



Faces of HPV and Cervical Cancer: A Book of Hope



cervivorTM
informed. empowered. alive.



Welcome to our little book of hope - packed with information, survivorship, and words of encouragement and support.

We at Cervivor want women dealing with HPV or cervical cancer to know they are not alone. We are a circle of friends, a circle of support and a circle of hope. Our network of survivors and their friends are all part of this circle – offering support for those who have received a diagnosis, education to those who want to learn how to protect themselves from cervical cancer, and advocacy to everyone who wants to help us stamp out this disease once and for all. Our vision for this book is that you will find what you need to help you through this time in your life, and, if needed, you will reach out to those of us in this book for further support. That's what we are here for!

Even on the darkest days, there can be a ray of sunshine just waiting to burst through. Knowing that women have struggled with HPV, battled with pre-cancerous cells, suffered from cervical cancer and won the fight can be the inspiration needed to help you become one of us – a survivor!

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Tamika Maryland



Founder of Cervivor, 13 years in remission

Age at diagnosis: 25

When I started my cervical cancer journey:

April 12, 2001. I was working in Washington, DC as a successful television producer and having the time of my life! I went in for a routine Pap after not having had one for a few years for some pretty typical reasons: lack of insurance and body image issues.

My diagnosis: Stage IIA cervical cancer

My treatment options: My doctors told me that my best chance at living was to have a radical hysterectomy. There was also a procedure called a radical trachelectomy. But, I would have to get pregnant immediately or freeze my eggs. Harvesting my eggs was very expensive – and my health insurance wouldn't pay for it because I was unmarried. It was impossible to raise the funds. Finally, everyone agreed just going ahead with the hysterectomy would be best for me. Chemo and radiation followed.

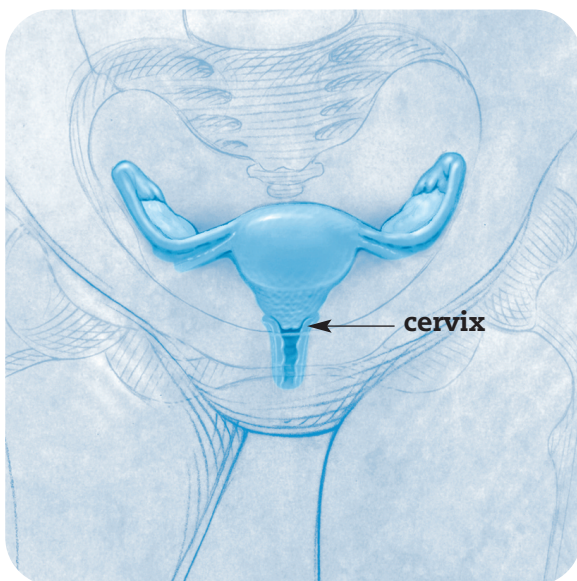
How I felt after treatment: Deep depression, heartbroken about the loss of a child I never had and the loss of everything I thought that made me a woman.

Life after my diagnosis and treatment: I still had my ups and downs, but I was so grateful for my second shot at life. I tried relentlessly to get back to normal life, my career, my world – one that didn't include cancer. But it's kind of hard once your body fails you and you're constantly going in for check-ups and everyone around is asking you, "How do you feel?"

Where I am today: I'm cancer-free and enjoying life!! I still hope to have a baby somehow some day. I know that one day, women will stop dying of cervical cancer. Cervical cancer has changed my life forever. But what doesn't kill you makes you stronger. I am strong. I'm a survivor!

You may be reading this book because you just found out you have HPV. Or maybe you have abnormal cervical cells or dysplasia. Or, you found out you have cervical cancer. It's possible that you're reading this because your friend or family member just received a diagnosis. Whatever the reason, take it all in, think about yourself or your loved one and what is needed during this time, and don't be afraid to discuss with your healthcare provider any concerns you may have.

It's your right to have answers and to know what's happening next.



What is cervical cancer?

Cervical cancer is cancer of the cervix, which is the opening from the vagina to the uterus. It is caused by a virus called *human papillomavirus*. ("Papilloma" is pronounced "pap-ah-LO-mah.") But from now on, we'll simply call it HPV.

I HAVE HPV. What now?

First of all, don't panic. *Having HPV does not necessarily mean you have cervical cancer or will get cervical cancer.* In fact, as women, 8 out of 10 of us will get HPV at some time in our lives. Nothing bad happens – it just quietly goes away.

There are over a hundred types of viruses called HPV – it's a very common virus. Most HPV types can cause warts – usually in the genital area, sometimes in the mouth or throat - but they don't lead to cancer.

However, some HPV types on your cervix (called high-risk HPV) can cause changes in healthy cells. The cells become abnormal and can eventually lead to cancer. It takes about 10 to 15 years for cervical cells to change to abnormal cells and then into cervical cancer. During this time, you usually don't feel ill in any way. Neither HPV nor the abnormal cells cause any symptoms.

If you had an HPV test and it came back as positive for HPV, it means that you have an HPV type that can potentially lead to cervical cancer. Having HPV means you and your healthcare provider will be keeping a close eye on your cervix since the HPV could stick around and create abnormal cells that can develop into cancer in the future.

And remember: **While most women have HPV at some point in their lives, few women will get cervical cancer.**

I HAVE AN ABNORMAL PAP. What does this mean?

First, you should feel reassured that abnormal cells are **not** cancer. But they **can** lead to cancer.

If you have an abnormal Pap, you may have heard the terms “abnormal cells,” “dysplasia,” “LSIL,” “HSIL,” “CIN I, CIN II or CIN III,” or “carcinoma in situ.” You also may have heard the word “pre-cancer.” But try not to be overwhelmed. All of these terms refer to some sort of abnormal cells in your cervix.

Two procedures your healthcare provider may do if your Pap test shows abnormal cells:

- a colposcopy to look more closely at the abnormal cells. Colposcopy views the cervix with a lighted magnifying instrument.
- a biopsy to determine if you need treatment for the abnormal cells. During a biopsy, a tissue sample is removed for analysis in the laboratory. The biopsy helps determine if the cell changes are minor or more severe and what treatment, if any, may be necessary.

