

Faces of Cervical Cancer:

Information and Support
for those Living with
Cervical Health Issues.



ACCF
AUSTRALIAN
CERVICAL CANCER
FOUNDATION

About this booklet

Australian Cervical Cancer Foundation (ACCF) welcomes you to the information and support booklet for those living with cervical health issues.

This booklet is host to a range of information to help you through this time, as well as stories from women whose lives have been touched by cervical cancer or cervical abnormalities. These stories are from ACCF's Faces of Cervical Cancer and provide you the opportunity to read about other women who have gone through the same things that you may be going through.

We hope to provide information to broaden your understanding, and offer answers to some of the questions you may have been wondering about. It may even be helpful to pass this booklet onto family and friends to help them understand what you may be going through.

Never forget that we are here to help and provide you with support throughout your journey.

Please contact us if you would like any further information or support.

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Faces of Cervical Cancer: Information and Support for those Living with Cervical Health Issues.
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Note to Reader
The information in this publication is intended as a general introduction to the topic and should not be taken as a substitute for medical advice from your healthcare team or practitioner. In the event that you require emergency or crisis support, we recommend that you contact Lifeline on 13 11 14, who provides free, 24-hour telephone crisis support in Australia.

Australian Cervical Cancer Foundation
Australian Cervical Cancer Foundation is a not-for-profit organisation with one clear goal – to eliminate cervical cancer. Through programs in Australia and developing countries, ACCF helps women and girls access the protection they need to avoid this deadly disease, while enabling treatment for those already affected and facing related health issues.

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Contents

1

Basics

- 08 The cervix
- 09 HPV
- 09 Cervical screening
- 10 Cervical abnormalities
- 12 My test results came back as abnormal

2

What is cervical cancer?

- 17 The stages
- 18 Possible procedures
- 19 I have been diagnosed with cervical cancer
- 20 Possible questions to ask your health practitioner

3

Treatments

- 25 Surgery
- 26 Chemotherapy and radiotherapy
- 27 Palliative care

4

Post treatment

- 30 Life after treatment
- 30 What if the cancer returns?
- 32 Relationships and sex
- 33 Fertility
- 34 The community

5

Glossary

- 38 Glossary
- 41 References
- 42 Appendix - Women's Comfort Checklist

Basics

1



What is the cervix?

The cervix is part of the female reproductive system. It forms the narrowed, lower part of the uterus that connects to the upper part of the vagina.

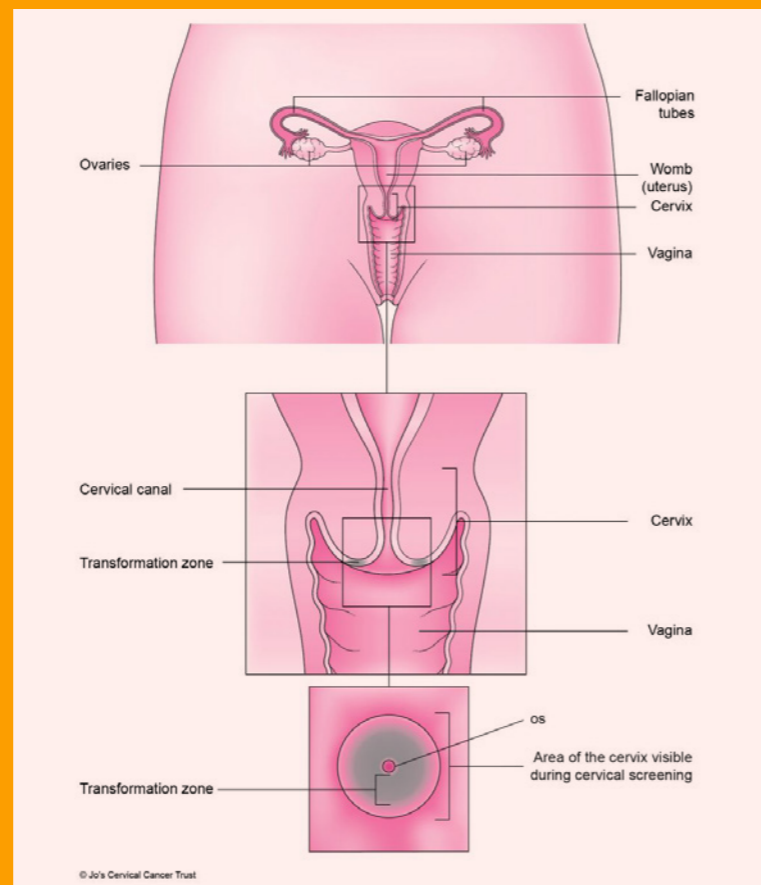
Various functions of the cervix include:

- Tightening to hold a developing baby in the uterus during pregnancy.
- Widening (dilating) during childbirth to allow the baby to pass through the vagina.

The external 'os' is where the cervix opens into the vagina. The two types of cells that line the surface of the cervix are called squamous cells and glandular/columnar cells. Squamous cells are thin and flat, and are found in the lower part of the cervix, which opens into the vagina.

Glandular or columnar cells are long and column-shaped, and are found higher up in the cervical canal. The transformation zone is where cells are constantly changing from columnar to squamous cells and is the most common site for abnormal cells to develop.

Image: Female reproductive system highlighting the transformation zone, the most common site for abnormal cells to develop.
© Jo's Cervical Cancer Trust



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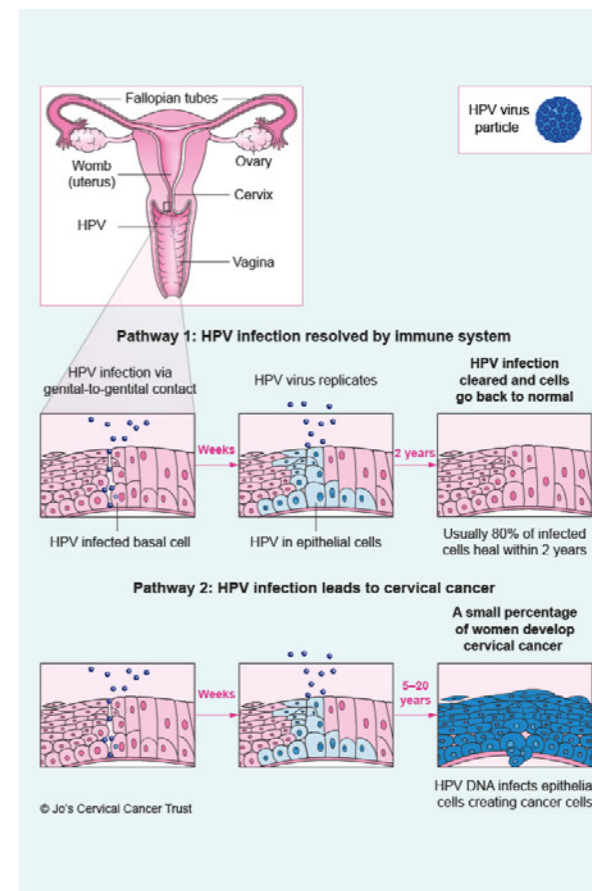
What is HPV

