

Voices of Women

Facing cervical cancer, human papillomavirus
and its consequences

TESTIMONIALS



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and its consequences

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Preface

This book of personal stories gives a voice to women affected by cervical cancer or genital pathologies associated with Human Papillomavirus (HPV). It is a snapshot in which women relate the course of their disease, recount their story and express in simple words their emotions, their fears and their hopes. The style is intentionally direct, reproducing the spoken word in order to faithfully relate the experience of a moment in life often described as a violent shock.

In this project, intended to be international, the WACC (Women Against Cervical Cancer) Foundation wants to focus on the person affected and not only the disease.

In the face of this disease, these women decided to demonstrate their desire for action:

- to break the silence and sweep away taboos,
- to share their experiences and emotions with others,
- to formulate their fears and worries, and their hopes,
- sometimes to shout out their injustice in the face of a disease which always leaves a trail of tragedy and of which they became aware too late for prevention,
- to deliver a message of encouragement to the young and not-so-young alike in order to reinforce their awareness of screening and prevention to give themselves the best chances of effective protection against the disease.

Women affected by the disease, their families and their loved ones will find in these accounts a reflection of what they are going through or have gone through in this testing time; they will hopefully feel less alone and less powerless.

For all other women, we hope that reading this will make them realise that it could all have been avoided and, for professionals, understand the difficulties of women facing these pathologies and gain a better idea of the importance of communication and inter-personal skills; and finally, for decision-makers, too often guided by economic considerations and remote from realities in the field, we hope that these few lines will raise their awareness of the individual and collateral dimension of each patient.

Ignorance is an evil which can be fatal.

The WACC Foundation hopes to make its modest contribution to this worldwide educational effort.

Many many thanks to these devoted women for this gift offered to all those who, thanks to these personal stories, will be saved tomorrow.

Doctor Joseph Monsonego
President, WACC International Foundation

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Learning the news

Anna, 40 years old, France

A false negative?

I found out I had cervical cancer as I approached my fortieth birthday, after a smear which revealed suspicious cells.

There were no particular symptoms, no "precursors", no pain, just a discharge which prompted me to consult my gynaecologist and to bring forward my annual appointment: I was all the more astounded as my previous smear was fine; without doubt a "false negative", I was told later.

And then the medical machine was set in motion: an appointment with the doctor I was told was the top specialist for this pathology, who quickly set a date for a conisation; there then followed various examinations and a diagnosis of invasive adenocarcinoma which needed brachytherapy, and a radical hysterectomy which fortunately was not to be followed by a further radiotherapy session. The course of treatment lasted from November 2007 to June 2008, followed by check-ups along with the inevitable "anxiety peaks".

How can I describe my feelings at the announcement of this disease, which is a real bombshell, affecting you and those close to you: a strong sense of injustice, first of all, and of guilt, for the origin of this disease is, according to what one hears and reads, due to a "carefree", unprotected sex life; this was not the case with me; my life as a single person was in

no way that of a "man-eater" and the sense of injustice was all the stronger because of this. Guilt also with regard to my husband and children, who had to live through these difficult times with me. But also with regard to colleagues at work: it's not a simple case of flu and the sick leave is longer, resulting also in an unscheduled career break.

My husband and I made the decision early on to "explain" the situation to our family and close friends: it's a difficult thing to announce, as "cancer" is still a frightening word, but I am convinced that it was important to do so and the expressions of sympathy from various people were like little "rays of sunshine" during those long months. It is however essential not to let yourself be overwhelmed by people around you who convey negativity and try to tell you about a neighbour or friend who had the same thing etc. Each case is different. Taking things step by step, focussing on the disease, closing the door on "gloom-mongers" and keeping as positive as possible: this is the battle I had to fight, with the help of my husband and the medical world. Also, keep active: work can be helpful as it forces you to think about something else and not to become trapped in a cloud of black thoughts.

Support from the medical world is just as important and I was able to appreciate the skill of the doctors who treated me, their tact in announcing the disease, and the objectivity of their diagnosis: the situation seemed clear and I knew I was in "good hands". This was one worry less. This did not stop me from spending time surfing the internet for explanations of the sometimes mysterious terms (why did I always think of questions after an appointment! my biology lessons were a long time ago!) But then I stopped short: the internet provides everything and anything, and from reading certain stories, I could imagine that my coffin was ready and waiting for me. I knew too that I was fortunate in that the situation "had been caught early" and I really must stress the importance of regular screening, at any age, and also explain that it is not a disease to be ashamed of.

I was also lucky to be supported by my husband; the experience brought us closer together.

So today I am being monitored; it should also be made clear that the consequences of major surgery fade slowly (it took me two years to

recover from bouts of anaemia, back pain and other problems) and you don't emerge "unscathed": apart from almost 10 months' accumulated emotional and physical fatigue, there lingers somewhere the feeling of "rupture" and a different and heightened sensitivity to the disease in "others" from among your family and close friends. The menopause is another factor, with the consequent effect on libido. But I am still looking ahead with the will (and hope) that this will eventually all become just a distant memory.

"In this type of situation, we have two options, to crumble or to fight; I chose the 2nd option"

~

Allison, USA

"To say that my diagnosis came as a complete surprise would be an understatement. On that day, my life was completely disrupted and irrevocably changed"

Thank you so much for inviting me to speak. It is inspiring and invigorating to be surrounded by so many women working to strengthen and improve the world for women! My name is Allison and I am here to tell you about my experience being diagnosed and surviving cervical cancer. I'll tell you how that experience led me to create The Hicks Foundation, a nonprofit dedicated to eradicating cervical cancer through education and medical resources. At the age of 29, I was diagnosed with advanced cervical cancer. I had regular medical care, but an irregular pap test went undetected and by the time I began showing symptoms the cancer had progressed considerably. To say that my diagnosis came as a complete surprise would be an understatement. On that day, my life was completely disrupted and irrevocably changed. Before I was diagnosed, I truly didn't know the depth of change that cancer brought.

In fact, when I received the call from my doctor, I wasn't alarmed, I

assumed my treatment would be quick and without much inconvenience. My doctor's response was sobering. She said "This is a really big deal. The best hope you have is that you survive your treatments. Hang up the phone, call a friend, and have someone come over immediately because you are about to start a huge process."

I am a young, single woman. I work as a doula, helping many women give birth and care for their little ones during those first few weeks of life.

My daily work had reinforced my own dream of motherhood. At times it was maddening to realize that as I worked helping women through this stage of life, the cancer was quietly stealing this stage of life from me. My cancer had progressed so that I needed a radical hysterectomy to survive. Treatment meant that my entire reproductive system was removed. What I thought would be a brief stay in the hospital turned into three weeks, with multiple surgeries and complications. I left the hospital with an open wound [[show on your body]]. I had a pump attached to my body and a daily visit from a nurse to clean the wound.

Surviving became my new job. Like anyone preparing for work, I packed my lunch each day and drove to the hospital for daily radiation treatment. Then, every Tuesday, I went to chemotherapy. I spent hours sitting in a lounge chair in a big room with other patients. I tried to relax while being pumped up with chemo cocktails, steroids and anti-nausea medication. I spent the rest of each week trying to recover. Through everything, I had great support and found ways to cope with humour and friendship.

But the reality of my loss kept pulling me under. The surgeries left me severely disfigured and unable to bear children. I cannot overstate the experience of having my body change from something beautiful to something that felt diseased and broken.

Cancer is a gigantic word. It is big. It is suffocating. It is scary and I felt tiny in the face of it. But as I healed I began learning that cervical cancer is somewhat different. Although it is the second most common cancer in women worldwide, almost every case of cervical cancer can be prevented with regular health care and tools such as the Pap test and new technologies including the HPV test and the HPV vaccine. Unfortunately, many women around the world don't know about or have access to screening

and vaccination. But I rallied around the fact that no matter how big, no matter how threatening, no matter how insidious cervical cancer can be, it is nearly 100% preventable...

One by one, I knew I could reach women. We named our education campaign "Mission Possible" because we believe that eradication is within our reach. Now, I talk to women, I meet with doctors, I join with advocates and I identify with them, not with cancer. I now feel anything but tiny. Take these messages with you to your families and communities. Together, we can eradicate cervical cancer!

~

Marie, 40 years old, France

"I found out about my cervical cancer just before my 40th birthday. The diagnosis had taken a long time"

My 1st gynaecologist thought my abdominal pain was due to stress. I started to bleed between two cycles, which made me think I had become intolerant to my IUD. When I woke up one morning, the pain was so intense (like contractions) that I decided to change gynaecologist and to find a female one instead. I thought she would be more thorough.

At the advice of a friend, I went to see another gynaecologist and she did indeed listen well and persevered in her search. After a number of examinations, she sent me to a doctor in Paris. Upon seeing my file, he carried out a biopsy and told me he wouldn't be astonished at a bit of a shock.