Abnormal cells can be called squamous intraepithelial lesions (SIL) or cervical intraepithelial neoplasia (CIN). They may be referred to as

- Low-grade SIL (LSIL) or CIN I, meaning the cell changes are mild.
- High-grade SIL (HSIL), CIN II or CIN III, meaning the cell changes are moderate to severe.

Many cases of CIN I go away by themselves. If you have results that are CINII, CINIII or CINII/III, usually your healthcare provider will directly treat these abnormal cells.

Malenis Illinois



Age: 28

How my story

begins: I had gone in for my yearly Pap smear, a few months late, with no thought in my mind that anything would be different than before. Two

days later, I found out my Pap had come back abnormal and the HPV test that I requested came back positive. I was floored.

What was most difficult for me: Explaining to my friends and family since I didn't want them to think anything bad about me. Coming from a Latino family, the first thing that people think when you tell them that you have HPV is that you are “sleeping” around.

Why doing research and getting all the facts helped me: I discovered that I had other friends who had HPV. I realized that there were so many other women that were going through the same thing. I realized that I wasn't alone. I even learned that my aunt is a cervical cancer survivor.

How I manage my HPV: I take care of myself and go to my follow-up appointments on time.

How I will try to help others: I am sharing my story and doing as much as I can to educate people in my area, including in the Latino community. HPV/Cervical Cancer awareness is something that I hold very close to my heart, something that I plan on never giving up on.

CIN III can also be referred to as carcinoma in situ or stage 0 pre-invasive cancer. Abnormal cells are found in the innermost lining of the cervix, but if left untreated, may spread further into the cervix.

You and your healthcare provider will discuss which procedure is best for you based on your diagnosis.

- **LEEP (loop electrosurgical excision procedure):**
A fine wire loop carrying a (safe!) electrical current removes abnormal tissue.
- **Laser or “cold-knife” conization (cone biopsy):**
A laser or scalpel (“cold-knife”) removes a cone-shaped piece of the cervix.
- **Laser therapy:** A tiny beam of high-intensity light vaporizes abnormal cells.
- **Cryotherapy:** A very cold probe freezes – and destroys – abnormal cells.

For most women, these procedures do not interfere with your ability to get pregnant. But if you get pregnant in the future, there is an increased risk of premature delivery with the LEEP. It’s a good idea to discuss this with your healthcare provider.

“My most heartfelt thanks goes to my provider who suggested the HPV DNA test and didn't just go on the Pap test alone.”

Michele

Michele New York



Age: 35

When my story begins: I had a history of normal Pap tests from the time I was 18, without ever missing a year. At age 34, I had an HPV test with my

Pap; the Pap was still normal but I had HPV. One year later, I was still HPV positive but my Pap now was inconclusive. After a colposcopy and a biopsy, the results came back as CIN III.

Why I was shocked: Not only did I have a history of normal Paps, but I was healthy in every other way and thought my immune system would fight off the HPV.

My treatment: A LEEP procedure. I am happy to say I no longer have HPV and my Paps have been normal since.

The moral of the story: If after my 17 year history of annual normal Paps, my provider had followed guidelines and not had me return for 3 years, the CIN III would have had the chance to develop further, possibly pushing me toward a cervical cancer diagnosis. My most heartfelt thanks goes to my provider who suggested the HPV DNA test and didn't just go on the Pap test alone. I really do credit her with saving my life.

I HAVE CERVICAL CANCER. Does this mean I'm going to die?

All of us at Cervivor, many of whom are cervical cancer survivors, are happy to shout out: **No!** There are many effective treatment options available. And there's also a lot of support available, like us, while you're going through a diagnosis.

First, it's important to understand what stage your cervical cancer is. The stages help determine the best treatment.

Stage I: The cancer is only in the cervix or uterus.

Stage II: The cancer has spread past the cervix and the uterus.

Stage III: The cancer has spread further – possibly into the lower vagina and the pelvic wall. It may be blocking tubes that carry urine from the kidneys to the bladder.

Stage IV: The cancer has spread beyond the pelvis. It is metastatic, meaning it has spread to other parts of the body such as the bladder, rectum, bone, liver, or brain.

Stages are divided further into sub-stages with letters and numbers. For example, the sub-stages of Stage I cancer are IA1, IA2, IB1, and IB2. There are also different types of cervical cancers. The two main types are squamous cell carcinoma, which is most common, and adenocarcinoma. A small percentage of cancers are adenosquamous carcinomas and an even smaller percentage are small cell and large cell neuroendocrine carcinomas. To make it easier, we aren't going to get into detail about each type of cancer and the various stages. For now, we'll just focus on helping you understand how to beat cervical cancer!

Next, before deciding on the best treatment for you, you and your healthcare provider will need to discuss:

- The stage of the cancer.
- The size of the tumor.
- Your age.
- If you're pregnant. For cervical cancer found in its early stages, or for cancer diagnosed during the last trimester of pregnancy, treatment may be delayed until after the baby is born.
- If you want to have children in the future.

Cervical cancer can be treated with surgery, radiation or chemotherapy – or perhaps a combination of all three.

- Surgery may be removal of the tumor, a hysterectomy, a radical hysterectomy, or a radical vaginal trachelectomy. The type of surgery will depend on the stage of the cancer and if you want to become pregnant in the future.
- A hysterectomy includes removal of the uterus and the cervix.
- A radical hysterectomy includes removal of the uterus and cervix, as well as the tissues next to the uterus, the upper part of the vagina, and sometimes the ovaries and the fallopian tubes. Some pelvic lymph nodes may be removed as well.
- A radical vaginal trachelectomy (RVT) may be an option if you want to become pregnant in the future and your cancer is in an early stage. The surgeon removes the cervix, the upper part of the vagina, and the pelvic lymph nodes while leaving the uterus in place.

