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Disclaimer: The information in this guide is available for educational purposes only. Information and Resources should NOT be interpreted as medical advice. *All health information should be discussed with your health care* provider.



www.sparkmedia.org

About the Film:

Rhythm Heals

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In March of 2008, six cancer surgeons from around the country met and discovered they shared a passion not only for medicine but also for music. What began as a one-time gig playing cover songs for fellow surgeons turned into a new rock band named for the words every cancer patient dreams of hearing, No Evidence of Disease (N.E.D.)

The award-winning documentary of the same name, No Evidence of Disease, captures N.E.D's struggle for success as musicians, as they strive to save lives as doctors. Emailing MP3s and meeting over long weekends to rework song structures, lyrics, and arrangements, the Band's soulful music tells the intimate story of the cancer experience from the inside. Interwoven into the trajectory of the band are the real life stories of ordinary women facing excruciating life transitions, losses and grief.

An eerie silence surrounds the experience of gynecologic cancers (women's cancers), so that wives, daughters, mothers, sisters and aunts fighting the disease often find themselves alone and unable to communicate the complex feelings that arise when they are robbed of reproductive choices, identity and voice. Throughout this all-too-human roller coaster, N.E.D.'s music guides viewers through an array of super-charged and intense emotions. The film aims to bring this vital cause into the limelight and to energize an awareness movement for GYN cancers.

SHATTERING THE WALL OF SILENCE

Tens of thousands of women are diagnosed every year with a GYN cancer. Nearly one in three will die. Every hour, approximately ten women are diagnosed with one of the five major below-the-belt cancers: cervical, ovarian, uterine (endometrial), vaginal and vulvar.

Survivors often say, 'I didn't know.' What they didn't know were the signs and symptoms of GYN cancers. That's why Spark Media produced the documentary No Evidence of Disease, and wrote this discussion guide. We want every woman to know what to look for and what to do about GYN cancers, because with early detection and self-advocacy we can help save lives.



THERE'S MORE!

Spark Media has also produced What Every Woman Should Know, a companion piece to No Evidence of Disease. WEWSK is a 16-minute multimedia guide to the signs and symptoms of the major GYN cancers. It features the N.E.D. doctors, survivors, N.E.D. music, graphics, and – most importantly – information you need to know.

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Easy to view chart of GYN Symptoms

Gynecologic Cancer Symptoms					
Symptoms	Cervical Cancer	Ovarian Cancer	Uterine Cancer	Vaginal Cancer	Vulvar Cancer
Abnormal vaginal bleeding or discharge	•		•	•	
Pelvic pain or pressure		•	•		•
Abdominal or back pain		•			
Bloating					
Changes in bathroom habits		•		•	
Itching or burning of the vulva					•
Changes in vulva color or skin, such as a rash, sores, or warts					•

Centers for Disease Control

Women's Reproductive Organs



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Questions for your GYN:

It's difficult to remember everything you should ask during your annual visit to the gynecologist (If you have a concern, don't wait for your annual visit.) And, your doctor may not cover everything you want or need to know, so **come to your appointment with a written list of concerns and questions**. Perhaps you can start by discussing:

- Symptoms you have, such as abdominal pain, discomfort or bloating; changes in bladder or bowel habits; weight gain or loss; genital itchiness, burning sensation, or rash; and other symptoms unusual for you – especially if they last for two weeks or more
- Post-menopausal bleeding or spotting or any vaginal discharge
- Your menstrual cycle, bleeding pattern and any vaginal discharge (Are they within the normal range?
- Anything abnormal your doctor felt during your pelvic exam
- Your family cancer and general health history (Does anything raise concern about hereditary cancer? If so, what are the next steps?)
- Your exam and other test results (What, if anything, should you do based on your results? Should anything be monitored?)

Questions for your GYN ONCOLOGIST:

Have you been diagnosed with a GYN cancer? The doctors of N.E.D. recommend asking your GYN ONC the following questions. They are not comprehensive, as each person has a unique situation depending on the cancer type and diagnosis, but these talking points are a good starting point, and can ease the stress of finding out everything you need to know from your doctor. We've got your back!

