek care due to legacies of institutional racism within health systems
- The importance of family communication and support around seeking care and treatment
- The importance of proactive medical care and genetic testing to improve health and increase survivability

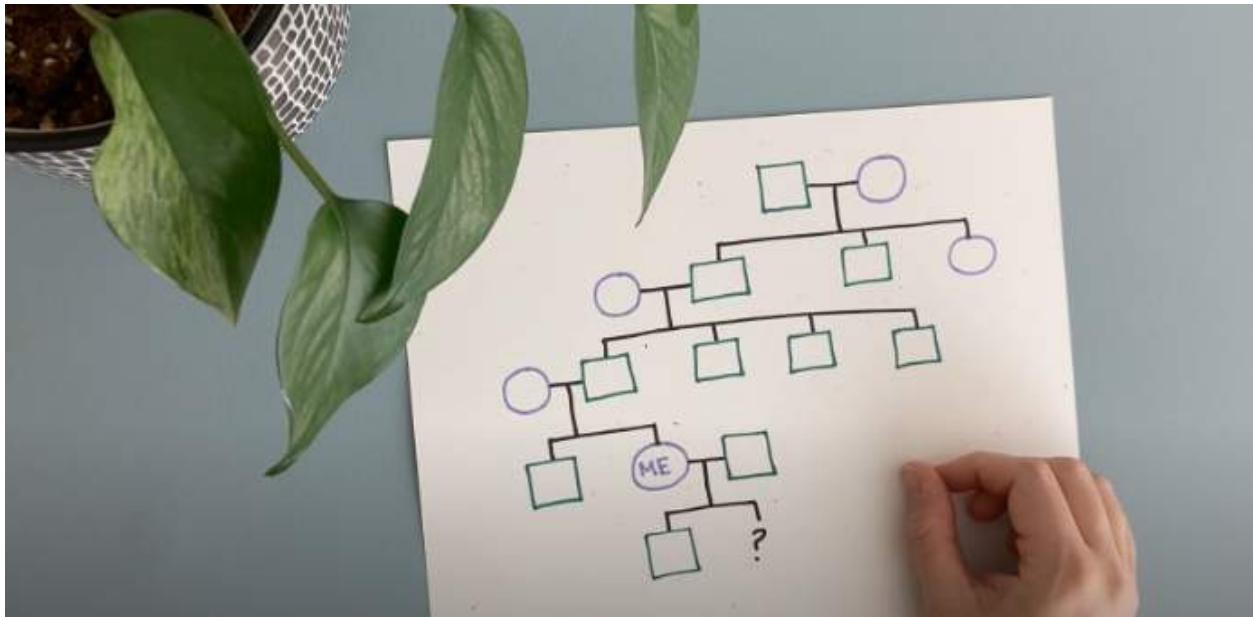


Discussion Questions for April's Story

- How might you go about discussing genetic testing and risk for breast and ovarian cancer with family members if your siblings had passed away from cancer? What challenges could you imagine with this conversation?
- How might April feel after testing negative for the genetic mutation, given her sisters' histories? If this were you, how would you have liked a health care provider to address potential survivor's guilt?
- How might stigma and institutional racism have influenced when April and her sisters received treatment?
- April's sister has offered support to others negotiating treatment and care. In what ways do you see yourself taking on a similar role, within your family?

CAITLYN: Let's Talk About It

Caitlyn got tested for the BRCA1 mutation after discovering both her father and great uncle carry it. When her genetic counselor called to tell her she had tested positive, Caitlyn immediately thought of her son, three years old at the time. A year and a half after receiving her results, Caitlyn still struggles with the fear of a potential cancer diagnosis, surgery, and the fact that surgery offers “no guarantees”. She reflects on her now four-year-old son and soon-to-be born second child, and how she and her family will talk openly with them about risk and the importance of genetic testing.