- Chemotherapy with radiation is generally used to treat stage II, stage III, and stage IV cervical cancer. After chemotherapy and radiation are complete, your healthcare provider may also suggest a hysterectomy.
- Chemotherapy uses anti-cancer drugs that are either injected into a vein or taken by mouth.
- Radiation therapy uses high energy x-rays to kill cancer cells. These x-rays may be given externally or internally. External radiation is like having a diagnostic x-ray; internal radiation is given through a cylinder placed in the vagina.

“Life stopped but at the same time, I had no choice but to look forward and continue.”

Lauren

Lauren New Jersey



Age at diagnosis: 33

When I was diagnosed: September 2008. Life stopped but at the same time, I had no choice but to look forward and continue. I was a mother of 2 and a wife, and was pursuing my degree in elementary education.

My diagnosis: Stage IB2 cervical cancer

How I spent my days after diagnosis: Procedures began - internal and external ultrasounds, biopsies, pelvic x-rays, cat scans, holes from blood draws, tattoos to prepare me for radiation, and a PICC line.

My treatment: Radiation therapy 5 days a week for 6 weeks and chemotherapy once a week for 6 hours a day for 6 weeks. Then a total hysterectomy and oophorectomy put me in surgical menopause.

How I kept on going: Positivity and a great spirit. My living room recliner became my best friend. Even decorating my chemo chair and pole for Christmas and keeping the radiation techs amused by my funky socks were necessary!

A day I'll never forget: February 19, 2009 when I was given a clean bill of health.

What I want other women to know: Keep up to date with your annual gynecological appointments and keep others aware. I quickly went from health to cancer in just a year's time. Awareness is the key to early detection and survival!

Safia New York



Age at diagnosis: 32

When I thought something was wrong: I began to experience abnormal bleeding. My Pap smear was normal so I decided to see if the problem would resolve itself. When it didn't go away, I went back to the doctor and was diagnosed with some sort of infection for which I received a prescription. When this didn't work, I went back to the doctor and this time, she could see a mass on my cervix.

My diagnosis: Stage IB1 invasive squamous cell carcinoma

Hearing the news: I recall standing in the bathroom of my apartment that night and letting the realization that I had cancer wash over me. I didn't cry then, but dread crept through my limbs. It was a shock to hear the actual "C" word come across the phone line. It's hard not to tune out the doctor speaking the moment the word fully registers; it's hard to think about anything other than whether you are going to die and, if so, when.

My treatment: First, I had a radical trachelectomy, with the hopes to protect my ability to have children naturally. The understanding was that if there was any indication from the initial pathology tests that the cancer had spread to my lymph nodes, my oncologist would perform whatever surgery was necessary to eradicate the disease. The mass was larger than the scans had originally revealed. Later pathology tests also showed that the cancer had affected one lymph node. I would have to undergo chemotherapy and radiation. I ultimately elected to have a second surgery as well to move my ovaries out of the radiation field (necessitating a hysterectomy) in an effort to stave off premature menopause resulting from damage to the ovaries during treatments, fertility treatments and egg retrieval.

How I felt after treatment: I felt physically drained. I was scarred and weakened from the surgeries, burned by and exhausted from the radiation, and bloated and pimples from the steroids that accompanied the chemotherapy. But I also felt mentally and emotionally powerful. I had never truly let myself believe that I could lose to this disease. I refused to give it even that small victory. And in the end, with the support of my family and friends, I WON my personal war with cancer!

Shawna Iowa



Age at diagnosis: 31

How I felt before the diagnosis: Perfectly healthy. I was a busy working mom with two children, teaching first grade and never expecting to hear the words, “you have cancer.”

Why I was surprised to hear I had cancer: I had a stack of 15 years worth of perfect Pap smears. I thought I was in great health, as I had just had a c-section with my 2nd child 9 months before. My Pap test was actually normal, although I had a 4cm tumor bulging from my cervix. But even my

doctor felt strongly at first that my tumor was not cancer given my medical history and my test results.

My diagnosis: Stage IB2 adenocarcinoma

My treatment: Radical hysterectomy and 5 weeks of radiation. They removed my cervix, uterus, and 44 lymph nodes that all came back clear.

How I felt after treatment: My energy was depleted. My sense of humor and zest for life were missing, as I dealt with physical side effects, hormonal imbalance, and complete exhaustion. Three years later, I was diagnosed with Post Traumatic Stress Disorder (PTSD), prompted by my cancer.

What I did to help myself: I was encouraged to embrace what it truly meant to walk in my survivorship. I sought help from cancer support groups, and networked with others to spread the message of cervical cancer prevention through HPV testing and regular Pap tests.

What I tell others going through this diagnosis: I want very much to emphasize how important it is to deal with the emotional/hormonal/spiritual side of being a "Survivor." I marched right past the survivor desk in the Cancer Treatment Center of my hospital. Perhaps I was too busy or maybe I thought I was strong enough to keep marching forward. That was a mistake for me. Please know the value of networking with other survivors. While many of you may not experience PTSD or any psychological issues from your cancer, be on the look out for those who may develop these symptoms. And please know that time, support, and prayer will help you truly be a survivor with a story to tell.

What's the best treatment?

We're not qualified to answer that. But we can urge you to bring plenty of questions to your healthcare provider.

Here's a start:

- How will you decide which procedure to use?
- What will the treatment cost?
- What are the side effects?
- How will this affect my sex life?
- How will this affect my fertility?
- Will I lose time off work?
- Do I have to stay overnight in the hospital?
- Does this cure me?
- How will I know if I'm cured?
- How can I handle this stress?

"Just because you hear those dreaded words, "you have cancer," it does not mean your life is over."

Jennifer

Jennifer New York



Age at diagnosis: 30

How I found out about my cancer:

A cancer center called telling me I needed to come in for a consultation. When the woman realized my doctor never called, she said, "Oh, Jennifer, you better call your doctor." My doctor did not want to tell me over the phone. But after begging her, she told me I had cervical cancer.