During the 2-week wait for the result, I tried not to think about it too much, but his secretary's call one Friday morning, asking me to free up the following Monday before the doctor left for a seminar made me realise immediately that the news would not be good. After having organised my schedule (one day's leave for me and my husband), we turned up for the appointment.

We had trouble finding a parking space. When we did find one, we didn't have a payment card so I had to go to the nearest newsagent and, seeing that we would be slightly late - less than 10 minutes - I notified the secretary. When we arrived at the doctor's practice, we were subjected to the doctor's views about our delay. I explained to him the reason why and we apologised. I confess that that surprised me and disconcerted me.

The doctor opened my file and announced coldly: "Cervical cancer". Personally, I knew that the news would not be good, but my husband was dumbfounded. Before writing this account, I asked him what his memory of this appointment was and he replied "Cold greeting and direct announcement - not a good memory." Nothing like the recommendations of the doctor's book which I read thanks to my gynaecologist who lent it to me.

Following an explanation with the help of a drawing, the doctor passed us on to his secretary to take the details of a colleague at the local cancer centre of our choosing. At this stage, we knew nothing further. I thought that it wasn't serious and at microscopic stage.

We quickly got an appointment at the Hospital. Another doctor examined me and, to our enormous surprise, told us that the tumour was as plain as the nose on my face. It turned out that it was 2 cm big. She was frank and very clear. She explained the protocol to us.

Hospitalisation for brachytherapy and, 6 weeks later, surgery for a "total" hysterectomy. We were able to ask all the questions we had and when we left this consultation, I decided to fight and to do all that was asked of me without hesitation. In this type of situation, we have two options, to crumble or to fight, I chose the 2nd option for my husband and my children.

So I underwent the brachytherapy for 5 days - hardly any visits, lying down the entire day, connected to an awful machine. A difficult but essential time.

Then 6 weeks of convalescence. I cancelled my planned holiday in Spain, but I asked my husband to go as planned with the children. I didn't know how I would be and I didn't want my children to see me in a bad way. We

decided not to tell our children that I had cancer.

As I said in the introduction, this word is still too frightening. We simply said that I had a health problem that I needed to sort out. Of course, we said that we would answer any questions they had.

I went to my parents to rest before the surgery scheduled for September. Everything went very well; the senior registrar who seconded my doctor was very nice. I did not encounter any particular difficulties during my convalescence. I went back to work in early November, i.e. 2 months after the operation and 4 months in total since going into the care of the Hospital.

The final agonising moment was the appointment to hear the results of the sample taken during the operation. My husband was once again at my side. When the doctor announced to us that it was all over, that I would not need chemo or radio or anything else, it was magical and a huge relief. We were very emotional and happy.

With regard to work: I didn't hide my cancer from my manager. The whole team was a real support during this testing time.

With regard to my family: I also had wonderful support from them.

I did not consider that I needed psychological help and in fact it was not offered to me either. In hindsight, I would strongly recommend it, as even if it doesn't seem necessary at the time, all that one has been through can surface again at a later date. In my case, it was very hard when I lost my father 7 months later from lung cancer. You cannot help yourself from going over everything you went through and telling yourself that others are not so lucky and do not survive.

The difficulties faced:

It is not easy to cope with an early menopause. Hot flushes, disrupted sleep. In my case, weight gain...

It was fortunate that my husband and I were both in agreement that we did not want any more children, otherwise we would have had to cope with that as well.

I was also angry at the start of this adventure, as I did not understand why my smears were all fine even though the tumour was in fact there. The talk is always about prevention, but sometimes that is not enough -

I am the proof of that.

I and my husband have no idea what the origin of this cancer could be. Being married for 16 years at the time of the disease, his doctor asked him if he had been faithful. Imagine the havoc that could wreak for a couple. I was also told that I could have been in contact with this virus early on in my sex life.

In short, the cause is very vague and we will never know when or how I caught this virus.

My message to doctors:

You need to learn how to listen to your patients. In my case, if Doctor hadn't listened, I may well not be here. I owe her an awful lot. Incidentally, at the IGR when talking to the doctor who operated on me, I mentioned this to him and he told me that if there had been a patient in my situation, with clear smears, they would not have looked any further. But given my experience, he would be more vigilant in future and I hope that this is true of all the doctors there.

Conclusion:

This whole experience prompted me to re-assess my values. My family's happiness and my health are what count most for me. Incidentally, I lost my job a year ago, after 20 years of good and loyal service (did it have something to do with my cancer? I don't know and I don't want to know); in any event, it is another hurdle to overcome. But as I said, I am making the most of the time I now have until I find an activity which I find fulfilling.

~

Facing fears and sufferings

Anneli, Sweden

"Before that, cancer was something that happened to other people"

Something told me that I should go to the doctor for that scheduled screening. I had not been to one for several years. Time flies and now I sit here 1,5 years later with a little candle burning while I'm writing. I was at that time 1,5 years ago that my journey to "know life" began, not only for me, but for my husband as well.

Everything started with a cervical smear test followed by another examination, (konisering) and finally the message; "You have cervical cancer". After my doctor told me this, I wrote down what he had said on a piece of paper and when I later walked home I thought: how will I tell this to my husband? ...

It was not long until a "circus" of examinations, tests and scanning followed one another.

Suddenly I was on sick leave and everything felt unreal. I did not feel my cancer at all and usually I only stayed at home from work for severe colds. I didn't feel ill, I felt like I played truant.

I associated the word cancer with my mother who passed away in 2004. Before that, cancer was something that happened to other people.

I think I first really understood what had happened to me/us, when I came home from surgery. The first days were horrible.

Pain, needles, feeling sick, vomiting, migraine and anxiety all together. Now it was time to start recovering,

I was to learn some things again, and learn completely new things from the beginning. I was supposed to learn how to like myself again... A beautiful little light was lit in all the darkness.

They had taken my uterus, the oviducts, a portion of the upper vagina, some tissue around the uterus and 40 lymphatic glands, but it turned out that the cancer hadn't spread! Yippie! Love to life!

Finally I got back to work again, all felt weird. I wasn't the same woman that had gone home a few months earlier and that now stepped in through the door at work.

I was a changed woman, a woman that had felt life. I understood then that I wanted to do something more of it.

I changed my job, started to paint and began practising Yoga again. Nothing is impossible if one only practises a little every day, I have heard someone say.

But between all of this I have had time for a depression, thoughts on death, thoughts on children and thoughts on life in general.

We were at a party only a few months after my surgery. One of the conversation topics were children.

"Do you have children?"

"Why don't you have children?"

... were questions that were asked around.

We sat there and just waited for them to ask us. What were we supposed to answer?

We didn't want to spoil the party, but we didn't want to lie either. Luckily we left before we had the question, it was just too much.

The journey to "know life" hasn't been easy and is still today not easy at times. Somehow I am still grateful that I'm on it.

I have learned incredibly much about myself. For example, it is not dangerous to stop in life and ask if this really is what I want to do. To get there can be a long road but one has to start somewhere...

But do I really understand what I/we have been through?... I don't know.

The way I feel today is in many ways thanks to my husband. I won't blow out the candle, I'll let it shine.

~

Oriana, 46 years old, Italy

"What do I need to do?"

"I would like to tell my story to make women understand the importance of prevention and above all how wonderful life is."

My journey started in October 2009, when, taking part in a screening programme for the prevention of cervical cancer, I went for a smear. The results arrived at my home about 3 weeks later.

I remember that on reading the response, I couldn't take in what it meant; I put the paper back in the envelope and got on with the other things I had to do. But my thoughts constantly returned to the words I had read: "atypical glandular cells, we recommend a colposcopy followed by a biopsy". So I picked up the envelope, read what was written and decided to tell my husband because it was something too important to keep to myself!

The next morning, I asked a friend who was a nurse to explain to me what the letter meant. "Try to keep calm; wait until you have these tests before drawing any conclusions or thinking the worst." That was her response. But it didn't calm me down; I was worried and I decided to go on the internet. I must say that this was a very bad idea because what I found on it frightened me even more. In the grip of this fear, I kept everything to myself because I wanted to protect my family. I waited for over a month before going for a colposcopy... I remember the expression on the doctor's face on the day he carried out the colposcopy; he told me he needed to take a biopsy, then a second and then a third...

His expression became more serious with each sample: he did not hide a

certain level of concern. I was sure, at that moment, that the situation was serious.

I had to go back 15 days later for the results - 15 days! Fifteen interminable days! It is strange to see how the concept of time has a different meaning depending on the situation... Time becomes a permanent enemy between what you could be and what you actually are: a sick person!

It seemed as though time was not passing, the tension grew. Being busy at work during the day helped me not to think negatively, but at night, thoughts raced through my mind, and I was caught in the trap of a dangerous whirlpool.

The fateful day finally arrived: the doctor had me sit down in his office; he told me that, unfortunately, the biopsies were positive and that I had cancer. I was to undergo a "conisation", with a sample of the cervical tissue taken, in the hope that the lesion was limited. Otherwise, the uterus and the ovaries would have to be removed, with the hope that other organs had not been affected.