Key Issues

- The reality that men can also carry the BRCA and other genetic mutations
- Motherhood, and feeling the need to be “strong” for one’s children and partner
- What it’s like to receive a diagnosis of a genetic mutation for hereditary breast and ovarian cancer
- The importance of support from family, friends, and others in the hereditary breast and ovarian cancer world



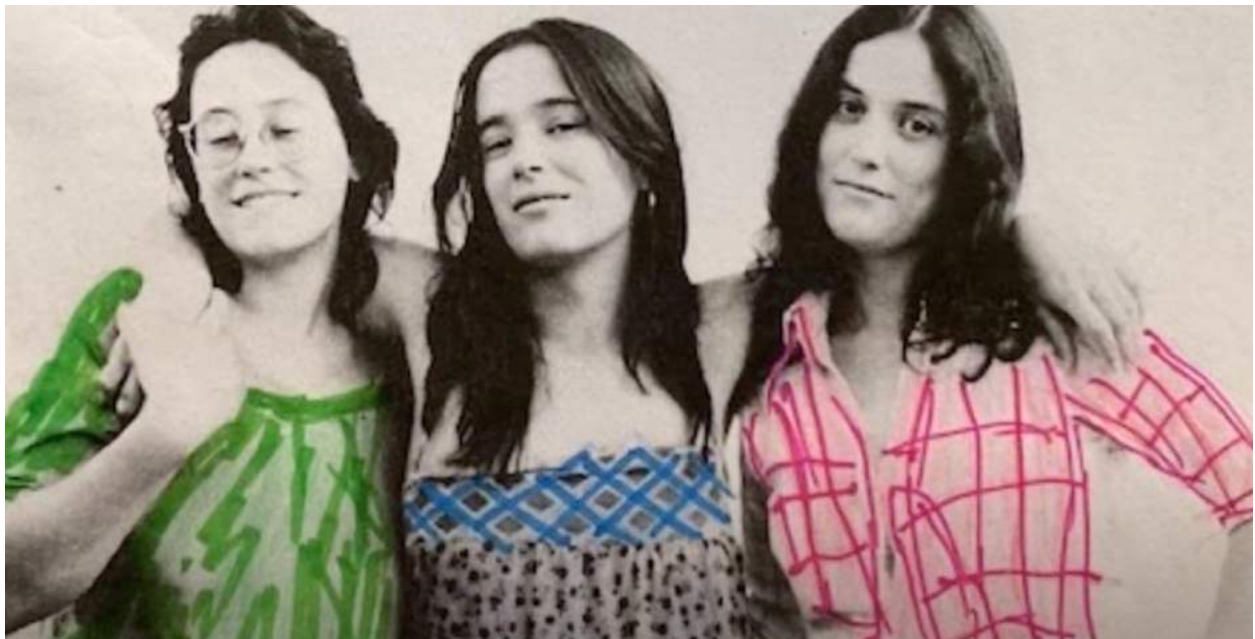
Discussion Questions for Caitlyn's Story

- Which side of Caitlyn's family did the BRCA1 mutation come from? Why is it important that she knows this information?
- How did Caitlyn react upon learning she could possibly have a genetic mutation, and how does she feel now? Who will she soon talk to about their family risk?
- Caitlyn kept her initial conversations with family members brief and factual, leaving room for them to ask questions in the future. How would you approach this conversation, within your family?
- What are effective ways of reminding people that testing positive for a genetic mutation for hereditary breast and ovarian cancer means there is time for early interventions which can reduce cancer risk?
- How might social support help address the fear and anxiety that can be provoked by a positive genetic test?

CARLA: Lucky

Carla's father immigrated to the United States in 1939, survived the Spanish Civil War, and served in WWII. Carla and her six siblings believed that, like their father, they could survive anything. Raised by a mother who stressed the importance of organic, healthy eating and a healthy lifestyle, Carla and her three sisters felt immune to serious illness. When she was 51, doctors found a stage III ovarian tumor and gave Carla five years to live. Sixteen years later and with no recurrences, she considers herself a "lucky one". In the time since her diagnosis, multiple family members have died from cancer. But because Carla's genetic testing was negative, her sisters and their doctors dismissed the need for testing.

Carla's sisters



Key Issues

- The importance of repeated genetic testing over time, as new cancer genes are identified
- The fact that family history can be a risk factor even when one family member tests negative for genetic mutations
- Facing the challenges that may arise when family members do not want genetic testing

Discussion Questions for Carla's Story

- In your experience, what impact does culture (family or otherwise) have on decisions about care seeking and genetic testing?
- What role might denial play in someone's decision to not seek genetic testing?

- Carla's sisters did not want to get genetic testing. If you were her, would you accept this choice or have difficulties with it? How might it impact your relationships with your sisters?
- Ovarian cancer is often detected at a late stage. How might primary care providers, specialists, and pharmacists help to spread awareness about early detection?
- Education and communication efforts about hereditary BRCA often overlook Black and Latino communities. What are ways that families, communities, and healthcare providers can address this omission?