My diagnosis: Stage IBI adenocarcinoma

How I felt when I heard the news: I screamed at the top of my lungs and starting saying "why?" over and over again. Hearing you have cancer and that you will never be able to have another child in the same conversation is horrifying.

My treatment: Radical hysterectomy but no chemo or radiation – after the surgery, I was cancer-free!

What gave me comfort: Knowing that I was not alone in this battle. You are never alone.

What I think helps through diagnosis and treatment: Surround yourself with people that will be there for you to support you in a positive, loving way. I have the best family anyone could ask for - my mother, my husband and our beautiful little girl. My family is my life and I feel so lucky to have them by my side. Educate yourself on what is going on inside you. Make a list of questions and any fears you might have to ask your oncologist.

My lesson for others: Just because you hear those dreaded words, "you have cancer," it does not mean your life is over. As much pain as this past 2 years has brought me, it has brought me so much happiness! I feel like this is a new life for me. There is nothing better than hearing, "you are cancer free." You feel like you can do anything!

If you are thinking about pregnancy in the future, you'll also want to ask your healthcare provider questions such as these:

- Am I a candidate for RVT (radical vaginal trachelectomy)?
- Will I be able to keep my uterus?
- Will I be able to keep my ovaries?
- Can I harvest eggs before or after my treatment?
- I don't have a partner. Can I freeze unfertilized eggs?
- If I keep my ovaries and have radiation, will I be able to harvest eggs afterwards?
- Can my ovaries be moved up higher for protection from the radiation?
- Can you recommend a reproductive endocrinologist?

If you feel you're not getting the attention you deserve or answers to your questions, remember, you can choose someone else to provide your care. You're in charge of your health – and you deserve someone to help you make choices.

Lori Washington



Age at diagnosis: 34

When I realized something was wrong: When I hadn't received my recent check-up test results in the mail, I called my gynecologist and discovered that my routine Pap smear was abnormal. Over the next 4 months, I had follow-up tests but everything came back clear. I finally asked for an HPV test (which was not the standard

of care at the time) and the results came back positive for high-risk HPV. I was then referred to a gynecological oncologist.

My diagnosis: Stage IB endocervical adenocarcinoma

My treatment: Surgery to remove my tumor, most of my cervix, and pelvic lymph nodes.

How I feel about the changes: The loss of fertility doesn't mean that I can't have a family...but it does mean that an option was taken from me, aggressively and without warning.

What I was most shocked by: The lack of peer support and cervical cancer resources in my local community when I was first diagnosed. I felt so alone as I was going through treatment, no matter how many loving people were actually around me. I needed to know that there was someone else out there who understood what it meant to have a gynecological cancer.

My personal health mission: To help local women in the Pacific Northwest facing the tough questions around HPV and cervical health. Through this journey and my belief in the power of philanthropy and personal outreach, I now speak to the media, local groups, and individuals to empower change in HPV cancer awareness and action.

What are the outcomes for cervical cancer treatment?

Many factors affect a person's outcome, including what stage you are diagnosed with, what your overall health is and how well your cancer responds to treatment. We also keep learning how important a person's state of mind is to a cancer diagnosis.

Some women may want to know the exact survival statistics for others who have been diagnosed with their particular stage of cancer. Other women may not want to know.

Just to give you an idea, women who are diagnosed with stage IA cervical cancer have a five-year survival rate of 95%. Five-year survival rates look at people who were treated at least 5 years ago and refer to the percentage of women who lived at least 5 years after their cancer was diagnosed. Women diagnosed in later stages will see a lower 5-year survival rate – but, remember, many women live a long, full life after a cancer diagnosis.

So try to stay positive and remember that we're here to work with you, fighting to make every day after diagnosis better and easier.

“Don't ever give up on yourself because the best is yet to come.”

Katharine

I'M IN REMISSION. Is there life after cervical cancer?

One day you may get the message: “You're in remission!” or “You're cured!”

It feels like you've waited forever to hear these words. And that means you are now a *cancer survivor*! After the initial feelings of excitement, you won't be the first to find you're feeling a bit strange, empty, moody, or unsure.

Here are some questions we as survivors have had during our lives after cancer.

Will my body ever be the same as it was?

Your body will take a long time to recover. And how it recovers can be unexpected. You may sleep longer than usual or less. You may eat more than usual or less. You may be more social or less. And just when you think you've got these changes under control, they may change again.

Simple things may become difficult. Things you never thought you could do suddenly are quite possible. Your memory may play tricks. You can't remember some things. Or old memories – good and bad – may come flooding back.

You may be in pain from surgery, radiation, chemotherapy, medication, or the memory of your pain. Your body might tingle, swell, feel numb, or just ache. Your stomach may act up at crazy times. You may look different than you used to.

Your body is different now. The trick is to find ways to gently wrap your mind around it.

Katharine Pennsylvania



Age at diagnosis: 23

My life when I was diagnosed: I had just finished school in 2006 and landed a job as a paralegal in Philadelphia. I packed up my things and moved 300 miles away from my home in Pittsburgh. Just when I thought things were getting a little too easy...I received a phone call from my doctor one morning after a routine Pap smear. She said the results were abnormal but not to worry. A few hours later, I had another phone call from my doctor with my diagnosis.

My initial diagnosis: Stage IIA cervical cancer

What I thought: I always thought this couldn't happen to me. We all think it can't happen to us... but then it does, and it changes our lives forever.

My treatment: External radiation therapy for about 8 months. My oncologists didn't see much of a change, but I didn't want to give up hope. I didn't want to give up the option of one day bearing children. I saw a therapist during my radiation and I was told that half of my road to recovery is how I approach my cancer. "If you believe you can overcome this, then you will overcome this!" So I started thinking positively. I dug deeper in myself to find the hope and faith I needed to beat this thing. But one day I realized that it wasn't about having hope and faith, it was about having a support system, a support system I had lost years ago - my parents who had both died years earlier.

My follow-up diagnosis and treatment: My cervical cancer advanced from stage IIA to IVA. The cancer had spread - fast. And no one caught it. And worst of all, they don't know how it happened. My oncologist gave me a 10% chance of survival with a hysterectomy. Without it, I was given 6 months to live. With a hysterectomy and chemotherapy, my cancer went into remission!