When I left hospital, I was gripped by a strange sensation: I felt as if I were inside a bubble; I could not see or hear the people around me; I felt as if I were suffocating; I wanted to shout... "Why me?" I asked myself as I walked. I thought: how can I make this OK for my family? What should I do about my adolescent daughter? And my nine-year-old son? I was desperate... I walked without knowing where I was going...

One week later, I underwent the first surgical procedure which was followed by another operation, the most important one: my uterus and ovaries were removed (another 4.5-cm tumour was found in the right ovary), as were 28 lymph nodes (negative results), then a sample from the liver, kidneys etc.

That day, my family waited for seven hours... hours of agony, uncertainty which knots the stomach and drives one insane. The personnel in the hospital ward kept close to them and comforted them.

Those days were difficult and painful. But just when I thought the problem had been resolved with the surgery, the head of department

called me to say that I still had to undergo a series of preventive chemotherapy sessions.

Everything analysed by the anatomical pathologist was negative; the ovarian tumour was encapsulated, and there had thus been no contamination of the vital organs, but the chemotherapy was an essential step.

So, month after month, I faced the six cycles scheduled, afraid but with a good dose of courage. What helped me was thinking that I was luckier than many others.

Unfortunately, after the first chemo session, my hair fell out like leaves in autumn... It was awful; I wanted to hide it; I was ashamed to let my children see me. I wanted to cry, and thought that would relieve the pressure somewhat. But no, I held back my tears, once again, even though they could have been a release: because my husband asked me to be strong, he needed me! He asked me not to break down now, and, kissing me, he cried like a baby.

When the chemotherapy was finished, the check-up went well...

I am very well now and I have started back at work.

My life will never be the way it was before, but the important thing is that I am alive, I can see my children grow and smile, I am reborn every day.

This year, my teenage daughter has a special gift... the vaccine against HPV, so that she never has to face what I have been through!

I would like to appeal to all women:

"LOVE YOURSELVES AND PAY ATTENTION:

"Prevention saves lives...

LONG LIVE SCREENING!"

~

When the questions arouse

Michelle, USA

"How are women able to make informed decisions without information?"

During my early 30's, I had an abnormal pap smear, which my gynecologist told me was likely related to HPV. I was completely shocked that a sexually transmitted infection could result in cancer and was terrified. Fortunately, a colposcopy showed no disease, and my physician told me that I should follow up with a pap smear every 6 months for the rest of my life.

I asked her:

- Should I tell a sexual partner that I had HPV?

She said no, that 99% of all sexually active people have HPV, so there was no reason to tell a partner.

I asked her:

- Could condoms prevent the spread ?

and she said that no, "HPV was passed groin to groin, so condoms would not protect."

So, after speaking with my physician, I believed that there was no action that I could take with respect to HPV that would change any outcomes except for getting a pap smear every 6 months. I believed there was no way to reduce the transmission of HPV, since condoms weren't effective, and no reason to reduce transmission, since everyone already had HPV anyway.

About 10 years later, in my early 40's, I had an abnormal pap smear and was diagnosed with HPV16. My GYN told me that LSIL almost always clears within a year or two, so there was no reason to worry. But, she wanted me to return every 3 months for a follow up pap. My pap smears progressed from LSIL to LSIL-H and finally, to HSIL. A colposcopy revealed CIN2 in 2 quadrants and CIN1 in two others. During this time, I asked my GYN whether it would make a difference to have sex with my boyfriend and whether we should use a condom. She said condoms wouldn't make a difference and having sex wouldn't change any outcomes.

During this time, my boyfriend and I were sometimes dating and sometimes not dating. During a period when we weren't dating, he had sex with an ex-girlfriend. Three months later, she was having abnormal pap smears. Since my GYN had told me it was OK to have sex, I resumed sex with my boyfriend. We were dating again. I didn't know he had had sex with his ex-girlfriend. I've always wondered whether my pap progression was due to my initial infection or whether it was a new infection from my boyfriend's recent sexual activity with another woman.

- Further, was I the cause of my boyfriend's ex-girlfriend's abnormal paps?
- And, was this the same HPV infection I had in my 30's?
- And, had I infected others with HPV during the 10 years between my first abnormal pap and my current abnormal pap?

I'd been very careful to be tested for every STD I could think of and they all came back negative. I hadn't known there was a test for HPV. Also, I believed, based on information from my GYN, that everyone already had HPV, so there was no reason and no way to avoid infection.

My boyfriend became my ex-boyfriend and he is now engaged to be married. I asked him whether he was concerned about infecting this new woman in his life with HPV and whether he and his fiancé had considered vaccination for HPV16. He said, "No, what are the odds that my fiancé would have a bad outcome from HPV?" I knew his ex-wife had had cryotherapy, so at least 3 out of his 15 partners had been impacted by HPV – 20%. In my opinion, the odds were higher than average that his new partner might be exposed and develop a problem related to HPV. However, my ex-boyfriend had read public health information about HPV and believed that HPV "almost always clears" in women with normal

immune systems, so, he was not concerned. After all, his fiancé had a normal immune system and was not suffering from AIDS and was not taking immunosuppressant drugs for organ transplant.

After the CIN2 diagnosis, my GYN told me that I needed to have a LEEP procedure. I tried to find out how many LEEPs were performed in the U.S. and whether there were side effects and the rates of success/failure. I asked as many questions as I could, but couldn't find answers. But, my GYN told me I "had to have" the procedure and assured me there would be no bad outcomes, so I had the procedure. Fortunately, I have had normal paps since my procedure. But, my cervix is shortened and narrowed and filled with scar tissue. I no longer have much cervical mucus and do not have the same sexual response that I had before the procedure.

Since my experience with HPV, I've been looking for answers.

- Why hadn't I heard about HPV until I received an abnormal pap?
- Who's tracking outcomes related to procedures?
- Why isn't HPV treated as an infectious disease with an emphasis on preventing infection?
- How are women able to make informed decisions without information?

In seeking answers, I've read countless research papers and attended three HPV conferences. I've spent thousands of dollars of my own money trying to understand why HPV is treated the way it is. I've developed theories and opinions and I have some suggestions. But... those will take up a lot more space than there's room to share here. So... that's for another time.

I realize that there's a stigma attached with STD's and that I may be stigmatized for mentioning sexual partners. But, I wanted to be candid about the sexual aspect of my experience with HPV, because I think we need to stop avoiding the subject. HPV is sexually transmitted and I believe that education and protocols need to address that fact. I think there's a huge opportunity to reduce the spread of HPV infection through education that treats HPV as a serious disease with serious consequences for women's health.

In my view, there are three legs to the "prevention" stool and one leg has been completely missing from discussions about HPV. To vaccination and

screening, we need to add education, awareness and strategies for reducing rates of HPV infection in the population. We need to treat HPV as the infectious disease that it is. The general public doesn't know much about HPV, because they haven't been informed.

Educational messages need to be honest that HPV doesn't always clear – that at least 10% of women who are infected will not “clear” their infection and may need some kind of treatment that might impact their fertility and sexuality. Clinicians need to be honest about the potential long-term consequences of procedures as well as their limitations in being able to prevent recurrence or progression to cancer.

Once informed, the public will be empowered to make informed decisions about their sexual and reproductive health. But if the HPV community continues to downplay the risk from HPV, then the public will not pay attention, will not understand the need for vaccination and safer sex, and rates of infection will continue to rise. Women will be the primary sex impacted by the sexual, emotional, financial and reproductive consequences of infection. This is not fair. It's time to end our tolerance and acceptance of HPV infection as “normal.”

HPV infection should not be accepted.

It should not be common.

It should be systematically eradicated, strain by strain.

~

Sandrine, France

“Talking about it helps!”

It all started after a smear. I received a letter from my gynaecologist asking me to call in. She announced that my smear was not clear; she talked to me about pre-cancerous cells and papillomavirus, and she asked me to make an appointment with a doctor.

I left with my mind in a whirl, everything was confused, I couldn't figure out whether or not it was serious. So I went straight to the internet for information.

From that, I understood that it could be very serious.

My husband was with me at my appointment with the doctor. For me, it was as if I were paralysed. We were planning to have a second child, and I had just stopped taking the pill; so my husband asked questions about the future, something which hadn't even entered my mind. I could only think about the present.

A conisation was thus performed. The medics (all men) said that it was nothing, that it wouldn't hurt. I felt rather humiliated to be in pain as this was apparently not “normal”. Apprehension and the fact that I didn't accept this disease meant that I felt each action during the conisation with massive pain.

I was a bit ashamed of this disease as there had been talk of a sexually transmitted disease, transmitted by the man at a particular moment in my life. My close family was kept informed, but did not necessarily fully understand, and at work I only talked about it to a very few people.

