

Rhythm Heals

re piled six high
cab alive
sweet July
ing all night

ashed to the bone
solve and roll moans
re tree
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- sweet

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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.



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About the Film:

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, 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 GYN cancer itself, 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 gynecologic cancers.

BREAKING THROUGH WALLS 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), vulvar and vaginal.

Survivors often say, 'I didn't know.' What they didn't know are the signs and symptoms of GYN cancers. That's why Spark Media produced the documentary, No Evidence of Disease, and has written this discussion guide. We want every woman to know what to look for and what to do so that early detection and advocacy can help save lives.

THERE'S MORE!



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



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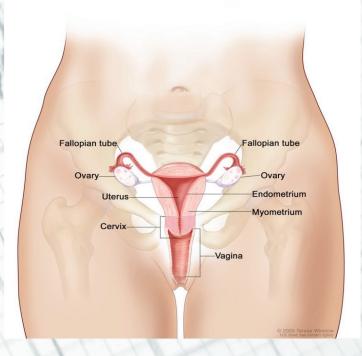
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Easy to view chart of GYN Symptoms

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 can be difficult to remember everything we should ask on that annual visit to the gynecologist. The following list of discussion points and questions come from the doctors of N.E.D. to use as a guide during your appointment. Don't assume that your doctor will tell you everything you need to know. Listen to your body, and take control of your own health!

- Discuss your menstrual cycle and bleeding pattern. Is it within the normal range?
- Discuss any vague symptoms such as abdominal pain, discomfort, changes in your bladder and bowel function, bloating, acid reflux, and weight gain/loss.
- Ask your Dr. if he/she felt anything abnormal during your pelvic exam.
- Discuss your family cancer history. Does it raise any concern for genetic syndromes?
- What, if anything else should be done, given your exam results?

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!

Cervical Cancer:

- Is there any sign the cancer has spread beyond my cervix?
- · What is my stage? Can you explain that to me?
- Would you recommend surgery or chemotherapy and radiation? Explain why.
- What is a radical hysterectomy?
- Are there clinical trials open here that I should consider?
- Is fertility preservation an option?

Uterine/Endometrial Cancer:

- Is there any evidence that the cancer has progressed beyond my uterus?
- If surgery is recommended, is there a minimally invasive option?
- What are the next steps after surgery? Is chemotherapy and/or radiation indicated? And what data supports those next steps?
- Are there clinical trials open here that I should consider?
- Is fertility preservation an option?



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Ovarian Cancer:

- Are you concerned that this problem has progressed beyond my ovaries?
 If the answer is yes:
- Should we start with surgery first and chemotherapy second or chemotherapy first and surgery second?
- What surgical approach would you recommend?
- Is there a role for intraperitoneal chemotherapy?
- Are there any clinical trials open here that I should consider?
- Is fertility preservation an option?

Vulvar Cancer:

- Is there any evidence that the cancer has spread beyond my vulvar?
- Will my sexual, urinary or bowel functions be affected by surgery?
- For big tumors, should we start treatment with chemotherapy and radiation or surgery?
- Is there a role for sentinel lymph node biopsies in my case?

Vaginal Cancer:

- · Could this be vulvar or cervical cancer?
- How big and deep is the tumor?
- · Has the cancer progressed beyond the vagina?
- Is surgery an option?
- What other forms of treatment are there?
- Will radiation and chemotherapy be used in my treatment?





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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. After talking with spouses and friends, here are some 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 information to 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 via cards, articles of interest, on-line games, and phone calls.
- Create a personalized web site for your loved one on www.caringbridge. org. People can send messages and learn how they can help.
- Early on, help your loved one record a video message and/or write letters to family members and friends. This may or may not ever be needed, but it if it is, everyone will see her looking and feeling good.





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General Discussion Guidelines

After screening No Evidence of Disease you may want to give people a few quiet moments to reflect on what they've seen. 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.foundationforwomenscancer.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 put more money into GYN cancer research.





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Resources

GENERAL:

- Foundation for Womens Cancer
- www.foundationforwomenscancer.org
- Livestrong www.livestrong.org
- 24 Hours Of Booty www.24hoursofbooty.org
- Gynecologic Cancer Support www.eyesontheprize.org
- Nueva Vida http://www.nueva-vida.org
- Help The Hoohahs www.helpthehoohahs.com
- Life Beyond Cancer Foundation www.lifebeyondcancer.org
- The Patrick Dempsey Cancer Center For Hope And Healing www.dempseycenter.org

WELLNESS:

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

OVARIAN:

- National Ovarian Cancer Coalition <u>www.ovarian.org</u>
- Ovarian Cancer National Alliance www.ovariancancer.org
- Ovarian Cancer Research Fund www.ocrf.org
- Teal Toes <u>www.tealtoes.org</u>
- Force: Facing Our Risk Of Cancer Empowered <u>www.</u> <u>facingourrisk.org</u>:
- Bright Pink: www.brightpink.org

REGIONAL:

- Rhonda's Club www.rhondasclub.org
- Ovarian Cancer Coalition Of Charlotte:
- www.tealthereisacure.org
- Ovarian Cancer Alliance Of Arizona www.ocaz.org
- Make A Noise Foundation, Columbus, Ohio
- www.makeanoiseforoc.com
- Ovarian Cancer Foundation, Philadelphia, PA
- www.sandyovarian.org
- Grace's Garden GYN Cancer Support Group, Syracuse NY www.gracesgarden.org

UTERINE:

• Marjie's Fund www.marjiesfund.org

CERVICAL:

- Tamika And Friends www.tamikaandfriends.com
- The Yellow Umbrella www.theyellowumbrella.org



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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 www.sparkmedia.org to see our work...and find out how you can get involved.





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