The Human Papillomavirus, or HPV, is the cause of almost all cases of cervical cancers. HPV is a common infection that is spread by genital skin-to-skin contact during sexual activity.

The HPV virus is so common that 80% of people will be exposed to the infection at some point in their lives as a normal part of being sexually active. For this reason, it is often referred to as the common cold of sexually transmitted infections (STIs), with both females and males responsible for transmission of the virus. HPV usually has no symptoms, so most people won't even know they have it.

Occasionally, low-risk strains of HPV can cause genital warts and benign (non-cancerous) cervical abnormalities. High-risk strains of HPV have the potential to cause cervical cancer and other cancers in females and males if the HPV infection is not cleared from the body. The body works hard to fight the virus and clear it on its own usually within 8-14 months after infection. In some cases, however, the body cannot always clear the HPV infection. If your body does not clear the HPV infection, it can cause changes to the cells in the cervix, which can eventually become cervical cancer.

Image: Pathways of HPV infection in the cervix.
© Jo's Cervical Cancer Trust



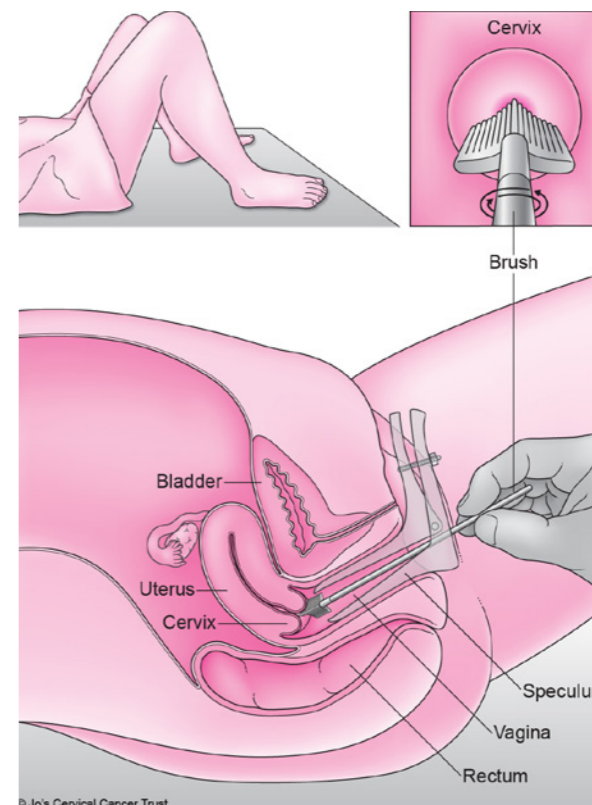
Cervical Screening

The Cervical Screening Test (CST) detects the presence of an HPV infection early, allowing your healthcare provider to monitor the infection and intervene if there are any changes to the cervix.

If you have tested positive for HPV, it does not automatically mean that you have cervical cancer, but indicates that you are at risk of developing cell abnormalities that can eventually become cervical cancer.

If you have tested positive for HPV, your healthcare provider may ask you to return for a follow up CST to see if your body has cleared the virus or monitor for cell changes. Follow up CSTs can occur anywhere up to 12 months following, depending on the guidance of your healthcare professional. It often takes up to 10-15 years after infection for cervical cells to become abnormal, and then to cause cervical cancer. However, this can vary between individuals so it is important to keep up to date with your cervical screening.

Image: Cervical Screening Test (CST) procedure. During a CST a speculum is inserted into the vagina so the cervix can be seen. A small brush is then inserted and used to collect some cells from the cervix.
© Jo's Cervical Cancer Trust



© Jo's Cervical Cancer Trust



My Cervical Screening Test says I have HPV – what does this mean?

Watch video



ACCF Comfort Checklist

Some women find a cervical examination uncomfortable or awkward.

ACCF has developed a Comfort Checklist for patients who may experience emotional or physical discomfort. Take the Comfort Checklist along with you to your appointment and discuss with your Health Professional how they can make the experience as comfortable as possible for you. The Comfort Checklist can be found in the Appendix A of this Booklet.

Read more

Cervical abnormalities

Cervical abnormalities highlight early changes to the cells in the cervix, caused by an HPV infection.

Many abnormalities resolve by themselves, however if left untreated, they have the potential to develop into cervical cancer.



You will usually be advised to return for cervical screening in 12 months to monitor low-risk cell changes.