I blamed myself too, and I thought it unfair that men don't keep this virus in their bodies, but women do. It was also unfair that part of my cervix was to be removed whereas my husband didn't have to undergo any sort of examination. We told ourselves (my husband and I) that this virus was

in me and that my husband could contract it and pass it back to me again... that it was a vicious circle.

I hardly need to tell you that our sex life was affected, and we made the decision to use condoms during sex (partly for protection, and also so that I didn't fall pregnant before having the test result). I had fantastic support from my husband. Especially as the question of unfaithfulness (as for any STD) could have reared its ugly head and created conflicts between us, which didn't happen.

We had lots of questions but no answers so I decided to make an appointment at the Hospital. I was sent to a gynaecologist who was very patient, very thorough, and very positive. This appointment made me feel better and slightly eased my anxiety about the virus. She answered my questions (as far as possible, as science is lagging a bit behind this virus). I made an appointment for my husband to check that he didn't have the virus. He proved to be clear.

Then three months after the conisation, I had a smear which once again was not OK. I had had enough of these examinations; I didn't want anyone to touch me anymore.

I felt that it was a failure, and I blamed myself even more, telling myself that my body was not fighting hard enough. I started to doubt having a second child. And this was confirmed by the doctor who strongly recommended removing my uterus.

I was severely affected psychologically by this relapse; I had to resign myself to only having one child and to my life possibly changing.

My husband really insisted on the doctor carrying out another conisation rather than removing my uterus. So another conisation was carried out, which physically was very testing.

Then, after this second conisation, order was restored. Bizarrely, I started to talk more openly about it to those around me, and I noticed that there were other women in the same situation, in particular a colleague of mine. And one day, we started to talk about it together, just the two of us, without any taboos, and we had the same questions.

I must say that discussing it like that with someone who had experienced

the same thing did me a lot of good. This dialogue with another woman is what I missed most during that period.

Today, we have a healthy second child.

Today, I approach each smear anxiously.

Before having sex without condoms, I have always done the necessary with each of my partners to have laboratory tests to detect sexually transmitted diseases. Why is this not the case for HPV?

In practice, it is not until a woman has a smear with pre-cancerous cells that HPV is detected. This is like the last chance. The fact of having part of one's cervix removed, the place where a baby lies, is not harmless for me and a woman is all the more sensitive about this part of her body because of the possible consequences.

~

Annie, 57 years old, France

"Why did no-one see it?"

I am 57 years old and since 24 September I know... I finally know what my body has been trying to tell me for several months.

Relief at knowing but also fear about the future.

An unfortunate set of circumstances and my lack of urgency in getting a second opinion delayed the diagnosis. The major and random bleeding which I suffered, I simply put down to the pre-menopause, but then other bleeding appeared.

I made an appointment with a gynaecologist in February. A smear and then an ultrasound of the pelvis did not reveal any anomaly...

I waited, head in sand... I, who was never ill, had flu (swine flu or not, I don't know) in June which laid me low for three weeks, and a urinary infection which took me to A&E in August.

Tired of feeling like I was 80 years old, I made an appointment with another gynaecologist in early September and from that point, everything passed in a blur: smear, colposcopy, biopsy, MRI and 3 new doctors in my address book.

I am in the best possible hands, they tell me. I believe them and repeat it to those around me, to reassure myself and to reassure those who love me. Telling my children that I had cancer was the worst moment. I don't want them to worry about me since I am not worried... not in front of them anyway.

This cancer, which is at a fairly advanced stage, must have already been there in February. Why did no-one see it? Why didn't I ask for a second opinion immediately? I am angry but I can't go back in time. Since 24 September, I have been living one day at a time, I wait for the results of examinations, I wait for the next appointment, I wait for treatment to start... And I am afraid...

We are now in November 2010 and my next examination is in 3 months, which means that I am doing well, very well even.

But let's go back to October 2009.

The lesion measures 45 to 48 mm. So I start an initial protocol comprising one session of chemotherapy and 4 sessions of radiotherapy per week. A PET scan confirms the lesion and indicates an extension and invasion of the lymph nodes.

In November, I go back into hospital for a lumbo-aortic curettage by coelioscopy. My surgeon decides against the curettage as I have a massive peridural dissemination in the pelvis. When he gave me the bad news, I understood that my case was not as simple as all that. But his way of talking, without waffle, reassured me. Since he got straight to the point with me, he would be just as resolute about eliminating this tumour. He explained to me that it was not good news but that I would have a new protocol with more chemotherapy to shrink the tumours before the operation.

The new protocol consisted of 5 chemotherapy sessions for one week, then 3 weeks off, then another 5 chemo sessions and so on, for 4 months. Each session lasted 5 hours. That was a long time, even though the nurses

were lovely. (I recently found out that this chemo is used for ovarian cancer). But things didn't go to plan...

After the 1st week of chemo, I couldn't eat, sores, the taste of cardboard in my mouth, nausea... and I fainted on a regular basis. The chemotherapist's nurse had given me her telephone number and I could call her any time of the day or night if I had a problem. So I called her and she had some blood tests done. I had practically no blood platelets or white blood cells left.

On that same day, I was back in hospital again..., in isolation..., losing my hair... A tough day; it was 8 December 2009.

I had had a very violent reaction to the treatment - a rare occurrence according to my chemotherapist. I shouldn't have lost my hair, amongst other things... 10 days in hospital, one month without treatment and a 3rd protocol put in place: 4 sessions of a slightly less strong chemo for one week and 4 weeks of rest, for a period of 4 months.

I still had the taste of cardboard or rusty iron in my mouth but I was a bit better otherwise and every week I dosed myself with EPO and my blood platelets and white blood cells were closely monitored.

In mid-April, some good news: the chemo had shrunk the tumour quite considerably. Physically, it had been tough for me but the cancerous cells had also had a hard time. I would remember for a long time the image used by my surgeon on that day: "You have moved from the back of the grid into pole position". At that point, I said to myself that in November I had been in a really bad way and that I hadn't been aware of it. I don't think that having a gloomy outlook would have helped me. 20 radiotherapy sessions later, I was ready for a radical hysterectomy, complete pelvic lymphadenectomy and lumbo-aortic curettage...

On 4 May 2010, the operation lasted six and a half hours, and on 5 May I saw my surgeon looking happy, and I was there on the podium... Returning home 7 days later was not such a happy event as I had great difficulty getting over the anaesthetic.

In September, after 2 weeks of brachytherapy, my treatment was FINISHED. Next check-up in March.

It took one year to get through my cancer. My hair is growing back

bizarrely; it is frizzy whereas it had been long and straight, but it's a new experience...

I was lucky to meet the best doctors and from the day I was in the hands of this team of doctors, I knew I would get through it. When I came out of the consultation with the doctor, I couldn't hold back my tears. His secretary said to me: "You are in the best possible hands"... that was the first and last time I cried about my cancer. My morale was unshakeable for a year, even when the chemo made me sick. The sessions were long - 4 or 5 hours - in a room which smells of the distress of the sick.

I was wonderfully lucky in being surrounded by fantastic people: my children ever present and with lots of kind gestures, friends who were not afraid of this disease and most of all my husband who shouldered everything throughout that year. At every check-up, at every treatment, at every appointment, he was there. He was totally ingenious in helping me feel better, making me eat, making me avoid the slightest tiredness, making sure I wasn't cut off from my friends by organising meals at home, by making me go out, take 3 steps in the street, then 4 and so on. He assumed all the responsibilities for one year. Some friends distanced themselves a bit. I understand them. They were afraid of making me talk too much about my cancer. Others, in contrast, became closer, showing a great deal of tact.

My disease brought us closer together, allowing us to see the little upsets of life in their proper perspective, to enjoy the present and to do everything for those we love.

I am a bit of a worrier with regard to those I love, in particular my children and my husband. But with regard to myself, I didn't know as I had never been ill. And yet, I stayed positive, even on the bad days. I told myself that each day which passed was one day less for my cancer and that, thanks to the doctors who focussed all their know-how on helping me, I would have the last word. Some people didn't believe me: "It's not possible to always stay that positive, you are just pretending..." Well, no, I was not pretending. My father asked my husband for news. "I want real news," he said. The answer to all questions about my health was "Don't worry, everything's fine", has become a standing joke between us.

Now, when I ask my daughter how she is, she answers: "Don't worry, eve-

rything's fine" and she laughs and I do too...

I urge all the women I meet to consult a gynaecologist and that if something worries them to change doctor.

What has changed in my life over the past year? 30 more contacts in my phone book: doctors, hospitals and check-up centres.

On a more serious note, I have met doctors who are very different from each other but all fighting tooth and nail to win this battle against cancer.

And now, life - thanks to them - is my most precious possession.

Thank you.

~

Relations with the Docs

Lilie, 22 years old, France

"Female intuition!"

At 22 years of age, there I was one day in May setting off for my annual appointment at the gynaecologist; little examination, little smear and that's it, and then, with a "See you next year", I was off to meet my friends, thinking that the smear would definitely be OK.