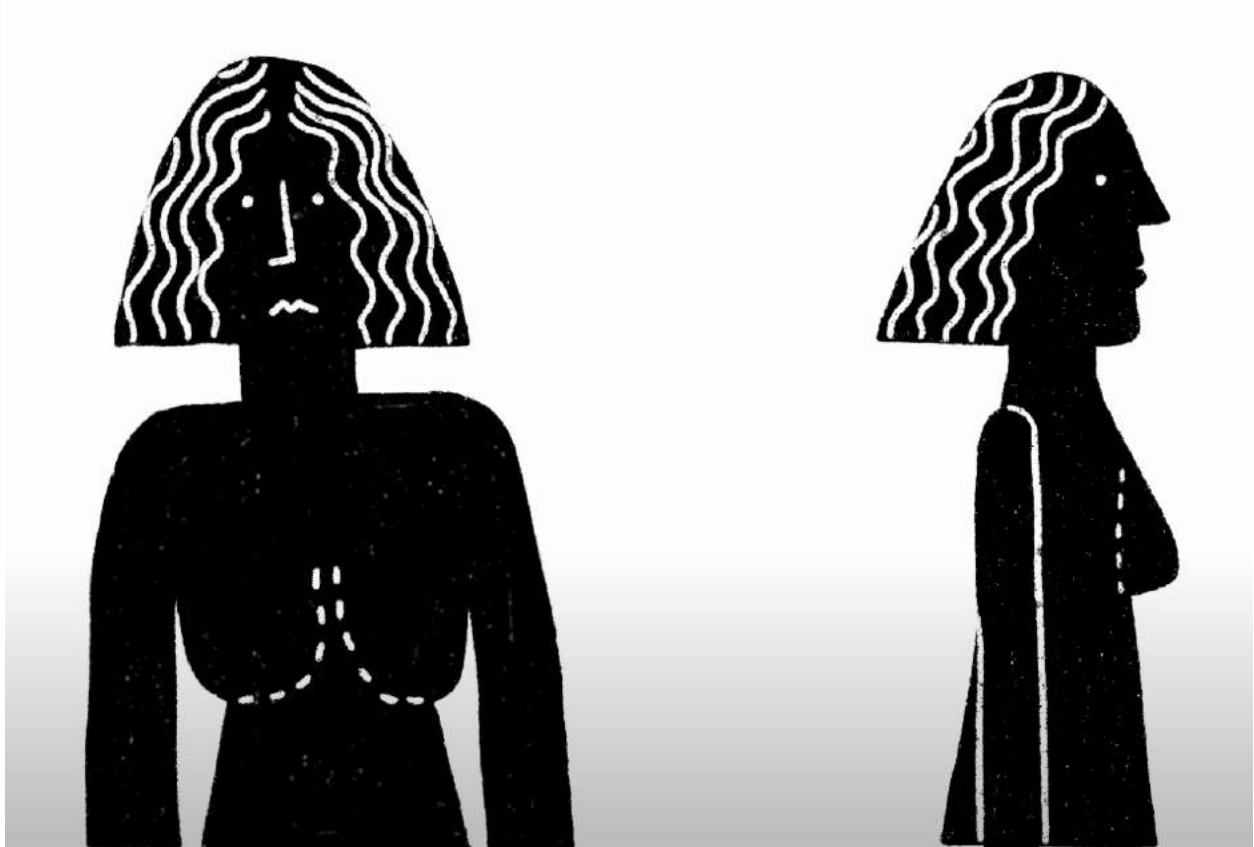
CHERIE TAYLOR: I Thought I was Safe

Thirteen years into remission from her first breast cancer diagnosis, Cherie tested positive for the BRCA1 mutation. She had a false sense of security from being in remission for so long and was more afraid of the preventative surgeries than the likelihood of cancer coming back. Cherie was never told by providers about the lack of early detection tests for ovarian cancer. Despite routine surveillance, she was diagnosed with late-stage ovarian cancer. She remains haunted by the words of a healthcare provider who asked, "why didn't you have the prophylactic preventative surgeries?"