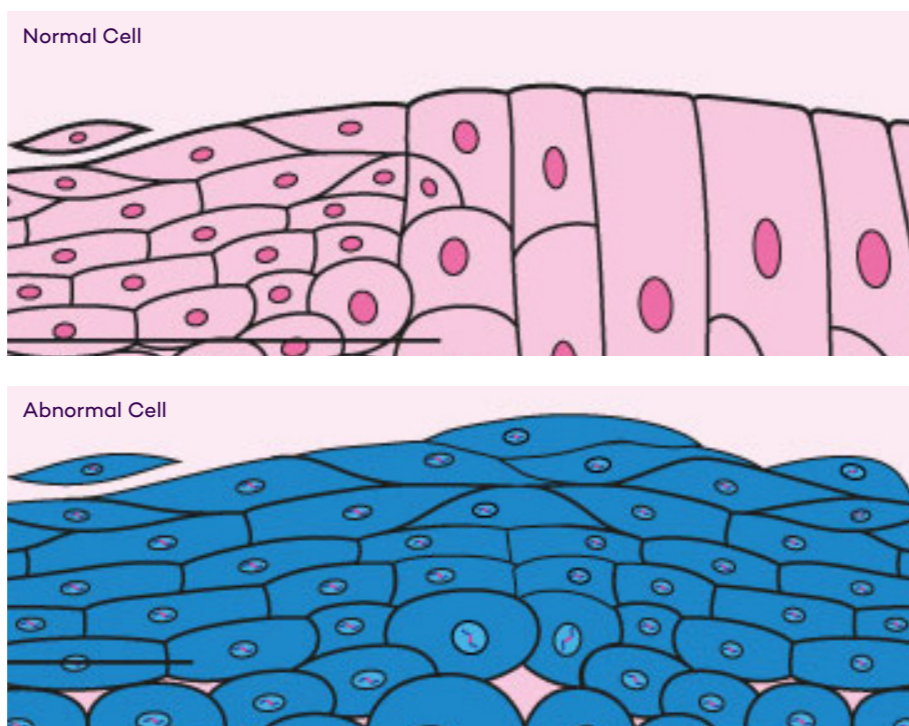


Image: Normal cells compared to abnormal cells in the cervix.
© Jo's Cervical Cancer Trust



Jacinda's Story

Location: NSW

Age at diagnosis: 30s

The first time I realised something was wrong:

At my 6-week check-up after having my 2nd baby, I had a CST. A week later, my doctor rang to tell me that I needed to see him again. He referred me to a gynaecologist for further testing.

I was told that I had low-grade cervical abnormalities and was asked to come back in 6 months to see if it would resolve by itself.

My diagnosis:

After the 6 months, I was tested again, and results showed that I now had high-grade abnormalities. I then had to have a colposcopy, and my diagnosis was confirmed as CIN 3. CIN 3 is the last stage before becoming early stages of cervical cancer.

Why I was surprised by my diagnosis:

I had never had any symptoms or signs that anything was wrong. It was lucky that I had a CST after the birth of my second child and caught the abnormality in the bud!

My treatment:

The next month, I was scheduled in for a LLETZ procedure (Large Loop Excision of the Transformation Zone), which went off without a hitch. Eight weeks later we found out I was pregnant with twins! However, at 18 weeks we lost both babies due to complications.

I have since continued with 6 monthly tests and colposcopies, and all so far have been clear. We had another bub in August 2016 and my last 6-month check was normal. I was so excited when the doctor rang me to say everything was all clear, and I can now go to back to 5 yearly CSTs.

My tips for Australian women about cervical health:

Get tested every 5 years or as required by your doctor. I'd never had any signs or symptoms and I had CIN 3 cells.

There are different types of abnormalities

Atypia:

Your cervical cells have only changed slightly. Sometimes, these abnormal cells can regress back to normal without treatment; however, they can also worsen. Atypia can be caused by infection or irritation, and does not necessarily mean that you have, or will get cancer.

Squamous abnormalities:

The squamous cells in your cervix have abnormalities. Abnormal cells are called SIL (squamous intraepithelial lesions) and are either classified as LSIL (low grade) or HSIL (high grade). In the past, abnormalities used to be called CIN (cervical intraepithelial neoplasia), with low-grade abnormalities classified as CIN 1 and high-grade abnormalities as CIN 2 or 3. Low-grade abnormalities (LSIL or CIN 1) may disappear without treatment, however, further testing is usually recommended. High-grade abnormalities (HSIL or CIN 2/CIN 3) are pre-cancerous, meaning that they can progress to cervical cancer if not treated.

Glandular abnormalities:

The glandular/columnar cells in your cervix have abnormalities. These abnormalities may be pre-cancerous or cancerous, so they will need to be assessed further.



Casie's Story

Location: NSW

Age at diagnosis: 20s

The beginning of my journey:

I was afraid of having a CST done, as my mum had CIN 3 pre-cancer and a partial hysterectomy. I didn't know much about it. When I decided to have my first CST, I was told that my results showed abnormal cells, and I would have to wait a year. After the second CST, I was referred to a gynaecologist for a colposcopy and a biopsy, to rule out cervical cancer. I was told that a golf ball sized lesion was removed. I went to my check up and everything was fine. My gynaecologist informed me it was like "I hadn't even had a procedure done on my cervix."

Why I was surprised by my diagnosis:

I never thought that this would happen to me. I was terrified, as I wanted to be able to have children in the future.

My ongoing battle:

Another year later, I found out that I had abnormal cells again and I was at medium risk of developing cervical cancer. However, as of my last check-up, HPV was not detected. I am now waiting to

see if my body can clear the abnormal cells before proceeding with other treatment. Unlike last time, I have a more positive outlook on my future.

My tips for Australian women about cervical health:

Go get regular CSTs. If there are any vaginal health changes that you may be worried about, go to the doctor and don't put it off. You may be uncomfortable for a couple of minutes just getting a check, but at least you'll have peace of mind.

My test results came back as abnormal. What now?

If your CST results have come back showing high-grade squamous or glandular abnormalities, your health professional may refer you to a specialist for further testing. Some of the tests that you may come across are:

1

Colposcopy:

Your specialist will insert a speculum into your vagina for a clearer view of your cervix. The doctor may coat your cervix with fluid to highlight any abnormal cells, before using a colposcope, which looks like a pair of binoculars on a stand, to look at your cervix. The colposcope will not be put inside you. You should not feel pain during a colposcopy, although you may experience mild discomfort during the procedure.

Biopsy:

Your doctor may perform a biopsy at the same time as a colposcopy. A biopsy involves removing a small amount of surface cervical tissue to send to a lab for examination. You will be given a local anaesthetic, so you will not feel any pain during the procedure. You may experience some discomfort during and after the biopsy, similar to menstrual cramping, and some light spotting/bleeding or vaginal discharge for a few hours post-procedure. It is generally recommended that you don't have sexual intercourse or use a tampon for 2-3 days following to decrease chances of infection and to allow healing.