Two weeks later, I received the results and these were the words which stood out: "Dysplasia, lesions, high grade and tumour". What?? What is this mumbo jumbo?? So doctor gynaecologist, there is a problem?! My gynaecologist confirmed that there was a small concern but without more ado, she prescribed some laser sessions. So off I went to the hospital, for an appointment with the gynaecologist, oops! a man doing that? eeeeeek - is there a mouse hole I can crawl into? SOS! But no, get a grip! In any case, it's his job and given his age he must have seen a fair few in his time, so what does one more or less matter...

So into the laser room, and the session goes smoothly; he explains to me that the papillomavirus is contracted by all women in the beginning of their sex lives but that many eliminate it naturally; so it is an STD and he goes on to talk about the different stages of development (tumour, cervical cancer). An STD, how is that possible when I've only had one partner

for several years? A little talk needed with the partner in question, Mr Faithful and Perfect; he confirms that you can catch it from unhygienic toilets... In the midst of doubt, the absurdity of love and youth... I believe him.

After the lasers I contact my gynaecologist who tells me to wait until everything heals before a check-up 6 months down the line. But 2 months later, I make an appointment as I feel that something is wrong, female intuition surely... Appointment in September: repeat smear and repeat problem - the tumour is still there!

The gynaecologist suddenly realises that the treatment was perhaps not the right one.. So at that point of course I said "Goodbye Gynaecologist, you are the weakest link!" So I then contacted the gynaecologist who had carried out the laser sessions; I get an appointment for Christmas. There then starts the series of biopsies and colposcopies right in the middle of the New Year party season. The parties go ahead in a spirit of joy and good humour as, whatever happens, smiling is key! Then January arrives and along with it, the results: the lasers didn't burn the tumour at its root; instead Ms Tumour has made herself comfortable and grown to twice the size. Verdict: immediate conisation and Happy New Year of course!

No worries, no panic; I am the stronger person and have good friends and family; so no conisation is going to frighten me! But actually, Mr Gynaecologist, what exactly is a conisation?? Because at times like that, so many scientific words are bandied about that you think you've forgotten how to speak English! He then explains that it is a minor procedure during which he cuts away the tumour with precision; slight panic: "Is it still possible to have children after this operation?" Mr G reassures me: it's a laser method developed a few years ago which doesn't destroy the gift women have of bringing a life into the world. REEEELIEF! So there I am armed to attack this operation with the support of my loved ones. In April: done! My conisation went well! A week of recovery follows, surrounded by my nearest and dearest: Mum, Dad, friends, flowers and chocolate!!!

Today, I am in great shape, I have smears regularly to monitor the situation, for even if the battle is won, you mustn't forget that Mr Cancer could come back for another go.

So, even if you love the man who shares your bed and you are sure of the two of you as a couple, don't overlook any probabilities of Mr Other Half going off the rails, which could - in addition to upsetting you - destroy your health!

Be vigilant, respect and protect your body and your life!

Have your smears regularly so that you don't have to experience moments which are not always easy to cope with and spread the word to your friends and your family, including your children.

As for you, gentlemen, I would not judge any indiscretions, but think about STD's and protect yourselves!!!

~

Fabienne, 50 years old, France

"Get a second opinion..."

Today, I have decided to tell my story, the unbelievable luck I have had; but to understand properly, I need to look back a bit, to a different health problem which affected me a lot, but which made me realise that I needed to take my health into my own hands.

I am a very bubbly, energetic person who loves life, and I am not at all the type of person who broods and feels sorry for themselves at the slightest scratch; any problem that arises, I tackle full on.

In 2006, 2007, a bladder operation, an unremarkable operation which nearly became a drama, side-lined for 3 months, and 6 months on anti-coagulants.

Psychologically upset by the slow reaction of my doctors, my recovery was slow.

In early 2008, a year of momentous resolutions, I decided to have a full check-up; I was 50 years old, I needed to be careful.

Mammogram, ultrasound - all good. Then the smear - my error: I hadn't

had one for 7 years, in fact since my tube ligation. There was definitely something wrong, especially as from time to time, I had abnormal bleeding, between my periods. I simply thought that I could have a hormonal imbalance and I pushed it all to the back of my mind until my appointment.

I admit I never thought about cancer or the papillomavirus. I got back from holiday, found a letter from my gynaecologist telling me to contact him urgently; there was a problem with the smear. Appointment at a hospital (I forget its name), with a gynaecologist specialising in colposcopy, on 14 May 2008. The one-to-one was cold, and the doctor made me feel guilty: no smear for 7 years, unbelievable; you are totally thoughtless. I understand him; I know all that but it's too late now.

I emerged from the examination feeling completely demoralised, crying, saying to myself: "Well, if you've got something, it's just too bad, you deserve it". The results were due on 14 June. But nothing arrived. So I telephoned and found out that the doctor was on holiday and no-one else could give me the results. I decided to see if my gynaecologist could help, if he could have the results, but the response was: "You've waited 7 years, another few weeks won't hurt you." The doctor's secretary finally called me on 8 July to tell me (yes, her not the doctor...) "There's no problem after all, here's an appointment for December".

I didn't receive the results in writing until August, with a yellow laboratory sheet enclosed. I must have re-read it, this sheet, dozens of times and each time my doubts grew along with my anxiety. So many negative things had happened with this hospital; I was worried. A colleague and friend urged me to get a second opinion. So I did, and got an appointment with a specialist on 15 January 2009.

So there I was at the doctor's expecting to be given confirmation that the results were negative. But quite the opposite: there was something wrong...

So another examination and then the bombshell: there is a cervical lesion. My world caved in, I couldn't grasp what I was being told. The conisation was scheduled for 17 February 2009. I left in tears. It was a mixture of anger and disappointment, I was so angry with myself.

The day of 17 February was a difficult one for me, I felt sick, with suspense and with fear, and still this incomprehension, I felt numb. The conisation was carried out and I had a one-month wait for the results: 30 March and it would all be over, my worries would be swept aside.

So 30 March arrived, appointments were running late, I didn't feel good, increasingly anxious. At last it was my turn and, for the rest of my life, I will never forget that day; it will remain engraved in my memory. I have not forgotten anything about that day, every word, every act, everything is imprinted in my mind. The doctor's voice: "So what made you take the initiative to see me? It's an amazing piece of good fortune". And at that moment, I understood that there was no going back, that the only thing I didn't want to have had happened: it was cancer, an invasive carcinoma, but caught in time. I was completely floored, the word which sends shivers down the spine had been pronounced: "cancer". A short word which says an awful lot.

Curiously, I immediately thought of my husband, my son, my mother and my sisters. How was I going to tell them the news? I thought about my father who I lost 30 years ago to lung cancer and I wondered how he had reacted.

I felt as if I had been run over by a steamroller, no tears, no rebellion, I was paralysed. I listened and had the impression that I was not taking anything in.

A list of appointments was made: scanner, MRI, blood tests, radiotherapy etc... I left the doctor's with all the documents in my pocket and this dreadful news to announce. On seeing my husband, I broke down, why me? My husband was wonderful. In the 31 years of our marriage, we have overcome difficulties, hard knocks, and this thing "this cancer" we would fight it together, him, my son, with the help of the family. I mustn't give up. So I tried not to think about the disease anymore; I charged ahead with the round of tests and examinations, until the appointment with the surgeon, an extraordinary man. I immediately felt I could trust him. I talked to him about my fears, especially when he told me that the operation was by laparoscopy, or at least in part. My bladder ablation had been a bad experience, so I was terrified and terrified of the anaesthetic too. But I was ignored and the operation was set for 25 May 2009.

Between my work and the appointments, time flew by. Only the nights were long, I didn't sleep well and endless questions came into my mind; when I got up, I was already exhausted.

I never felt alone and I was wonderfully supported both at work by my colleagues and my bosses, and of course my family, my mother, my husband and my son.

My meeting with the anaesthetist was vital to me; I talked to her about my fears, the fear of not waking up; she listened to me and reassured me. When I woke up, I didn't have that cold feeling; I was warm.

The operation lasted four and a half hours and triggered the menopause, hot flushes, irritability...

I admit that I found it difficult; the hot flushes were worse at night, I woke up constantly. At work, I was very embarrassed when it happened in front of customers; in winter, I didn't bother with pullovers as the pharmacy is heated and I'm often drenched with sweat. That's not serious in itself but it is a nuisance and really changed my life. As for intimacy, it's not like it used to be; I am always apprehensive and don't feel anything. Perhaps it's psychological. I take Trophygil capsules, but sometimes it hurts. And yet I adore my husband, he is very patient.

I spent a week in hospital, then I returned to work which did me a lot of good. During this time, my file was studied by two teams to decide whether or not I should undergo brachytherapy. They couldn't agree. In the end, the decision was made not to do anything. My reaction was odd: I was happy not to undergo this treatment and yet it left me perplexed and worried whether there was a risk of it returning. After my operation, I had a check-up every three months.