Key Issues

- Failure of healthcare providers to be clear about the lack of tests for the early-detection of ovarian cancer
- Fear of mastectomy ("getting amputated") and early menopause overshadowing fear of a breast cancer return or ovarian cancer diagnosis
- Stigma and judgment from healthcare providers, particularly when the system is at fault for not giving accurate information



Discussion Questions for Cherie's Story

- Why do you think Cherie was never told about the challenges with testing for ovarian cancer— lack of early detection testing and challenges with diagnoses?
- Discuss the reality that healthcare providers can make mistakes. One of Cherie's providers told her the cancer is not her fault; another was judgmental. How can patients be better supported?
- What conflicting emotions might Cherie feel about her sister's preventative hysterectomy?
- Why might people with mutations for breast and ovarian cancer fear preventative surgeries? What role can family, social networks, and healthcare providers play in addressing these fears?

DEBORAH: It's Time to Have the Conversation

At age, 50 Deborah began having medical symptoms that made her think she was going through menopause. Instead, she was diagnosed with ovarian cancer. Deborah was advised to get genetic testing, due to her Ashkenazi Jewish heritage and the prevalence of cancer in her family. She tested positive for the BRCA1+ gene and decided on a bilateral mastectomy. While some people in her life viewed this as an extreme decision, it felt right to Deborah. Now that her son is 21, she is preparing to have a conversation with him about the importance of genetic testing.

Some of Deborah's family



Key Issues

- Genetic risk and Ashkenazi Jewish heritage; the importance of family testing
- Resistance from loved ones regarding prophylactic surgery
- Trusting one's choices and decisions
- Discussing genetic risk and testing with children



Discussion Questions for Deborah's Story

- Deborah is the first in her family to get genetic testing, despite cancers in the family and their Ashkenazi heritage. When she tested positive for BRCA1+ Deborah encouraged her mother, siblings, and cousins to get tested but very few did.
 - How might you, your family, or healthcare provider encourage families to get genetic testing?
 - What are the reasons family members at-risk for HBOC and other genetic cancers may not want to get tested?
- At the time Deborah got genetic testing she had to advocate to her health insurance company to cover the cost.
 - Is there complete access to testing in your community or healthcare system?
 - If not, what can be done by healthcare providers and systems?
- In the beginning of her story Deborah mentions a friend of the family who is a doctor that helped her receive excellent care. How might her story have been different without this "inside connection"?
 - How might healthcare systems ensure equitable access to quality treatment?
- Deborah's son was 10 at her diagnosis. He is now 21 and considering genetic testing. How would you approach the conversation about genetic testing at these different ages?

DEBRA

Debra gets inconclusive mammogram results soon after her older sister's death from breast cancer and her younger sister's breast cancer diagnosis. Debra's doctor suggested they "wait and see." Debra insists on being referred to a specialist, and is diagnosed with early-stage breast cancer within two months. Debra is grateful for her sister's communication with her, which she credits for her early diagnosis. Now Debra communicates about cancer risk with her mother-in-law, niece, and sons.

Debra's grandmother and sons



Key Issues

- The importance of proactive family communication about cancer incidence and risk
- Lack of communication in families about cancer, especially in older generations
- Inequitable access to preventative screening and specialist care for women of Color
- Importance of self-advocacy within the healthcare system
- Negative impact of prophylactic preventative surgeries on quality of life



Discussion Questions for Debra's Story

- Debra and her mother-in-law are Black. Her mother-in-law had annual health checks but was never referred for a mammogram. Debra's doctor told her to "wait and see" after her inconclusive mammogram and despite her sisters' aggressive breast cancer diagnoses. Discuss the role of race on access to care and treatment. What measures can healthcare providers and systems take to ensure equitable access to screening, care, and treatment?
- Debra receives a second breast cancer diagnosis despite her double mastectomy. She counsels her niece to reconsider the preventative removal of her breasts and ovaries based on this experience and the impact the prophylactic preventative surgeries had on her quality of life.

- o What impacts on her quality-of-life might Debra have experienced?
 - o Debra's niece also tested positive for the BRCA2 gene mutation, but does not have a cancer diagnosis. What decision would you make in this situation? What would factor into your decision-making process?
- Debra stresses to her sons the importance of self-advocacy within the healthcare system, based on her experience and that of her mother-in-law. How did it make you feel to hear about these experiences? What can be done to prevent this kind of institutional racism?