2

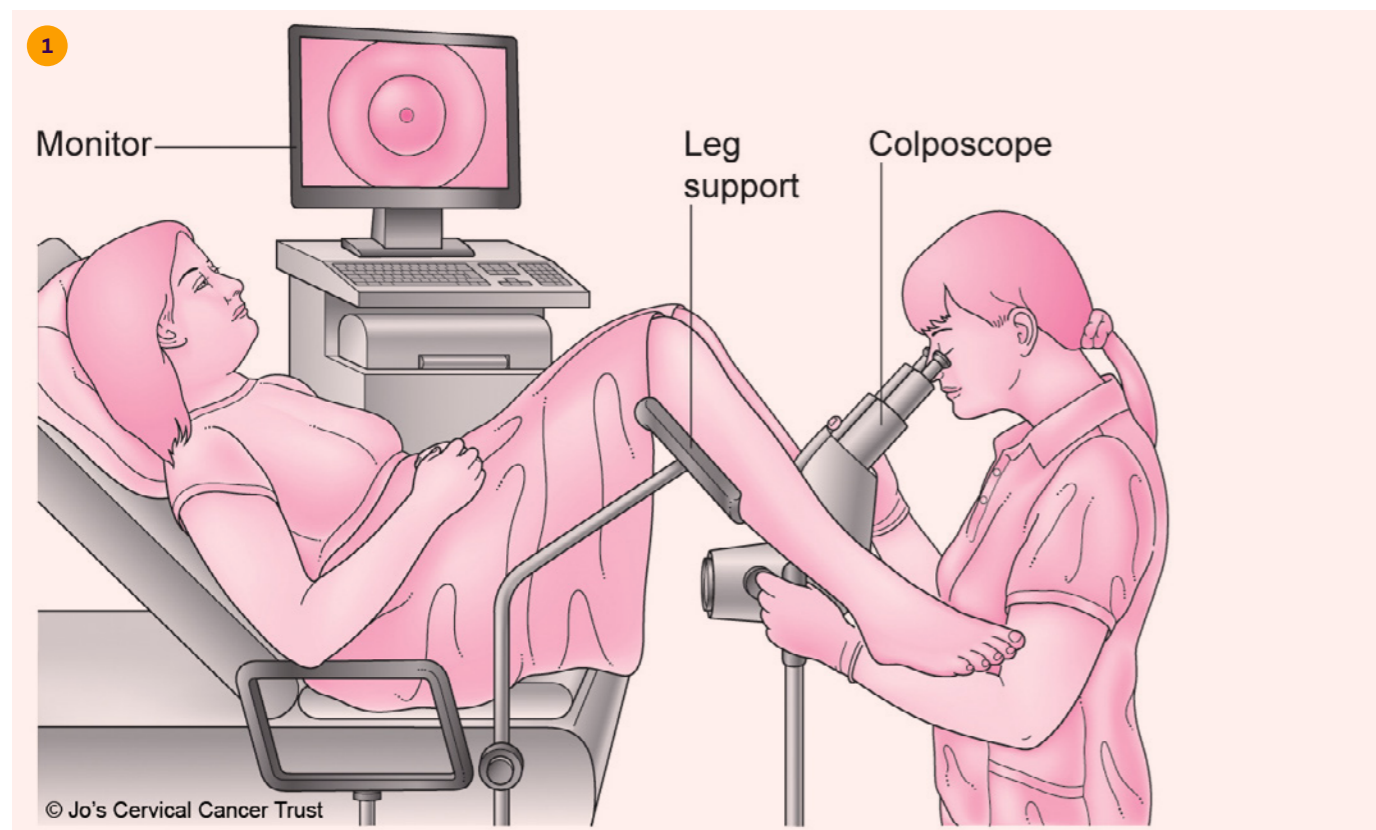
Loop Electrosurgical Excision Procedure (LEEP) or Large Loop Excision of the Transformation Zone (LLETZ):

Occasionally, a LEEP or LLETZ is performed at the same time as a colposcopy and a biopsy. This procedure is usually done under local anaesthetic, however, can also be done under general anaesthetic in a hospital, and can be used to remove tissue for examination as well as to treat cervical abnormalities. A thin, electrically heated wire will be used to remove abnormal cervical tissue. It may be possible to remove all abnormal cells using this technique. Post-procedure, you may experience mild spotting/bleeding and cramping, which should ease over the following weeks as your cervix heals. It is generally recommended that you do not use tampons or have sexual intercourse for 4-6 weeks following to allow time for healing and to prevent infection.

Laser therapy:

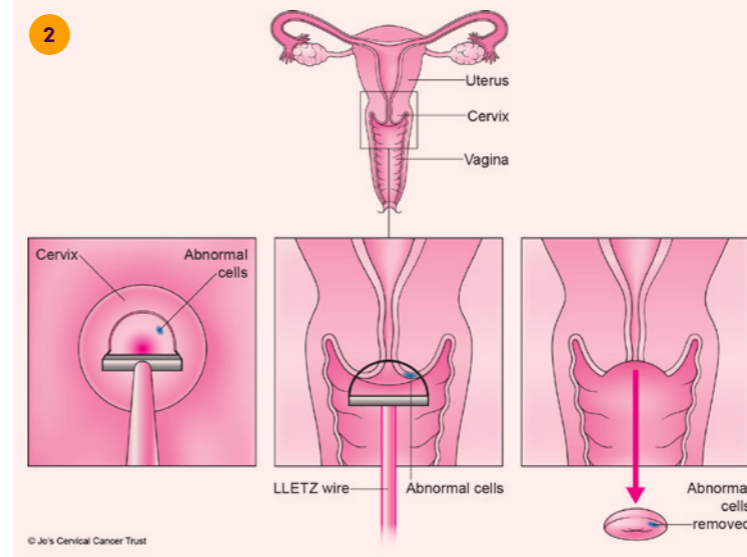
Laser therapy is performed with a local anaesthetic and involves the use of a laser to remove abnormal cells from your cervix. Side effects of this procedure are similar to those of LEEP/LLETZ procedures.