It will soon be a year and a half since my operation and I have not seen the doctor since April 2010. I am due to see him on 1 December. I am very anxious about going; I don't feel good, I have put on weight and I'm sure he will mention it.

There is this 5-year barrier to get past, but even after that I will still have a check-up every year.

I threw myself into it so wholeheartedly from the outset, swept along by the wave of examinations, that when I suddenly had nothing, no appoint-

ments, no examinations, I was lost. I felt all alone, an empty shell. The worst thing was that I didn't understand why I felt that way. I became extremely sensitive and I would fill up for no good reason. I felt ugly, not at all feminine. Perhaps it was the fact that customers asked me if I was pregnant ... My GP told me that this was normal, that I was just properly coming to terms with what had happened to me. I questioned everything.

I said to myself: "Pull yourself together, think how lucky you are, you have been operated on really well, you are properly monitored, you don't need any more treatment".

It's true to say that this disease has had a major impact on my life; it has changed me.

I am and I try to be as bubbly and energetic as I was before. I see things in perspective better and I am not put out by little things which would have troubled me before. I regard each moment as a gift, I try to be as close as possible to my family, to share more and to listen to others.

I know that I have beaten my first record, one and half years has already passed. I am proud of myself because I didn't let things happen to me, I fought, sick with fear but with a burning desire to beat "this little crab". I fought for my husband, for my son, for my family and for me.

You have to fight and not let yourself be beaten. I have much before me I hope, but I must be vigilant. I have questions, little problems to resolve, but I repeat to myself every day that I have been unbelievably lucky.

I have been given a second life, a second chance, a second birth.

You need to dare to talk about it, to break down taboos.

~

The precious support from husband, family, friends and caregivers

Sophie, 28 years old, France

“There was just one objective: to stay alive”

I am now 35 years old, married since 2002 and mother to a little girl (by adoption).

I developed cervical cancer. It was discovered on 09/02/2004; I was 28 years old. Diagnosis: an endocervical adenocarcinoma, size of the resected tumour: 7x5x4 cm.

These words still echo in my mind. At first I thought there was some mistake, since I asked my gynaecologist for a smear every year. I knew about STD's and their consequences. I was particularly well informed as I had had herpes for many years, for which I am treated several times every year and the GP who monitored me at the time had explained everything properly. I was one of those vigilant women.

I quickly took myself off to the IGR, where the diagnosis was confirmed with an extra in the way of an extension: 1 inguinal lymph node affected. Announcing the disease was difficult, and the hardest thing was the consequences: giving up any hope of pregnancy. A real cataclysm. The after will NEVER be the same.

I will NEVER produce a new life. This also meant reflecting on us as a couple.

Then there are many other emotions to cope with: anger, denial, before trying to accept the disease and its consequences (work, family...).

The doctors explained clearly what would happen to me. I was monitored by a wonderful multi-disciplinary team which helped me keep my head above water.

The battle against the enemy (the disease) was conducted by the various treatments, even if at times my own flesh went through hell. Radiotherapy, chemo, brachytherapy, surgical operations. There was just one objective: to stay alive. I did not fight this battle for myself, but for my husband and loved ones.

Physically and psychologically, it was very very tough. I had wonderful support. This cancer affects our intimate selves. It is a difficult experience. The treatments and their immediate consequences are serious: depression, heartburn, vomiting, diarrhoea, weight loss, loss of appetite, hair loss ...

I am 174 cm tall and I weighed between 62 and 65 kg; I now weigh about 53 kg.

The disease and the treatments had various irreversible consequences:

- Hormonal: sterility, menopause (tiredness, dry skin and mucosa...), onset of osteoporosis (with joint pain), long-term incontinence (the bladder and the rectum have lost their elasticity). The impression of being 50 to 55 years inside my body.
- Physical: persistent tiredness, serious intimacy problems even today.
- Psychological: chronic depression, anxiety attacks.
- Then come the social consequences.

At work, I am an advisor for an insurance company.

This is a very stressful and tiring career with its long hours. You need to be on top form. I was excessively invested in my work (more than 45 hours per week) and was well paid.

I had to inform my employer that I would not be returning immediately. I tried to return full-time, but as I was exhausted, I did not perform; my manager put pressure on me due to the fact that I no longer managed to

achieve my sales objectives.

I cried at work: another failure. But I had, and still have, a need to work as staying at home alone becomes intolerable (my husband is often away on business and I don't have any family living nearby). I felt that I was no good for anything.

So I now work part-time. My husband works, but if I were single it would be difficult financially.

It is difficult finding a good balance between the body's need for rest and a "normal" life or a life "like before". But my mind and body no longer follow the same infernal rhythm.

My loved ones understand my fatigue and my blue moods.

Now I need to be monitored for the rest of my life. My uterus has to be watched carefully, and it is agonising on every occasion. Even if I sometimes manage to tell myself that everything is OK, there is always a little part of my brain which says: "Remember, everything was fine BEFORE too".

Physically, it's difficult. I often get up feeling as if I've been run over by a steamroller or been through a boxing match in the night.

It takes me a while to recover from little excesses (an evening out which lasts a bit too long, for example, which is hardly extraordinarily excessive!).

I really need a lot of sleep, rest, recuperation, a calm life, and positive energy. Now, stress and lack of rest cause anxiety attacks and it's psychology which takes the strain.

I have organised my social life around my now vital needs, but I confess it's rather the life of someone in their fifties.

I realise that now my physical and psychological balance is very fragile - another thing I have had to accept and learn to cope with!

In conclusion,

This cancer completely overturned my life. The physical and psychological consequences will follow me to my grave. Every day, I am aware of how lucky I am to still be here.

I am lucky to have a loving husband who I love to bits.

We became parents in late 2010 to an adorable little girl by adoption -

a family project which is taking shape after all these very tough years. I am happy. I need to take care of myself and not overdo things so that I can see her grow and be with her as long as possible.

I will stack everything I can in her favour so that she escapes this dreaded cancer by vaccination, prevention and regular screening.

There are enough cancers which cannot be healed! Protect yourselves and have regular check-ups. There is life BEFORE this CANCER and there is life AFTER this CANCER.

~

Edelma, Nicaragua

“Many also share the same fears I had”

I began getting Pap smear exams, and everything was normal at first. Then, one day they found something, and said that there was a severe growth present...

The Pro Mujer organization (member of WACC) helped me with the private procedures, and I did not have to pay for my surgery at the public hospital.

This was a huge benefit for me.

Without this support, it is very difficult to pay, and you usually have to wait a long time in between the payment and procedure. I made my payment on a Thursday, and had my surgery the following Monday.

It was very quick... Everything is better now.

I even feel brave enough to talk about it in our support group meetings when there are women going through similar situations. The staff and other clients tell women to come to me about these types of problems because many also share the same fears I had.

I try to educate women about my experiences because it is something

that could happen to them in the future.

At least, that way, they learn about it and are prepared.

Difficult issues become easier when you bring them to the surface.

You feel liberated, and can then go on to help others.

Now, I always tell women- “Get tested and take care of yourself!»

~

Seeta, 60 years old, Sri Lanka

To earn for her family

She has cancer of the uterine cervix, stage 2 B. She is living in a rented room in a slum colony in Delhi. She has 3 children, one of whom, her son, remarried and does not want to visit her anymore. Her second son is a drug addict whose wife is the only earning member in the family. The daughter is a widow who works hard to support her own family.

Seeta is receiving palliative support after external radiotherapy and incomplete ICBT failed to cure her cancer.

The cost of these treatments also pushed her below the poverty line.

Seeta enrolled with the CanSupport home care patient in 2004. At that time she was suffering from the side effects of on-going treatment.

She remembered her husband and used to cry a lot.

With the help of the care team she started gaining her confidence and learnt to fight her disease.

She also expressed a desire to earn for her family and so CanSupport bought a hand cart for her. Now, every evening she makes savories (idlis, pakoras) and sells them in the nearby market.

The association also helped put her son in a de-addiction centre. He is now free from drugs and she is very happy when he comes to visit her.

Her own experience has taught her the value of early detection and so she is the first to remind her daughter and daughter-in-law not to forget to go for their cancer check-ups; she does not want them to suffer like she has.

Her wish is that cancer detection tests should be a national priority and everyone should have access to affordable treatment.

Emotionally, she feels very strong now and declares: "I do not mind my sisters not visiting me anymore, because I have the home care nurses with me."

Story contributed by Harmala Gupta, president of CanSupport, member of WACC.

~

About being a survivor: living with, living after cancer

Jacqueline, 54 years old, France

"Have regular check-ups"

"You are very lucky, everything is going well; it was a micro-invasive cancer and everything has been properly treated by the conisation."

I had been confident at all times since the biopsy which took me to the clinic.

When I got the result of the biopsy, as it revealed papillomavirus, I ensured that my partner was kept informed. He reacted confidently too. He wasn't afraid of catching something. He also came with me for my outpatient procedure; he enveloped me in his complete attention and his love.