All GYN Cancers:

- Is there any sign the cancer has spread beyond my cervix/uterus/ vagina/ovaries/vulva?
- What is my stage? Can you explain that to me?
- Would you recommend surgery, or chemotherapy and radiation? Explain why. What data supports the next steps?
- If surgery is recommended, what surgical approach would you recommend? Is there a minimally invasive option?
- Will my sexual, urinary or bowel functions be affected by surgery?



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Rhythm Heals

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- For big tumors, should we start treatment with radiation first, or surgery first?
- What other forms of treatment are there?
- Is fertility preservation an option?
- What is a radical hysterectomy?
- Are there clinical trials open here that I should consider?
- Is there a role for sentinel lymph node biopsies in my case?

Ovarian Cancer:

• Is there a role for intraperitoneal chemotherapy?

Vaginal Cancer:

- Could this be vulvar or cervical cancer?
- How big and deep is the tumor?







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Caregivers and Family: What You Need To Know

When a woman is diagnosed with a GYN cancer, it affects everyone around her. Loved ones want to provide support and care. Is there one right way to do this? Not really. Spouses and friends offer these suggestions:

- Listen to your loved one. Some women want lots of help and people involved and others don't. Let her take the lead.
- Find out what services are available in your community to assist with driving, meals and emotional support.
- Share the load. If possible, form a team of support, with each person taking on designated responsibilities. All are equally important. Work together, and communicate with each other.
- Keep a chart/log of medicines, food, etc...at her home, so at a glance, the caregiver(s) can be updated.
- Out-of-town family and friends can keep in touch through cards, articles of interest, online games, phone calls, texts, social media and email.
- Create a personalized web site for your loved one on www.caringbridge. org. Others can send messages and learn how they can help.
- Remind your loved one to keep a notebook of questions and concerns that she can share with her doctor at each visit.
- Arrange to have someone accompany your loved one to each doctor's appointment.



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Post-Screening Questions

After screening No Evidence of Disease you may want to give people a few quiet moments to reflect on what they've seen and heard. Often a general prompt helps open the dialogue.

- Describe a moment or scene in the film that you found particularly disturbing or moving. What about the scene was especially compelling for you?
- What information about GYN cancers resonated most with you during the screening? What was most surprising?
- Have you and your friends ever talked about below the belt cancers?
- Do you know the 5 main types of GYN cancers? Did the film build on your knowledge? If so, how?
- Do you know the signs and symptoms of GYN cancers?
- Do you know anyone who has or has had a GYN cancer?

Call to Action:

- Make an appointment to see your gynecologist for a routine exam and pap smear if you have not done so within the last year.
- Encourage friends and family to see their gynecologist.
- Visit <u>www.endwomenscancers.org</u> or <u>www.cdc.org</u> for information about the symptoms of GYN cancers.
- Spread the word about the signs and symptoms of GYN cancers.
- Host a screening of No Evidence of Disease, and What Every Woman Should Know.
- Contact your Congressional representative urging him/her to provide more funding for GYN cancer research.





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Resources

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GENERAL:

- Cancer Schmancer <u>www.cancerschmancer.org</u>
- Cancer Support Community www.cancersupportcommunity.org
- Eyes on the Prize <u>www.eyesontheprize.org</u>
- Foundation for Women's Cancer
 <u>www.foundationforwomenscancer.org</u>
- HysterSisters <u>www.hystersisters.com</u>
- Life Beyond Cancer Foundation <u>www.lifebeyondcancer.org</u>
- Livestrong <u>www.livestrong.org</u>
- Nueva Vida <u>www.nueva-vida.org</u>
- The Patrick Dempsey Cancer Center for Hope & Healing www.dempseycenter.org
- 24 Hours Of Booty www.24hoursofbooty.org

WELLNESS:

- HERA Women's Cancer Foundation <u>www.herafoundation.org</u>
- Shannon Miller Lifestyle <u>www.shannonmillerlifestyle.com</u>

OVARIAN:

- Bright Pink <u>www.brightpink.org</u>
- FORCE: Facing Our Risk of Cancer Empowered www.facingourrisk.org
- National Ovarian Cancer Coalition (NOCC) <u>www.ovarian.org</u>
- Ovarian Cancer National Alliance (OCNA) <u>www.ovariancancer.org</u>
- Ovarian Cancer Research Fund (OCRF) <u>www.ocrf.org</u>
- Sharsheret: <u>www.sharsheret.org</u>
- Teal Toes <u>www.tealtoes.org</u>