Image 1: Illustration of a colposcopy procedure.
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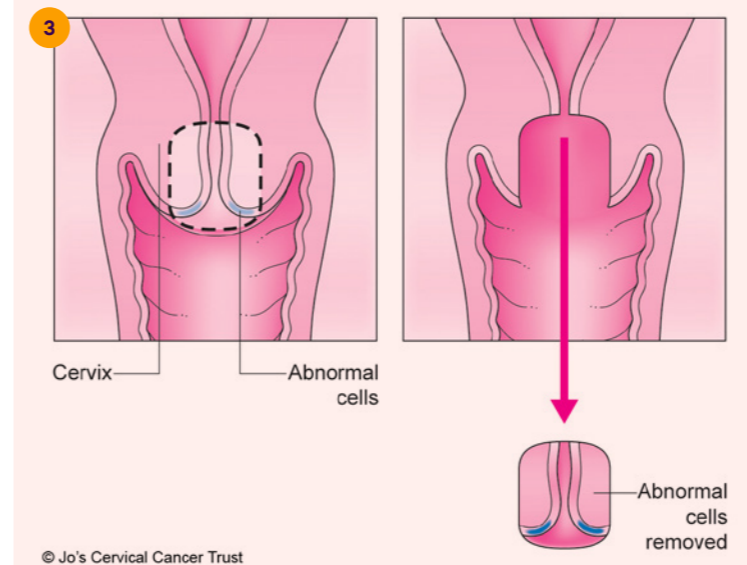
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Cone biopsy:

A cone biopsy is a procedure in which a cone-shaped piece of abnormal tissue is removed from the cervix. The procedure can be performed to determine how far pre-cancerous/cancerous cells have spread beneath the surface of the cervix and can also be used to remove early stage tumours.

This procedure is generally conducted in a hospital under general anaesthetic. You may experience spotting/bleeding and cramping for a few days post-procedure. It is recommended that you do not have sexual intercourse or use tampons for 4-6 weeks following, to allow time for healing and to prevent infection.

Although a cone biopsy or LEEP/LLETZ will not affect fertility, there may be a higher chance of premature birth or miscarriage due to a weakened cervix.

i

If you are planning to have children, talk to your specialist before the procedure. Some women who become pregnant after a cone biopsy choose to have stitches put into their cervix to strengthen it. These stitches are removed before the baby's birth.

Image 2: Illustration of a LEEP or LLETZ procedure.
© Jo's Cervical Cancer Trust

Image 3: Illustration of a cone biopsy procedure.
© Jo's Cervical Cancer Trust



Kym's Story

Location: QLD

Age at diagnosis: 40s

My diagnosis:

When I went to my gynaecologist to have my Mirena replaced, he asked how long it had been since my last CST. I had totally forgotten. We decided to do a CST then and there. Unfortunately, the results of the test came back with high grade lesions CIN 3.

My reaction to the news:

I was a right mess. Luckily, I had a brilliant gynaecologist who set me straight, telling me not to stress; that it is NOT cancer, but needs to be dealt with ASAP. I asked why I couldn't just have a hysterectomy and get the whole lot out. At this stage I was way past wanting more children, and I just wanted it all gone. He advised that an incorrect treatment could mean a worse outcome.

My treatment journey:

I went in for a LLETZ/LEEP procedure to remove the abnormal cells, however, at my 3-month check-up the results came back with the same abnormalities. Off I went again to have my first Cold Knife Cone Biopsy.

Again at 3 months, I was still high grade CIN 2, so I had another Cold Knife Cone biopsy. I'm sure the guys at Redlands Mater knew me by name! At my next 3-month check-up, I was still CIN 3. I thought I was never going to be rid of this horrible thing living inside of me. In April 2015, I went in for my hysterectomy without removing my ovaries, to prevent early onset menopause.

Post-treatment recovery:

Since then, my recovery has been brilliant, and I've bounced back into normal life. I was given all clear margins and have had my 3-month check-up with no dramas. I'm now free of abnormalities and can go back to 5-yearly CSTs!

My tips for Australian women about cervical health:

Ensure you talk to your doctors, raise any concerns and don't be shy! Take the time to ensure you are looking after you!



What is
cervical
cancer?

2

What is Cervical Cancer?

Cervical cancer is when abnormal cell growth in the cervix develops into malignant tumours, meaning that if left untreated, the cancer will spread and move into other tissues (metastasise).

There are two main types of cancer:

1

Squamous cell carcinoma
Begins in the squamous cells of the cervix. Around 80% of all cervical cancer cases are squamous cell carcinomas.

2

Adenocarcinoma
Begins in the glandular/columnar cells of the cervix. This type is less common, and is harder to diagnose, as it occurs higher up in the cervix.

The Stages

If cancer cells have been found, the next step is to stage your cancer. Knowing the stage of your cancer helps your doctor in determining the best method of treatment for you.

Early stage cancer is localised, meaning that it is still confined to your cervix. Late stage cancer has spread, or metastasised, to a different part of your body.

Stage I

The cancer is localised, meaning it is still confined to your cervix.

Stage II

The cancer has spread past the cervix into neighbouring tissue.

Stage III

The cancer has spread to other pelvic tissue, and/or the lower part of your vagina.

Stage IV

The cancer has spread beyond the pelvis to other organs/tissue.

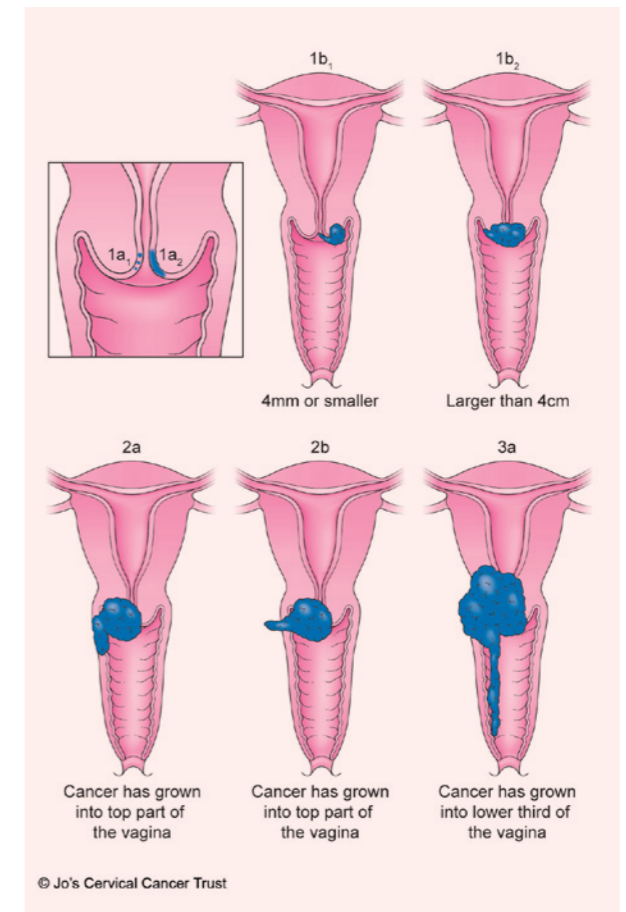


Image: Cervical Cancer: Stages I, II and III.
© Jo's Cervical Cancer Trust



Anahita's Story

Location: QLD
Age at diagnosis: 20s



The relationship between HPV and cervical cancer:

[Watch video](#)

The beginning of my journey:

My story begins 7 years ago, running my own small business and I had just booked an open-ended ticket to Europe. A week before I left, I decided to go for a full check-up with my doctor. Results came back and I was asked to have another set of tests. This happened on the Friday before I was supposed to jet off on the Sunday. My doctor called and advised me to go in for a discussion, and upon me insisting that I had no time; I was advised that I have CIN 3 and needed to have a procedure.