What keeps me going: If there's one quality I strongly possess, it's endurance - the act, quality, or power of enduring or bearing pain, hardships or stress; the ability or strength to continue to last.

My life now: I never thought I would get here - to that point in my life, post-cancer, where I'm deliriously happy. Maybe it's the fact that I have worked so incredibly hard to turn my life around and make it something I'm proud of. But whatever it is, it's so good.

My advice: If there's one piece of advice I could pass on to anyone who's battling cancer, survived cancer, or even those going through a rough patch, it's to never, ever give up. Life does get better, happiness does exist, and life after cancer can be some of the best years of your life, but you have to find the strength, passion, and determination to want it all. Don't ever give up on yourself because the best is yet to come.

Libby Georgia



Age at diagnosis: 33

About me: I'm a prenatal genetic counselor and I'm married with a wonderful daughter.

How I found out: I went for my annual physical and learned that my Pap was abnormal, the first time in 17 years that I had an abnormal Pap. Follow-up tests showed I had severe dysplasia with gland involvement - CIN3/HGSIL. I was devastated but my doctor reassured me that since my previous Pap smears had been normal, this was likely something that could be resolved with a small surgical procedure called a LEEP.

My diagnosis: After the LEEP, I found out I had stage IA2 invasive cervical cancer.

How I felt when I learned of my diagnosis: To say I was devastated is an understatement. I ate right, exercised several times a week and had no health problems. I felt as healthy as I'd ever been. How could this be happening?? I was also angry. I felt outraged that I had never missed my yearly exams, even though recent guidelines suggested I only needed to have a Pap smear every 3 years. I was also shocked because everything I had read supported that cervical cancer is a slow growing cancer. There is really no way I could have been "cancer free" the year before and now have invasive cancer. The explanation is that Pap smears are an excellent screening tool, but like all "screens," they are not perfect.

My treatment: Radical hysterectomy

My first thought: "Wow, maybe I'll lose a few pounds with this surgery." But, I sadly learned later that all those tissues weigh very little. The next thing I thought was "1/3 of my vagina gone??" Holy moly, that sounds bad. It is one thing to think about losing organs you don't plan on using again but I was immediately concerned that this would have a devastating effect on my marriage and love life. There is also this feeling of "not being yourself" or "not being a complete woman." After all, our reproductive organs are one of the most fundamental parts of being a woman. I worried that I might not feel the same after surgery. Not to mention my fears of becoming a hormone crazed, hot-flash having, she-beast on hormone replacement for the next 20 years! I have to say, that was a bad day.

One of the hardest parts of finding out I had cancer: Breaking the news to my family. My mom had been diagnosed with ovarian cancer just 2 months before and I honestly didn't know how in the world I could add more stress to their already overwhelmed lives. In some strange way, however, I think it brought my Mother and I closer as we were now both members of this terrible "cancer club."

What kept me going: My desire to live and be there for my daughter. It also didn't hurt that I've been feisty since birth and I felt like this was a challenge that I knew I had to win. I also felt that things happen for a reason and there was something good that would come out of this. Hey, maybe God figured GYN cancers needed an advocate and for anyone who knows me, I've never been short on words!

Sex? After having cervical cancer???

Cancer isn't sexy, whether you're in a lifelong relationship or on a first date.

After cervical cancer, many women experience some or all of the following:

- vaginal dryness
- vaginal tightness
- painful intercourse due to a shortened vagina

But the problem, of course, isn't always in the plumbing. Sex really happens in the mind and heart. And when the mind and heart are wounded, desire can be hard to come by. The desire to have sex (also called libido) can also be decreased due to treatment that altered your hormones.

- If you're in a relationship, you and your partner are going to have to commit to some heavy-duty communication. Your partner may have been your caregiver for a while – it's not easy to tenderly slide back into “normal” life as a “normal” couple. There will be fear, sadness, loneliness, and anger. You'll both need to allow each other to voice these feelings as you move back to an intimate life.
- If you're single, there will be the issue of when to drop the “cancer” bomb. On a first date? Fifth date? The first time you have sex? In a few months or years? Do you think you can get away with never?

Cancer is tough stuff, and we'd be lying to you if we said everyone who cares about you can deal with it. Cancer tested you, and it will test them. We'd be fools to tell you not to take rejection personally. It is personal. You can be rejected for having survived a disease that scares everyone.

If you have to, you will leave some people behind – and find better ones. We've met some of the better ones. We know they're out there.

Alex Connecticut



Age at diagnosis: 24

The first sign something was wrong: Bleeding 3 months before I was diagnosed.

Why I wasn't that worried: I had been to the gynecologist a year prior, I was only

24, and I had just come off the Depo shot. So I thought I was just having a really bad period.

Where I first learned something was wrong: I visited my local Planned Parenthood and learned that I had a tumor in my cervix that was causing the bleeding.

When my life changed: July 20, 2009

My diagnosis: Stage IIB invasive squamous cell cervical cancer

My treatment: Laparoscopic surgery to move my ovaries out of the radiation field. Then, I had 6 weeks of Cisplatin chemo with daily pelvic radiation for 8 weeks, followed by a hysterectomy.

A big blow to my recovery: I got the news that my ovaries had shut down and I was in fullblown menopause at age 24. My dream of having my own biological children was gone.

I am now coming up on 2 years of remission and daily learning how to live this life we all need to understand after cancer.

Is it possible to have a baby after cancer?

Whether or not you can have a successful pregnancy will depend on your stage of cancer and your treatment.

If you find that your cancer treatment will prevent you from having children biologically, you can look into harvesting your eggs.

If you are able to have your eggs harvested, they can be frozen unfertilized for future insemination. Or they can be inseminated with sperm and the embryos frozen for future use. This can be an expensive process, so be sure to ask about costs and financial options.

If you have had a hysterectomy, a surrogate mother can carry your child to term when you're ready to become a parent. This can be complicated, so be sure to research surrogacy thoroughly and know all the legal issues that surround this option.