On the other hand, for a long time I was really angry with my ex-husband who I thought was responsible for contaminating me. This anger faded gradually as I became better informed. I never talked to my parents about it; my mother would have been too anxious about me.

What is the point of crying before you're ill? So as long as no diagnosis was reached, I continued to live without being swamped by anxiety all day long, without continuously thinking about the possibility of a catas-

trophe. When the crucial moment arrived, that would be the time to break down or not...

Increasingly, I let events pass me by like clouds in the sky. I don't hang on to them, I don't remember them. I do not own them. It is not "my cancer", it is "a cancer" which appeared at that moment to draw my attention to where I was in my life. I have always been very attentive to the messages from my body; when it signals something, the inner being is suffering... That has always allowed me to readjust my choices in life.

"If you want, for peace of mind, you could think about having a hysterectomy".

Here too, the question arises of living with or without fear. Why would there be any need if everything is going well? Why have my uterus removed simply as a precaution? If it's not necessary, if it's not essential? I explained my decision not to consider this solution and I was monitored regularly for 4 years.

This year, my uterus thickened and there was some bleeding. It was not even possible to access the cervix for a biopsy even under anaesthetic. So no diagnosis possible. A hysterectomy was suggested to me again. I accepted because the context is different. I do not want to run the risk of a cancer which would diffuse and be detected too late.

Everything is going well.

I am confident. I do not feel I have cancer. It is my colleagues more than me who are waiting for the results of the tissue analysis. What I am waiting for is above all being able to start running again. The post-operative consultation confirmed that everything is OK.

Life goes on.

I don't forget to appreciate all the good times and the everyday little things which make my life rich and happy.

~

Rosi, 47 years old, Portugal

"I must say that my testimonial might not be so short, but each line should give more strength to all who will read this early enough!"

I have lived a grade 4 carcinoma of the cervix, a few years ago and, at that time, due to gravity after removal of the affected area, I was observed during three long years.

I had recurrence of grade 2, was operated on 30th December 2010 and my scar is already optimal.

Today I'm at the end of a recovery and new, thank God, always with the full force of the world to fight for myself and family members - four years ago I lost my father (lung cancer) and two months after him my second father, a fabulous uncle (cancer of the intestines).

A cousin of my husband (breast cancer, savvy, survived three months) had, two and half months ago, a friend who did not survive (cancer of the pancreas). A sister of my husband and my cousin also had breast cancer - thank God they are alive and remain very scrappy! Due to illness of my sister (breast cancer) and the fact that my mother still have Alzheimer's, my father could not bear the suffering and the 12th of October 2009, his birthday, he died. Since then I have had my husband very depressed about all this!

As you see, is not easy!! I have in my family a great predominance for Cancer, and perhaps this is why I feel comfortable with of SHOUT loudly, that we must give voice to those who struggle and fight with cancer, even if it is running with the Portuguese League Against Cancer, which is what I have done more.

I know that, in fact, I'm not like many people who are devastated with the fact that they have cancer! And with all respect that is due to me suf-

fering, I leave here ever since my support to fight STRONG!

I learned to have much strength in difficult moments of my life and, God willing, that strength that He gives me every day is always strengthened by all the people with whom I share these experiences and seek help! Because, as I usually tell my friends, each day that is born is a new blessing for me and not to waste!

I can say that I have spoken with lots of ladies and young people who have shared their experiences and I always find people who are very strong that encourages and empowers others and it is this force that I've been working and getting more and want to leave anyone in need!

~

Ramo, 48 years old, India

"The family still works hard and lovingly takes care of her"

She was diagnosed with cancer of the cervix in 2008. She was earlier working in a brick factory with her husband. Physically strong, she could previously carry a number of bricks on her head.

Presently she is undergoing treatment for cancer in a government hospital.

She has brought up seven children among whom four are married and three are unmarried.

Her husband is very caring and regularly takes her to the hospital, carrying her on his back because she is unable to walk.

Ramo was referred to the home care programme of CanSupport (member of WACC) in 2009. She is a very brave woman who has fought against all odds.

Despite severe pain, bleeding and side effects of treatment she has always welcomed us with a smile. She takes her medicines regularly and her children, who are still studying, take good care of her. Her husband continues to work as a casual labourer in the nearby fields and they barely make ends meet. He, too, requested us for a vegetable cart so that he can start a trade on his own.

Ramo, a woman with a strong will, is preparing her children for her early death. She counsels them to take care of each other and of their father.

What touches one most when one visits is that despite their obvious poverty, the family still works hard and lovingly takes care of her.

When the children come back from school, they do all the household work and feed their mother as they know that their father has gone out to work.

Ramo feels that cancer must be detected at an early stage so that timely treatment is possible.

She prays to God, that her end will be painless and peaceful. She welcomes the visits of the home care team and is confident that under their care she will suffer no pain. She has already managed to overcome her fear of dying and is a role model to all.

Story contributed by Harmala Gupta, president of CanSupport, member of WACC.

~

Prevention and screening save lives

Tami, Israel

**"If I had this test before, I would have prevented it all ...
But I did not know"**

I was alone when I got the news of having cervical cancer. I had the Pap test and my dr. asked me to arrive to get the results and said it didn't look good. I asked her to explain to me how bad it was, what does it mean, do I have cancer? Could it be? She said that everything can be, now I know and realize that she probably knew already from the first visit. When I left her clinic I called my husband, mother and sister, I told them something was wrong, everyone assured me, you'll see that in the end everything will be fine. Who would believe that I who am normally very healthy would get a disease that can be very destructive? I'm taking care of myself, I'm young, still of childbearing age, it cannot be!

To the gynecologist meeting, I brought my sister and my mother, they joined me to hear what the doctor said, to prove to me that it was not true, everything was fine with me and I was healthy.

Meeting with him and being with them was very difficult. It was then that we realized I had the disease, it was not maybe, I was sick and I

needed to be treated and move on. It didn't stop there, it was just the beginning. I came out crying, I wanted to be alone, I cried, I realized that I had a problem and I promised myself I'd get over it, it will not be simple but I'll get over it.

I'm 33, married and mother to two wonderful children, a boy and a girl. Who would have thought it would be so significant that at least I have both sexes that I gave birth, that I would appreciate what God has given me so far. I got home and shared the news with everyone around and went on a new way, a way of which I know the beginning but not the end. It turns out that the little test, Pap smear, the test that is so significant, if I had this test before I would have prevented it all.

But I did not know and I'm here to tell and ask every woman and girl to go and be checked, do not say it will not happen to me, I used to believe it will not happen to me, till now I cannot believe it happened to me. If there was a woman who would have asked me to get tested as I ask you to do, I imagine I would do it.

Today, I am after hysterectomy surgery 8 months ago, I went through a difficult time, with lots of psychic powers before the physical forces, forces that I do not know from where I got, but I got them. Thank God the surgery was successful, my doctors treated me perfectly. They are very professional doctors that first and foremost give me support and are always there for me. Currently, I am healthy and get tested every several months, there are plenty of fears from the worst, yet I know how to be strong and move on because I know that only there I'll get the strength to continue.

May we all have a lot of health and...

Do not forget to be tested!

~

Prathibha, 37 years old, India

"Let us hope that stories such as Prathibha's will help raise public awareness, and that millions of women will learn to battle a disease that, for the present, they don't even know they can conquer"

One day she heard from her neighbours that there was a team conducting cervical cancer screening in her area. When Prathibha arrived at her house, she saw two women from a cancer hospital talking to her husband about cervical cancer screening. He gave them permission to explain the procedure to her. They informed Prathibha that cervical cancer was the most common cancer in women in her region, but if detected early, it was a preventable disease.

Prathibha was not sure about getting screened, but the village elder, the panchayat, whose mother had died of cervical cancer when he was 10 years old, had already given his tacit approval, so her husband and mother-in-law agreed. The test was free, and she underwent the test even though she had no symptoms.

Prathibha's test results were positive for cervical cancer.

She was shocked, as she felt perfectly healthy.

Further testing confirmed that she had cancer and the doctor advised she get a hysterectomy. Prathibha couldn't believe that she was in such a dire predicament – going from feeling perfectly healthy to being diagnosed with cancer in a matter of days! She then underwent hysterectomy. While in the hospital, Prathibha talked with another woman who had advanced cancer and was very worried about the future of her young child. It was at this time that it struck Prathibha how lucky she was to get the opportunity to be screened and treated.

She said, "These people saved me. They have not only saved a woman but they have saved the mother of a small child. I am lucky that I live in the

village of Osmanabad District, which has been selected for this program. I am thankful to these people, who put in so much effort to convince me to get tested and prevent cancer. They saved my life and my family."

This story clearly illustrates the challenges of women's lives in low resource settings. It also shows the challenges posed by husbands, mothers-in-law, local myths and fears, and, poor health services that prevent women from being screened for cervical cancer. Many women continue to die from the ravages of cervical cancer.