My journey to cervical cancer:

I didn't understand, I had been vaccinated and thought I was covered. Only now I understand that regular cervical screening must also take place. At the time, I was not up to date with my cervical screening.

Against my doctor's request, I went on my European adventure. Four months later I got a call from my doctor urging me to return to have the procedure. I reluctantly returned and got it all sorted... so I thought. After the procedure I was meant to attend a number of follow up appointments, however life got in the way and I made many excuses as to why I didn't have time. Eventually, I made the time and was given the news that I now had cervical cancer.

In the year of my diagnosis I had two surgeries and six rounds of radiation therapy. My time-poor excuses were no longer important because if I didn't make the time, I realised that I might not have much left.

My determined and no-drama attitude helped me cope with my cancer diagnosis and helped support the people around me deal with it as well. In hindsight, I should have been more responsible about my health, prioritise Cervical Screening Tests and never use the excuse that I don't have time as a scapegoat.

My tips for Australian women about cervical health:

If you are not up-to-date with your Cervical Screening Tests because you are worried that it's not a pleasant experience, please think of the alternative. If you say you don't have time to get tested, think of your family, your children or your partner, and how they will feel when their time with you is limited. If I can urge any woman to get a check-up or encourage women to be up to date with their Cervical Screening Tests and get vaccinated against HPV, then my job is done.

Possible Procedures

In order to find out if your cancer has metastasised, you may have to undergo one or more of the following procedures:

Chest X-Ray

Your doctor may want to check your lungs for cancerous cells.

CT (computerised tomography) Scan

This scan can help your doctor check whether the cancer has metastasised to other organs in the body, as it gives a detailed, 3D image of the inside of your body. You may be given a dye in the form of a drink or injection and asked to insert a tampon into your vagina to help make the images clearer and easier to read.

MRI (magnetic resonance imaging) Scan

During an MRI scan, magnetic and radio waves are used to create detailed images of areas inside your body. You may be given a dye in the form of an injection to make images clearer.

PET (positron emission tomography) Scan

For this scan, you will be injected with a small amount of sugar solution containing radioactive material. The solution will spread throughout your body over the next 30-60 minutes. Your body will then be scanned for the radioactive glucose.

Cancer cells will appear brighter in the scan, as they will absorb more of the solution. The amount of radiation given is very small and will not harm you.

Examination under anaesthetic

For this procedure you will be given general anaesthetic in a hospital. Your doctor may examine your vagina, cervix, uterus, bladder and rectum for signs that the cancer has spread. Tissue samples will be taken and sent to the lab if any abnormal cells are found.



Tracy's Story

Location: QLD

Age at diagnosis: 30s

My diagnosis:

I was first diagnosed with adenocarcinoma of the cervix in March 2008, exactly 1 month before my wedding.

My treatment:

My doctor told us to postpone the wedding, but we were determined to go ahead with it. We were married on a Sunday, and the next Thursday I had surgery. I started chemo/radiation the next Tuesday.

I had 8 weeks of chemo & radiation, then 72 hours of intense brachytherapy, but thankfully we were given the all clear!

A big shock:

In January 2016, I had an awful cough and started to cough up a bit of blood, so I was sent for chest scans, which revealed a 'mass' on my right lung.

A lung biopsy confirmed it was in fact, cervical cancer. My oncologist explained that the cancer had metastasised and was back after 8 long years of being clear. We were devastated. We had been through chemo, radiation, surgeries, immunotherapy, the works! The tumour shrinks, comes back, shrinks again; it's an ongoing round-a-bout.

Nevertheless, we go about every day as normally as possible, and I try to live every day to the fullest. We've been in this fight now for almost 3 and a half years and it's scary, frustrating, sad and annoying. I could go on and on but instead we choose to remain positive, as we believe that attitude is half the fight against this dreadful disease.

Looking back on my journey:

We were a bit blasé about the whole thing the first time around. The main issue we were dealing with back then was the possibility that we would never have children. Sadly, it was confirmed after the treatment in 2008 that this wouldn't be possible. Instead we have a beautiful Border Collie puppy who fills our lives with joy!

My tips for Australian women about cervical health:

Listen to your body! Only you know when something is not right so get it checked as soon as possible and don't be embarrassed. Don't be scared of cervical screenings. Yes, they're not nice. But trust me, having cervical cancer is much, much worse.

I have been diagnosed with cervical cancer. What now?

If you have not been seeing a specialist already, after diagnosis, you will be referred to one for treatment.



If you are feeling nervous about your appointment with your specialist, it can help to take in a list of questions you would like to ask.

This way, you will not forget anything important, and you will be able to leave your appointment feeling informed. Do not be afraid to take a family member or friend to your appointment for support. Your specialist will not mind, and it may even help you to relax.



Emma's Story

Location: ACT

Age at diagnosis: 20s

My diagnosis:

My only symptom was at 31 weeks pregnant when I had some bleeding. I went up to the hospital straight away and was told the baby was fine. Unfortunately, the obstetrician also felt a large mass. I had a spinal tap (a sample of the fluid surrounding my spinal cord was tested), biopsy and an MRI, and was given a diagnosis of Stage 1b2 adenocarcinoma cervical cancer.

Why I was shocked with my diagnosis:

I had previously been up to date with my cervical screening and had been due to go for this at the beginning of 2016 but didn't because I was pregnant. I feel like the fact that I was pregnant perhaps hid the symptoms; when I had the bleeding before I was diagnosed, I just assumed it was something to do with the baby.