Even if you can't have a successful pregnancy or harvest eggs, adoption can be a wonderful option – there aren't enough homes for children who need them.

Jacqueline Arizona



Age at diagnosis: 36

My diagnosis: Stage IB adenocarcinoma

How I took care of myself before my diagnosis: I always had yearly Pap exams, exercised, took care of my health and have been a strict vegetarian for decades. My story clearly dispels the myth that cervical

cancer only happens to women who have neglected their own medical care...I am not that example.

My treatment: Radical hysterectomy

How my recovery went: I recovered successfully but it was a long process physically and emotionally. I tried to return to work after 3 months recuperation but I could not keep up with my job and help others as a social worker. I was too fragile myself.

What I did to help myself heal: Since I was a social worker, I looked into all avenues of healing that I would have suggested to clients. I attended cancer support groups, young adult cancer retreats, and participated in walking, yoga, acupuncture, massage, and reiki. I also started writing poetry, which was an instrumental outlet to channel grief and anger. I wrote over 30 poems that I still consider a beautiful testament to my recovery experience.

What I've learned: I've accepted that cancer came into my life and stole my uterus and the opportunity for me to have children. I choose to see cancer as a blessing and the positive it has brought into my life. I am still connected with and advocate for cancer survivors and families. I believe I was lucky because way too many beautiful souls have died too early.

Will my cancer come back?

It would be insane to not have the thought that the cancer might come back. There's no way to really know.

Some women live every day in fear of their cancer returning. Others are scared only when they get a cold, cough, or any type of ache.

And some women only worry while in the waiting room for follow-up checkups.

The fear of your cancer returning is certainly understandable. However, we think that as time goes by, you can begin to see time as your friend. You have been cancer-free or in remission for this amount of time; and the odds are that when you wake up tomorrow that will continue to be true.

If you find your fears are taking control of your life, you could try therapy to help you handle these feelings.

“This whole experience has taught me so much more than I could have bargained for.”

Laurie

Laurie California



Age at diagnosis: 45

When I knew something was wrong:

I began to have intermittent bleeding problems and pelvic pain. I had always been a go-getter, someone who did not have time for "important things" like having an annual Pap smear (like I should have), but did have time to work 60 plus hours a week. I finally made an appointment to see my

OB/GYN. I knew something was wrong when I experienced severe bleeding for 3 days following a simple pelvic exam.

My diagnosis: Stage IA2 cervical cancer

My biggest fear: My mom had died in 2006 just 2 weeks after being diagnosed with cancer, and I had a real fear that the same thing would happen to me.

The first thing I did after I found out: I went to McDonalds and bought 20 ice cream sundaes to break the news to my co-workers. I have no idea who I was trying to soothe, them or me (especially because I am a crisis worker).

My treatment: Radical hysterectomy

What I continue to struggle with: Some ongoing complications from my surgery a year later (namely lymphedema, bladder problems, and scar tissue that will require future surgery to correct).

What I am very grateful for: To be alive today! This whole experience has taught me so much more than I could have bargained for. It taught me patience, with those I work with, as I was given patience and comfort when I needed it. It has taught me to really listen to the needs of others. I have the ability to give back, share my experience and advocate for those who need it, offering resources and hope. That is why I feel it is important to share our stories with each other. That is where I got my hope.

Am I the only one who is scared of dying?

Fear of dying is useful. If we didn't have it we'd all have done enough stupid things to be dead a thousand times over. But fear of living has no use at all.

Let's be clear. We're not saying that you need to run around like a sunbeam and say everything is great. Everything is not great. Indulge yourself: Spend a day in bed eating ice cream, watching reality television, and feeling really sorry for yourself. You've earned it. But don't make it a habit.

Please join Cervivor in living!

What do I do if I'm told my cancer is terminal?

If it's terminal cancer, you still fight like hell. Get on your fighting face. Fight. And know that you are not fighting this battle alone!

Colleen California



Age at diagnosis: 38

When my life changed: August 14th, 2006

My diagnosis: A rare and aggressive type of cervical cancer called small-cell neuroendocrine cervical cancer

Why I was surprised with my diagnosis: I never missed my annual exam. I had a Pap test every year and just had a normal test 10 months prior to my diagnosis.

What my first thoughts were: We had lost my adoptive mother only 4 years before to a rare ovarian cancer and my beloved Aunt Mary to breast cancer two years before. How could I do this to my husband and children? How could I do this to my sister and my friends? They were all going to be devastated to be facing this once again.

My treatment: Very harsh and debilitating chemo and internal and external radiation for my first diagnosis, and more chemo and a hysterectomy when my cancer came back in 2009.

How I felt when I finished treatment: I felt like I had aged 10 years and been hit by a truck....but I was cancer free.

What scared me most after treatment: I was looking for other survivors of this particular cancer and not finding any. I felt isolated, uncertain of my future, and anxious waiting for my scan results every 3 months.

How I help others with this rare disease: I set up a website called "Cancer Comrades" with another survivor, Melanie. We now have a Facebook group for survivors of Small/Large Cell Cervical Cancer with more than 100 members. We comfort, inspire and encourage each other; fundraise for research; and promote awareness.

As a result of this cancer: I gained new friendships with a phenomenal group of women. If something good can come from something so horrible as cancer, I would have to say it is these friendships that have been forged that will last a lifetime. For that...I am grateful.

Who can I talk to about everything?

If you need support beyond the medical nuts-and-bolts, here are some other people you can consider talking with:

- **Your healthcare provider's support network**
Often a large medical practice will have people on staff who can give you more counseling than your primary caregiver. Don't be afraid to ask if others are available.
- **A professional therapist such as a psychologist, psychiatrist, counselor, or social worker**
- **A member of your faith community**
- **Family and friends**
Remember, there are people who may love you very much, but who are not the best people to help you in this kind of crisis. Choose family members and friends who not only care, but also can take care of themselves while they help you.
- **Cervivor**
That's why we're here.