Let us hope that stories such as Prathibha's will help raise public awareness, and that millions of women will learn to battle a disease that, for the present, they don't even know they can conquer.

Story contributed by Shobha S. Krishnan, M.D, Giahc (member of WACC).

~

Christine, USA

"Again, I started to sing and to talk and to SCREAM because I realized I had something to SAY!"

It happened to me. I never thought it would. But then 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...

Invasive cervical cancer - extensive lymphatic invasion. Ten days later, a hysterectomy. Month later, a laparoscopic surgery. A week after that, 5 weeks of daily pelvic radiation. At the same time - 4 rounds of chemotherapy. After that, 3 rounds of internal radiation. Then I was done.

LOL? Not really laugh out loud at all.

I was 31. I was sad and mad and confused... it sucked. Everything I knew was different. I felt like shit. I thought I was no longer me and never

would be. BEFORE cancer I liked to sing. BEFORE cancer I liked to hang with my friends. BEFORE cancer I had energy. Everything was BEFORE cancer, and now I was AFTER... and it would never be the same.

BUT then I found my voice.

Again, 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. so I did. I got friends to come and sing and play and help me spread the word: CERVICAL CANCER IS PREVENTABLE!

Talk to your doctor - get the best pap available - get your HPV test if you are 30+ -

And NOW get the HPV vaccine if you are 9-26 years old... because we CAN prevent this cancer.

It's the ONLY one we KNOW what causes it - and we have PREVENTION and DETECTION tools - we should use them.

To save fertility. To save lives.

~

Jeanne, 16 years old, daughter of Laurence, 40

10 February 2009 - "Mum has cervical cancer"

It rocked my world when the doctors told us the unimaginable, the inconceivable: "It's not possible".

And yet, yes! It has happened to our mother, our pillar.

With the strength of her 40 years, she chose to fight. She accepted eve-

rything: the mutilating surgery, the "burning" radiation, the loneliness, and the hardships.

She gave up everything in order to recover.

What she was and loved. She also learnt to savour each moment of happiness, each instant of freedom.

She was a courageous and strong mother. Mum is exhausted; will she find the strength to continue to fight?

I would like to hope that things can return to normal, like before.

~

You who have people dear to you, children you love, you obviously understand Jeanne's anxiety.

Having a young mother or a loved one with cancer - what could be more awful, more unfair?

No-one is safe; every day in Europe, some 140 women hear these dreadful words.

Just fifty years ago, this disease had 6 times as many victims and death was inevitable. But even today 4 women out of 10 die within 5 years.

WACC works to prevent these situations; it has made the prevention of cervical cancer its cause.

Pamela Morton, UK, WACC taskforce member

Patients and Doctors, a special dialog

~

Real-life experiences and the psychological burden of the disease

The anxiety that I observe in my consultations is usually due to ignorance about what can be expected of screening and what an abnormal smear or a positive HPV test means. In addition, the fact that the smear is sometimes called the cancer-screening smear only adds to the confusion.

The anxiety starts at the very moment the woman has a smear. Some fear being examined by a male gynaecologist.

There is also a great deal of confusion about the concept of cancer and pre-cancer of the cervix. For many women, the fact of being symptom-free, not being sexually active, not taking any contraception and being in good health justifies not having a smear.

This of course reflects an incorrect understanding of screening, as vaginal discharges or bleeding are occasional symptoms of the disease but unfortunately only at an advanced stage.

The anxiety is also increased by the – oft inappropriate – use of the HPV test and the incorrect interpretation of a positive result by the doctor. In the minds of many women, papillomavirus equals cancer, which is a misconception as over 70% of young women exposed to the virus are not even aware of it and eliminate it naturally.

Types 16 and 18 are, of course, persistent more often than other strains of the virus, but the initial lesions are always benign. The fact that HPV is a sexually transmitted disease also generates a sense of guilt and a number of questions about the partner. Let us sweep aside the misconceptions: papillomavirus infection is not a transmissible disease like others as it is directly associated with the immunity status of the subject. As women are more receptive than men, we humans are unequal in the face of HPV.

It is estimated that 7 women in 10 have been exposed to HPV at least once during their lifetime. Even someone in a stable relationship with one partner can therefore be affected.

The colposcopy consultation can also increase anxiety levels. "If my doctor

has referred me to a specialist, something serious must be wrong," is what the majority of women think. It is for the GP to inform his patient and to reassure her so that the wait for the examination, which can sometimes be a lengthy one, does not cause her undue distress.

Clearly, the position for the examination is not elegant and the patient may not like it, but the examination itself is quick and not painful. Here too, as I have explained in previous chapters, my visual findings will allow me to draw certain conclusions without waiting for the result of the biopsy.

I say: "There is no cancer but just a benign lesion, and here is the treatment expected", or: "There is no abnormality and this is why the smear was unclear." Reassurance provides perspective and sweeps aside received wisdoms and misunderstandings.

Furthermore, I know that the operating theatre is over-awing and that the personnel moving around the patient raises many women's anxiety levels and causes them embarrassment. A few explanations before the examination will help you better understand this event and will be very useful to you.

The wait for results is also a worrying time.

This is why, whatever the circumstances, I give reassurance immediately after the colposcopy. If the physician is well-trained, the examination is visually very reliable. If I am in any doubt about the result, I explain why, and if I suspect cancer, I start to prepare the way.

The announcement of cancer will be made with sensitivity and tact.

The therapy plan needs to be explicit; the future disruption to the patient's social life and the couple's life together needs to be discussed. Any form of guilt can be wiped away with clear explanations. The announcement tool will be followed.

The woman and sometimes her partner will always need a minimum of advice and support, even if they do not necessarily ask for it.

I hope that this book will help them.

J.Monsonego MD

An emotional and psychological burden not to be ignored

The incidence of the cervical cancer, in the sixties was around 40 per 100.000 women per year, being now 7 per 100.000 new cases year, in Spain.

Fortunately, this previous depressing scenario has change in the developed countries, but still there is much to do in the so called developing countries. It is not my aim to focus in the very important aspects of screening, vaccination or anything which could be useful for detecting cervical cancer in preinvasive stages.

Each of these women will have a personal tragedy which very often is totally ignored.

Cervical cancer as any cancer needs much more than science and technology, it needs a human being giving support and love to another human being.

Professor Santiago Dexeus, Spain.

Stopping invasive cancers thanks to the power of information

"If we're able to inform and make all women aware of the importance of both primary (vaccination) and secondary (screening) prevention, we can really stop most of the new cases of invasive cervical cancer, as well as other serious diseases caused by HPV."

Professor Carlos de Oliveira

President of the Portuguese Cancer League

ABOUT WACC WOMEN AGAINST CERVICAL CANCER

Cervical cancer, caused by sexually acquired infection with Human Papillomavirus (HPV) continues to claim the lives of more than 270 000 women every year, of whom 80% live in poorest countries. But the greater tragedy is that many of these deaths could be avoided. Though we have no effective preventive strategies for most other types of cancer, this is not the case with cervical cancer.

The burden of the disease has declined in developed countries because measures were taken to screen and treat for precancerous lesions and to vaccinate girls and women before exposure to HPV infection. Today we have at our disposal all the tools and resources necessary to stop the disease claiming more lives.

WACC initiative aims to improve awareness of cervical cancer and HPV-related diseases, and to move cervical cancer prevention to the top of women's and public health agendas.

WACC's missions are to inform and to educate, and also to unite all the actors concerned, and work with them to empower women and to fight against the injustice of this disease.

Since the launch of Women Against Cervical Cancer, the WACC international network has steadily grown in number and continued to gain momentum. It now has in its ranks numerous patient groups, health organisations and institutional partners from every continent, together striving to make change happen.

SHARE YOUR STORY WITH WOMEN AGAINST CERVICAL CANCER

Sharing testimonial will help other women and men understand better what this cancer is about. It will help face the silence or taboos and empower women to make informed choices. This is to help raise awareness on HPV and related cancers but also to promote available means of prevention and detection.

Testimonials can be short or long, signed or anonymous, in English or any language. It can also be illustrated.

Email us at: testimonial@wacc-network.org
or write on line at: www.wacc-network.org

WACC INTERNATIONAL FOUNDATION

contact@wacc-network.org

www.wacc-network.org

Facebook: WACC women against cervical cancer

Utube: waccadmin

Support Women Against Cervical Cancer: make a donation

<http://www.wacc-network.org/foundation.php>

*Special Thanks to
Carole Schaal, Dabrowka Franquelin and Marie Agnès Ricard for their
dedicated and persevering work in 2010 and 2011,
allowing these stories to be published.*

The logo features the letters 'WACC' in a large, elegant, dark red serif font. The 'W' is particularly stylized with a large loop. Below the letters is a dark grey horizontal bar with a fine, grid-like texture.

WOMEN AGAINST CERVICAL CANCER

www.wacc-network.org