My treatment journey:

I had a caesarean at 35 weeks pregnant to deliver my son. I then had surgery where they took out a metastasised lymph node. Five weeks after that I really went downhill. My breastmilk started to disappear. I was admitted twice to hospital for clotting and had several blood transfusions. The pain was intense, and I was pretty much bedridden. I started chemotherapy when my son was about 5 weeks old. I had 5 lots of chemo and 25 radiotherapy treatments in total. Following this, I had brachytherapy, which is what finally knocked it on the head.

The hardest part of my journey:

There is a lot I don't remember about this time, which is sad in terms of not remembering much in relation to my son. It was a very difficult time and I just wanted to disappear; I didn't even want to be in any photos with my son. I didn't want the memories to be captured when they were full of such sadness. I wanted to forget.

My experience with treatment side effects:

The early onset menopause made me feel old before my time in terms of lagging energy levels and I still seem to have much less energy than I did before. I try to regularly rest and recuperate to combat this. My treatment also left my body unable to conceive and carry a child in the future. Brachytherapy has shortened and narrowed my vagina but seeing as I wouldn't ever be in the position of having a baby again, it seemed to be a nuisance more than anything else.

My tips for Australian women about cervical health:

Remember to stand up for what is important to you and be willing to advocate on your own behalf.

Reach out and network to find out what others have done to make this time easier. Know you are not alone in this, however isolated you feel, there are hundreds of women knuckling down to beat this right at this very moment and we are here to help you, to be your voice when you feel lost. I would also stress the importance of having a good support network, including counselling.

Possible questions to ask your health practitioner.

A good starting point:

- What stage is the cancer at, and what does this mean for me?
- How large is the tumour, and how will this impact on my treatment?
- Where can I receive treatment?
- What is the next step?
- Which health practitioners will I need to see, and why?
- Is there a support network where I can meet others going through similar circumstances?

When deciding on the best treatment:

- What are my treatment options?
- What treatment is recommended for me, and why?
- How much will treatment cost?
- Am I able to get help for treatment costs, or is there funding available?
- Who can I contact for practical assistance such as home nursing care?
- Are there any clinical trials or research I can take part in? If so, what would they involve?
- When should I start treatment? When am I likely to be finished? How long will treatment take?
- How much time will I need off work?
- How can I prepare?
- Are there any risks or side effects of the treatment?
- Will the treatment cause much discomfort or pain? Are there options to manage this?
- Are the side effects temporary or permanent?

Sex life and fertility:

- Will this affect my relationship/sex life?
- Will I be able to have children after treatment?
 - Can I keep my uterus/ovaries?
 - Can I harvest eggs before/after treatment?
 - Can I freeze my eggs unfertilised if I don't have a partner?
 - If I have radiation therapy, will I be able to harvest eggs afterwards?
 - Can my ovaries be moved up to protect them from radiation?

Post-treatment:

- Will I need to come in for regular follow-up appointments post treatment?
- How often will I need to come in?
- What if the cancer comes back? How will I know if it does?

Treatment



3

What treatment will be best for me?

This is something you will need to discuss with your healthcare practitioner. The best treatment for you will depend on the size and stage of the cancer, and if you are currently pregnant or would like to have children in the future.

Whatever treatment you and your health practitioner decide on, make sure to give yourself plenty of time to rest during and after.

Surgery

You may be recommended for surgery if you have a small, localised tumour confined to the cervix.

Hysterectomy

A hysterectomy involves removal of affected parts of the reproductive system. Surgical removal of the uterus and cervix is termed a total hysterectomy.

When discussing this type of surgery, you may hear the terms laparoscopy, meaning that the surgery is performed through a keyhole incision, and laparotomy, meaning open cut surgery. A hysterectomy also includes the removal of extra tissue surrounding the uterus and cervix as well as a small portion of the upper vagina.

Bilateral salpingo-oophorectomy

If the cancer has spread to your ovaries and fallopian tubes, a bilateral salpingo-oophorectomy may also be performed to remove them.

Trachelectomy

If you would like to have children in the future, and have been diagnosed with early stage cervical cancer, it may be a good idea to ask your health practitioner about the possibility of a trachelectomy. A trachelectomy includes removal of your cervix and surrounding tissue, however, the uterus and ovaries are left in place.

Lymphadenectomy

During surgery, your surgeon may perform a lymphadenectomy, which involves removing and dissecting pelvic lymph nodes for the purpose of investigating whether the cancer has spread beyond the cervix.

After surgery, you may feel pain and discomfort. You may experience;

- short term problems with bladder and/or bowel function,
- lymphoedema (swelling in legs), menopause (if you have a bilateral salpingo-oophorectomy),
- decreased libido, and
- internal scarring or adhesions where tissues in the body stick together.



If you are experiencing one or more of these side effects, have a chat to your specialist team. They may be able to help you minimise your symptoms.



Samantha's Story

Location: QLD
Age at diagnosis: 30s

The beginning of my journey:

In May 2009, I went for my CST (I'd had another cancer before, so I'm more vigilant with tests). I'd been having strange discharge between periods but was discussing it with my GP. We thought that it was due to my age (it could be my body gearing up for menopause). It turned out that I had adenocarcinoma, and further investigation was needed to find out if it had spread. At the time I was living in outback NSW, so it was a three-hour visit (one way) to see the gynaecologist.

My treatment journey:

My GP warned me that the gynaecologist would do a cone biopsy, and chances of removing the uterus were quite high. I had the cone biopsy and on my next visit the gynaecologist stated that I was cancer free. My husband questioned that statement as it contradicted my GP. In the end we were not happy and went back to my GP where we all agreed that removing the uterus was the best option. I then had to fly to Sydney to see another gynaecologist who agreed removing the uterus was the best option, as I had adenocarcinoma.

After the removal of my uterus I honestly thought that was that. Then I received the dreaded phone call, 'after careful consideration the specialists who review all gynaecologist operations at the hospital suspect that the cancer has spread'. So it was back to Sydney once more. This time for a radical hysterectomy where both lymph nodes were removed.

Finding out I was cancer-free:

After this final operation, I was told that the cancer had not spread to my lymph nodes. It was the best Christmas present anyone could ever get. The experience was an emotional roller coaster as I had a 3-year-old with developmental issues and a 7-year-old. Living in the outback is hard enough without regular services but without the dedication of my GP (who was a Flying Doctor), my amazing husband, and our spectacular friends (who were there helping daily), I'm not sure where I would have ended up.