Doreen Maryland



Age at diagnosis: 47

My diagnosis: Invasive cervical cancer

How I felt when I was diagnosed: I felt alone, mostly because I didn't personally know anyone who knew more about this disease than I did. At that time, in 2004, not a lot of information was available and there were no commercials or magazine ads like there are today about

HPV and cervical cancer. There were no patient or survivor stories either. It was a very scary time for me.

Being diagnosed with cervical cancer: I was presented with the biggest challenges I had ever known. Throughout my life, I've always been able to overcome challenges and rise above adversities. What I experienced in the months that followed changed my life forever.

My treatment: I had surgery, chemotherapy, and radiation treatments, all of which presented new challenges far beyond anything I could have ever imagined. I went through all of this with an uncertainty of what to expect or whether or not I would survive.

How I helped myself get through this: I had this silent courage within me, a strength within me. I never allowed myself to think this was something I would not overcome. All I knew for sure was I had cancer. I dug deep, did extensive research and prayed, prayed and prayed. It worked for me - I'm a SURVIVOR.... I never gave up! Today, once again, I am proud to say, "I'm a Survivor!"

When I met Tamika Felder and learned of her organization: I knew instantly - within minutes - I wanted to be a part of the work they were doing. I learned how important it is to know other cervical cancer survivors and to share our stories. I hadn't known any survivors before Tamika. I now know that emotional healing is also an important part of the recovery process.

What can I do to help others?

When women share their personal stories, it is powerful not only for the person telling the story but for those who hear it. The stories on these pages are from women who have survived cervical cancer and have decided to share their stories to not only help empower themselves and move past cervical cancer, but educate and empower other women who might be going through similar situations. And if you're a survivor, we want you to share your story with us!

You could also become active with Cervivor – either online or in person. Join us for one of our walks; participate in our Cervivor School; or hold your own **House Party of fiVe**. In 2010, we held our first annual Cervical Cancer Day on the Hill in Washington, DC to meet with our state legislators and advocate for increased cervical cancer awareness and increased funding for cervical cancer prevention and treatment services. We are always looking for more survivors to become advocates, join us and speak up!

Visit **www.cervivor.org** to learn how you can get involved.

Judy New Hampshire



Age at diagnosis: 49

When I found out something was wrong: In July of 2008, I finally admitted to myself that I had to see a doctor. I had been putting off going to see a doctor for nine years mainly because I hated the gynecological exam. But something was very wrong. At the doctor's office, the gynecologist told me that I had

advanced cervical cancer and he thought some lymph nodes were involved. I asked him whether I was going to live. He said that if the CAT scan results were good, I would have a 50% chance of survival.

My diagnosis: Stage IIIB cervical cancer

How I felt after my diagnosis: I felt guilty at what a stupid thing I had done to not get a Pap test for that many years. I blamed myself for putting my family and friends through this nightmare.

My treatment: Chemotherapy, internal and external radiation

Why I am grateful for what I went through: It is 2 years since finishing treatment and I realize what is important in life and what is not. I now do yoga, work out, spend more time with family and friends and volunteer for those in need. I realize how extremely lucky I am just to be alive.

Why I share my story: I hope that women won't make the same mistake that I made. Please don't think you won't be the one. Get all your preventive screenings (including a Pap) when it is recommended. Trust me - the pain and embarrassment of getting a Pap is nothing compared to what might happen to you if you don't get one.

Patti New York



Age at diagnosis: 42

When my life changed: I had just retired from the NYC Police Department after more than 20 years as a Police Officer. My husband, who had already retired, and I had so many plans – we were going to travel, stop to smell the roses and just plain enjoy life.

Why I hadn't been to the OB-GYN in more than 3 years: Too busy, no time, I felt fine, I hate going, I've been married for 10+ years – the same reasons many women have.

Why I finally went to see my doctor: I had started bleeding on and off between menstrual cycles a few months before I retired. I had ignored it, thinking that it was from stress due to leaving my job. But when I started feeling very fatigued as well, I went to the doctor.

My diagnosis: Stage IIB squamous cell carcinoma

What the doctor told me: My tumor was too big (it was already protruding from the cervix), so I was not a good candidate for a hysterectomy. My treatment was going to consist of chemotherapy, and external and internal radiation. He also brought up the fact that I would lose the ability to have children.

How I felt when I left the doctor's office: Numb.

How my husband supported me: We took time to do a lot of crying and a lot of hugging. And then we had to recharge. So my husband, a pretty smart man in my book, sat down and began to empower himself with knowledge of the disease. Due to lack of education and misconceptions of the disease on my part, I was ashamed that I had cervical cancer due to HPV. My husband at no time questioned me or looked at me with any doubts. Instead, he began to educate me about the disease.

My treatment schedule: I had radiation every day for 8 weeks and chemo once a week for 8 weeks, followed by internal radiation. And then - my tumor was GONE and there were no cancer cells visible. The nightmare was over!!!

How I got back into circulation: My brother insisted we walk in the NYC Walk to Beat the Clock, a walk for awareness and prevention of cervical cancer. Meeting Tamika and other survivors inspired me and made me so grateful for my second shot at life.

How I help other Latinas: Knowing that Latina women are twice as likely to get diagnosed with cervical cancer in comparison to non-Latina women and the death rate for them is nearly 50% higher than that of non-Latina women, I decided to do my part in sharing my story and educate Latinas on the measures to take to prevent a cervical cancer diagnosis. We as Latinas have to be up to the challenge to make our health a priority in our lives. We also need to have more discussions about our bodies and sexuality and open up the doors of communication to our daughters and sons.

How do we educate others?

Talk, talk, talk! Tell others how to protect themselves from HPV and cervical cancer. Cervical cancer is preventable. You just have to know what to do.