FELICIA

Felicia was 15 when her mother underwent a double mastectomy. She recalls the fear and anxiety she felt while waiting at the hospital, and also the silence within her family— despite the fact that three generations have had breast cancer. When Felicia is diagnosed with metastatic breast cancer, she decides to break the family silence. Now she is prepared to discuss risk and the importance of genetic testing with future generations of her family.



Key Issues

- Multigenerational silence about hereditary breast and ovarian cancer, compounded by legacies of discriminatory care and institutional racism within the healthcare sector.
- Mental health impacts on children, of family silence about hereditary breast and ovarian cancer
- Communication about risk and the importance of genetic testing



Discussion Questions for Felicia's Story

- Felicia's story begins with her memory of being 15 and waiting in the hospital during her mother's double mastectomy.
 - How might her family members have better supported her at this time?
 - What other support is important for children to receive if a parent or loved one is undergoing treatment for hereditary breast or ovarian cancer?
- Felicia mentions that genetic testing was not available to her mother's generation.
 - What impact do you think the lack of testing for older generations had on the lack of communication in her family?
 - How do you think older generations may feel about the increased access to testing and information that can benefit younger generations?

LESLIE

Leslie's 72-year-old mother had recently had a double mastectomy and started chemotherapy, when Leslie attended a Jewish women's convention where a speaker stressed the importance of genetic testing for cancer. Leslie suggested that her mother get tested, but the genetic counselor discouraged it, saying the odds were low and her insurance would not cover it. Leslie's mother decided to get genetic testing anyway, and found she carries the BRCA 1 mutation. Soon after, Leslie also tested positive for the mutation and had two preventative surgeries. Leslie's sisters and their children have gotten genetic testing, and when Leslie's children are old enough, they will as well.

Leslie and her mother



Key Issues

- The importance of genetic testing for Jewish women, even if there is no known history of breast or ovarian cancer
- Options for breast and ovarian cancer prevention and treatment for people that test positive for the BRCA 1 mutation.
- Knowing or learning about your family history, and encouraging family members to get genetic testing if someone gets a positive result

Leslie and her family



Discussion Questions for Leslie's Story

- Leslie's mother is not aware of family members with breast or ovarian cancer. She does remember a great grandmother who had "stomach cancer." The genetic counselor discourages genetic testing and says the odds of Leslie's mother having the BRCA 1 mutation were low, given her late diagnosis, no known family history, and lack of insurance coverage for testing.
 - o How does lack of awareness and communication about family history of breast or ovarian cancer influence risk?
 - o Should genetic testing be required for all women of Jewish heritage who receive a breast or ovarian cancer diagnosis?

- o What could have been done differently in this situation?
- How should families discuss the risk of hereditary breast and ovarian cancer, given the lack of access to testing and information experienced by older generations?
- Leslie's mother and siblings appeared to be very open to getting genetic testing.
 - o What factors do you think might have influenced their willingness?
- Leslie uses humor when she mentions that her mother should get tested "just for fun."
 - o What do you think about this approach? Would this work in your family?

SHANA

Shana was diagnosed with breast cancer and tested positive for the BRCA gene mutation at age 25. She asked her future husband to come with her to an appointment with her treatment team, knowing how important it is to communicate about her medical history. Shana's diagnosis saved her mother, who discovered her own cancer in the earliest stages after Shana's positive genetic result. Shana reflects on her hope that her future husband would value learning about her diagnosis, rather than deciding it's "too much." She also thinks about having the conversation with their three daughters, when they're old enough to understand.

Shana and her husband



Key Issues

- Sharing news of a cancer diagnosis with significant others
- Fear of losing a partner after disclosing a HBOC or BRCA 1 gene mutation diagnosis
- Deciding when to have a conversation with children about the potential for a BRCA 1 gene mutation

Shana's daughters



Discussion Questions for Shana's Story

- Shana worries about disclosing her diagnosis to her future husband.
 - Have you been in this situation? How did or would you approach this conversation?
- Shana receives her diagnosis at age 25.
 - How might age influence people's communication about hereditary breast and ovarian cancer?
- Shana's diagnosis prompted her mother to get genetic testing. Leslie is confident her diagnosis saved her mother
 - How might you incorporate a parent or family member into your conversations with your children, about their risk for hereditary breast and ovarian cancer?

SCREENING GUIDELINES

Below are guidelines for how to responsibly incorporate the digital stories as part of ongoing cancer prevention and management outreach, education, and clinical care. Specific guidance is provided regarding what to consider *before* screening stories and *when* stories are screened.