CERVICAL:

- National Cervical Cancer Coalition (NCCC) <u>www.nccc-online.org</u>
- Tamika And Friends <u>www.tamikaandfriends.com</u>
- The Yellow Umbrella <u>www.theyellowumbrella.org</u>

REGIONAL:

- Arizona · Ovarian Cancer Alliance of Arizona <u>www.ocaz.org</u>
- California Oasis of Southern CA <u>www.oasisofsocal.com</u>
- Colorado Ovarian Cancer Alliance <u>www.colo-ovariancancer.org</u>
- Washington, DC Ovarian and Gynecologic Cancer Coalition (OGCC)/Rhonda's Club <u>www.rhondasclub.org</u>
- Florida Lydia's Legacy <u>www.lydiaslegacy.com</u>
- Florida Ovacome: Gynecologic Cancer Alliance <u>www.ovacome.org</u>
- Georgia Ovarian Cancer Alliance <u>www.gaovariancancer.org</u>



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- Georgia Help the Hoo-Hahs <u>www.helpthehoohahs.com</u>
- Iowa · NormaLeah Ovarian Cancer Foundation
 <u>www.normaleahfoundation.org</u>
- Massachusetts Ovarian Cancer 101 <u>www.ovariancancer101.org</u>
- Michigan Belinda Sue Fund for Ovarian Cancer Awareness & Research <u>www.belindasuefund.org</u>
- Michigan Ovarian Cancer Alliance (MIOCA) <u>www.mioca.org</u>
- Minnesota Ovarian Cancer Alliance <u>www.mnovarian.org</u>
- Montana Ovarian Cancer Survivors Foundation <u>www.ocsf.net</u>
- New Hampshire Madame Ovary <u>www.madamovary.org</u>
- New Mexico Gynecologic Cancer Awareness Project
 <u>www.thegcap.org</u>
- New York Grace's Garden <u>www.gracesgarden.org</u>
- New York Western NY Ovarian Cancer Project <u>www.wnyovariancancerproject.com</u>
- North Carolina Lydia's Legacy <u>www.lydiaslegacy.com</u>
- Ohio Jaymie Jamison Foundation <u>www.jaymiejamisonfoundation.org</u>
 - Ohio Make a Noise Foundation <u>www.makeanoiseforoc.com</u>
- Ohio Rose Mary Flanagan Ovarian Cancer Foundation <u>www.rmfocf.org</u>
- Oregon Marjie's Fund <u>www.marjiesfund.org</u>
- Pennsylvania Sandy Rollman Ovarian Cancer Foundation www.sandyovarian.org
- South Carolina Help the Hoo-Hahs <u>www.helpthehoohahs.com</u>
- Tennessee Chic Awearness <u>www.facebook.com/ChicAwearness</u>
- Texas Diana's I Will Live Foundation <u>www.diwlf.org</u>
- Texas Judy's Mission Ovarian Cancer Foundation <u>www.jlrfoundation.org</u>
- Texas Susan Poorman Blackie Ovarian Cancer Foundation
 <u>www.spbovariancancerfoundation.org</u>
- Australia Cervical Cancer Foundation <u>www.accf.org.au</u>
- Australia New Zealand Gynaecological Oncology Group (ANZGOG)
 <u>www.anzgog.org.au</u>
- New Zealand Gynecological Cancer Foundation <u>www.nzgcf.org.nz</u>



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Project Supporters

Inova Health Foundation <u>www.foundation.inova.org</u> Marjie's Fund <u>www.marjiesfund.org</u> GOG Foundation, Inc. <u>www.gog.org</u> Tikkun Olam Women's Foundation <u>www.towf.org</u> Globe-athon <u>www.globeathon.com</u>

For a full list of project supporters go to www.nedthemovie.com/project-supporters

About Spark Media

Award winning, Spark Media was founded by film maker Andrea Kalin in 1989. Since its inception, the Washington, D.C.-based company has specialized in making meaningful documentaries that build bridges between diverse cultures and perspectives. Spark Media strives to both inform and inspire audiences with stories that are compelling, entertaining and real. Spark's stories connect people, changing one family, one community, one struggle at a time. Visit <u>www.sparkmedia.org</u> to see our work...and find out how you can get involved.



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