Here are some facts to get you started:

1. Any woman who has ever had sex or sexual contact can get HPV. Most people get HPV through vaginal or anal intercourse, but HPV can also be spread by skin-to-skin contact in the genital area (the area around the vagina and penis). Even if you've had only one partner your entire life, you could have been infected by HPV.
2. The HPV types that can cause cancer don't cause any symptoms. No warts. No blisters. Nothing. Abnormal cell changes don't cause symptoms either. In fact, the early stages of cervical cancer often don't cause symptoms. Over a period of years your cervix may be developing a problem without you suspecting a thing. That's why it's so important to get tested regularly.
3. The best way to avoid HPV is not to have sex or sexual contact. If you choose to have sex, have your partner use condoms. Condoms can help protect against HPV. But since you can get HPV from skin-to-skin contact in the genital area, even people who use condoms can get HPV.
4. HPV vaccines can protect against the two types of HPV that cause approximately 70% of all cervical cancers. Both available vaccines are approved for girls and young women ages 9 through 26, but are recommended specifically for girls ages 11 or 12. One vaccine, which is approved for boys and young men ages 9 through 26, is also recommended for boys 11 or 12 to help prevent the spread of HPV and protect them from other HPV-related diseases. But remember, just because you've been vaccinated, you still need to get screened for cervical cancer!

5. Two tests provide an early warning system: a Pap test and an HPV test. Cervical cancer testing uses samples of cells taken from your cervix during your gynecological exam. (Collecting cells from your cervix only takes a few seconds and, though not comfortable, generally isn't painful at all.)

A Pap test looks for abnormal cells. If needed, these can be treated before they become cancerous.

Possible Pap test results are:

- **Normal Pap result:** The lab didn't find any abnormal cells.
- **Unclear or inconclusive Pap result:** The cells don't look clearly abnormal, but they don't look clearly normal either.
- **Abnormal Pap result:** The lab found abnormal cells that could become cancer.

An HPV test looks for high-risk HPV that can cause abnormal cells. Knowing you have HPV lets your healthcare provider monitor you more closely for cell changes.

6. Begin getting Pap tests at age 21. When you reach age 30, get an HPV test along with your Pap test. Speak to your healthcare provider about how often you should be screened and at what age you can discontinue screening.
7. If you've ever had sex with anyone, you need to be tested. Some women think they don't need to be screened. But they do! This includes women who have been in long-term relationships, lesbians, women who haven't had sex in many years, and women who've only had sex once or with only one partner. An HPV infection can take years or even decades to appear. Insist your healthcare provider gives you the testing you need. If your healthcare provider won't help, find another who will.

Carrie Virginia



A little bit about me: I have a wonderful husband and we have 2 beautiful girls and 5 beautiful nieces.

Age at diagnosis: 30

When I learned something was wrong: I always scheduled my yearly Pap exam around my birthday. I liked my OB and unlike most of my friends, I didn't mind going to the "coochie doc." No big deal - I went, I joked, and I left with a new script for birth control. A week and a half later, I received a call from Joan, my Doc's nurse. She stated that my Pap results were "questionable." The cells didn't look abnormal, but not exactly normal either, so they wanted me to come in for a colposcopy.

What a colposcopy feels like: I compared it to someone using a melon baller, just on my cervix. I bled for a few days. Again, no big deal.

When my husband began to worry: A week after my colposcopy, my Doc called to say that to his surprise, the cells needed further testing and I needed to schedule a cone biopsy. The biopsy was scheduled for my husband's birthday, and 5 days before we left for vacation. I went in that morning, had the procedure, and was home that evening feeling guilty for messing up his birthday.

How I found out that I had cancer: My Doc called and proceeded to ask me if I was in love with my uterus. I kind of laughed and stated that we had been together a while, but I could part with it if I had to. He proceeded to tell me that it needed to come out, along with a bunch of other stuff. I could remember NOTHING past "we need to schedule a hysterectomy."

What I was diagnosed with: I have read many blogs where women give the levels and initials that identify the type and severity of the cancer they have. I still haven't read the pathology report. All I knew was I didn't want it in me any longer than it had to be.

How I explained things to my daughter: My oldest daughter asked me if I felt bad and why it had to be me. I explained to her that I was glad it was me. I think she and my husband looked at me like I had lost my mind. I told her that if cancer chose me who had the ability to have an everyday procedure that would offer me a 95% cure rate, then I was glad it chose me.

What life is like after cancer: I still haven't really dealt with how I feel about all of this with the exception of a few nights crying over not being able to have another baby. One day, I may come to terms with everything. But for now I am just taking it day by day, waiting for the reality of being a survivor to hit me.

Christine Massachusetts



Age at diagnosis: 31

How my story begins: I never thought it would be me. I went for my Pap - like I did every year - but this time it was different... they had me come back, then had some more pieces looked at, and then I got the phone call...

My diagnosis: Stage IB cervical cancer with extensive lymphatic invasion

My treatment: Ten days after my diagnosis, I had a hysterectomy. One month later, a laparoscopic surgery. One week after that, 5 weeks of daily pelvic radiation with 4 rounds of chemotherapy, followed by 3 rounds of internal radiation. Then I was done.

How I felt: I was sad and mad and confused... Everything I knew was different. I thought I was no longer me and never would be. BEFORE cancer, I liked to sing. I liked to hang with my friends. I had energy. Everything was BEFORE cancer, and now I was AFTER... and it would never be the same.

What I did to help myself and others: I found my voice. I started to sing and to talk and to SCREAM because I realized I had something to SAY! I didn't know anything about cervical cancer before I had it. But I learned and then I wanted to share with EVERYone. I got friends to come and sing and play piano and help me spread the word: CERVICAL CANCER IS PREVENTABLE! I took my singing show on the road and called it The YELLOW UMBRELLA Tour.... and now I just keep on singing and talking to ANYone who will listen!

Why I continue to share my message: Because we CAN prevent this cancer. Cervical cancer is the ONLY cancer we KNOW what causes it - and we have PREVENTION and DETECTION tools - We need to use them to save fertility, to save women from disease, and to save lives.



Resources

American Cancer Society
www.cancer.org

Livestrong
www.livestrong.org

Cervivor
www.cervivor.org

Please visit the website of Cervivor
for an extensive list of resources.



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