Before You Screen Stories ...

Know when and where NOT to show them

The sensitive nature of the stories demands that they be shared in closed, structured settings where an audience's attention can be captured fully and where healthy discussions can emerge. They should NOT be shown at large, unstructured community events, where follow up conversations are not possible.

Know your purpose and audience

Think about and identify your goals for sharing stories, and create an agenda to meet them. Consider your audience carefully. For example, will your viewers be breast and ovarian cancer patients and survivors? Medical students or clinicians? Family members or other at-risk individuals? The more you know about your audience, the better prepared you can be to plan discussions and address questions and issues that might arise.

Trauma-informed practice

The contents of some of these stories may raise strong feelings and responses among viewers. Proactively plan for individuals to express a range of emotions after watching and discussing stories. Be prepared to provide viewers with resources and information on accessing relevant local mental health support services.

Practice cultural humility

Cultural humility refers to an on-going practice of self-reflection regarding one's own beliefs and privileges, regarding race, sex, gender, ethnicity, religion, and ability. The end goal is understanding across differences. The practice of cultural humility in a clinical setting encourages providers to recognize the power imbalance in the patient/provider relationship, acknowledges that patients and providers can learn from each other, and values the lived experience of patients.

When You Present Stories ...

Introduce the stories appropriately

Please be sure to explain the following points prior to showing any of the digital stories:

- These stories were created in participatory media workshops led by a nonprofit organization called StoryCenter (www.storycenter.org).

- Every effort has been made to honor and protect the dignity of the storytellers in these videos. Please refrain from making negative comments about the storytellers and their life experiences, which they have so generously shared.

Provide content information for viewers

Some viewers may have a strong emotional response to the contents of particular stories, depending on their personal experiences. Offer an introduction prior to any screening, regarding the nature of the stories you're planning to show.

Establish an open space for discussion

Make the room comfortable and relaxed by arranging chairs in a circle, taking tables out of the room, and starting with games or ice breaking activities, as time allows. Provide refreshments when possible!

Set ground rules

Ask your audience for their ideas about rules that everyone can agree to. Examples include active listening, respect, openness, and confidentiality. This will promote a supportive and inclusive environment.

Try to involve everyone

Watch out for who is dominating the discussion and who is not contributing, and be respectful of different reasons people may have for being quiet. Gently suggest that more talkative people allow others to participate, and invite quieter people to join in.

Practice empathy

Think about how you will respond with empathy to a viewer who shares a difficult personal story about their own experiences. Appropriate responses might be, "thank you for telling us your own story ... how can we support you right now?" or "that's a very powerful story, thank you for bringing it up because it relates to what we've seen." Remember to validate people's experiences and relate them back to the discussion.

Discourage judgemental attitudes

If viewers suggest that what happened to a storyteller is that person's own fault, take care to talk about the role played by the structures (social, economic, and political factors) influencing the storyteller's life. Ask them to reflect on an experience in their own lives when they felt nervous about revealing something that happened to them or seeking help. Remind people that the stories capture a moment in time and should not be viewed as "ultimate truths" about storytellers' lives and identities.

Evaluate what worked and what might be improved

Allow time at the end of the screening and discussion to get viewer feedback. Brainstorm what questions promoted conversation, and which might be changed.

ADDITIONAL RESOURCES

With gratitude to the storytellers for the suggested resources.

- American Cancer Institute: <https://www.cancer.org/cancer/cancer-causes/genetics/understanding-genetic-testing-for-cancer.html>
- Basser Center for BRCA: <https://www.basser.org/>
- Centers for Disease Control and Prevention (CDC) *Bring Your Brave* Campaign:
https://www.cdc.gov/cancer/breast/young_women/bringyourbrave/hereditary_breast_cancer/talking-family-history.htm
- FORCE: <http://www.facingourrisk.org>
- Genetic Support Foundation: <https://geneticsupportfoundation.org>
- ICARE: <https://inheritedcancer.net/>
- National Association of Chronic Disease Directors:
<https://chronicdisease.org/>
- NIH: <https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet>
- The Ovarian Cancer Research Alliance, the oldest and largest OVCA charity in the world ocrahope.org
- Sharsheret: <http://www.sharsheret.org>

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<http://www.storycenter.org>**

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