Out of all this, I have come to use one saying as my mantra, by Charlotte Lawrence... "If it weren't for cancer, I'd say I had the perfect life. But if it weren't for cancer would I even realise this?"

My tips for Australian women about cervical health:

A little bit of discomfort and maybe even some embarrassment is worth it, because what is the other option? Get regular CSTs. Don't ignore what your body is telling you and if you're not happy with what the doctor says get a second opinion.

We only get one chance at life.

Chemotherapy and radiotherapy

Chemotherapy

Chemotherapy is generally recommended for people diagnosed with late stage cancer, where it has spread beyond the cervix. Chemotherapy drugs are most commonly given intravenously, however, some can be administered orally. These drugs aim to kill or slow the growth of cancer cells, while leaving healthy cells as undamaged as possible.

Radiotherapy

Radiotherapy uses targeted radiation to kill cancer cells. External radiotherapy is painless and is conducted much like a routine x-ray scan.

You will be asked to lie on a metal table, with a radiotherapy machine above you. Internal radiotherapy, or brachytherapy, involves having a small implant placed in your vagina and cervix under general anaesthetic or sedation and epidural. In order to keep the implant in place, gauze padding may be placed with the implant, and a small stitch may be put into your labia. A source of radiation will be placed inside the implant for 15-30 minutes.

The number of treatment sessions needed is different for each individual. In some cases, once the treatment plan is complete, the implant will be removed. If you would like to have children in the future, ask your health practitioner about the possibility of having your ovaries surgically moved up out of the range of the radiation, as radiotherapy can cause them to stop working. Your specialist will discuss the best treatment plan for you.

Chemoradiation

Chemoradiation uses a combination of chemotherapy and radiotherapy and is the most common treatment for women with late stage cervical cancer.

Side Effects

Some side effects you may experience after treatment include; vomiting, decreased immunity, tiredness, loss of appetite, hair loss, diarrhoea, dry and itchy skin, cystitis (burning sensation when urinating), menopause and vaginal stenosis (where scar tissue forms in the vagina, narrowing and shortening it).

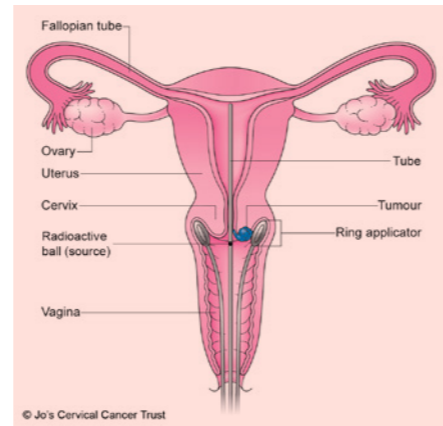


Image: Illustration of the brachytherapy procedure
© Jo's Cervical Cancer Trust



Sarah Maree's Story

Location: VIC
Age at diagnosis: 20s

When I first started noticing something was wrong:

In 2009, I started to notice a few changes in my body. I was run down, losing my voice a lot (which is not ideal as a radio announcer) and I'd had a couple of infections. I went to my GP in Darwin, and we started to rule things out, including cervical cancer, as I was up to date with my CSTs and hadn't had any abnormal results previously.

After a few weeks my doctor suggested that with all my lower abdominal pain it would be a good idea to find a gynaecologist and investigate if I had endometriosis. I resigned from my job at the end of 2009 and flew home to Melbourne to get the ball rolling.

How I found out I had cancer:

I found an amazing gynaecologist who informed me about the possible causes of my pain and said that the best way to find out would be by having a laparoscopy. In January 2010 I was booked for my operation and gave my doctor permission to remove anything they found concerning during the procedure. The operation went well however, a couple of days after I received a call from gynaecologist saying she wanted to talk to me in person. I knew there was something slightly more serious than endometriosis that she wanted to talk about. I asked her to tell me as much as she could over the phone, and that was where I learnt I had the early stages of cervical cancer. I was shattered, however, I held on to two words: early stages.

My treatment:

Over the course of a year I had two laparoscopies and numerous LLETZ/ LOOP procedures. I also had to make some small lifestyle changes to reduce my risk of infection, such as not wearing tampons, swimming in public pools or wearing underwear to bed.

My post-treatment journey:

I was given a 2 ½ year remission period where I had CSTs every 3-6 months as well as blood tests. In December 2012, I got a phone call from my gynaecologist saying that as I had successfully gone through my 2 years with no abnormal results, my remission period had been shortened and I was clear to start having my CST every 5 years.

My tips for Australian women about cervical health:

- Have regular CSTs. If you think getting a CST is awkward or uncomfortable, I promise having them every 3 months instead of every few years is more awkward. As is having multiple doctors look down there.
- Don't smoke. There are many studies which show the link between smoking and cervical cancer, something that my Doctor attributes my diagnosis to.
- Always wear protection to lower your risk of getting HPV.
- Get vaccinated. People ask for a cure, but we have the next best thing.

Palliative care

The main aim of palliative care is to reduce pain and discomfort in order to improve quality of life; however, it does not attempt to cure the cancer.

Your health practitioner may recommend palliative care in conjunction with other treatments aimed at killing the cancer. For those diagnosed with terminal cancer, palliative care can provide symptom and pain relief, support and comfort. The aim is to enable you to live your life to the fullest for as long as possible.



Sam's Story

Location: VIC
Age at diagnosis: 20s

When I felt that something wasn't quite right:

Knowing I had put my health on hold, I visited the doctor's as I accepted my health was 'unhealthy' — I was tired, I was experiencing heavy blood loss, stomach cramps, depression and overall weakness. I knew something was not right, but I never in my wildest imagination thought it would be cancer, as I have always had my CSTs regularly. It was the day my Mirena required removal that I knew everything was not alright.

Being diagnosed:

I was sent to the Royal Adelaide Hospital for a biopsy. That same day I was admitted into the hospital and underwent a CT scan, MRI and PET scan. My head spun as the doctors said, "You have cancer," followed by, "It is terminal, and you have about a year to live".

My treatment:

I started radiotherapy immediately, 10 rounds in total. This was followed with chemotherapy. My body initially responded well to treatment. Unfortunately, tracking forward into the future, a recent scan shows that the cancer has reappeared in my liver and pelvis. This is just another hurdle for me to jump over and a push to challenge me to get to where I need to be. I will find my destination through this.

What I struggled most with:

One of my hardest obstacles while trying to look after my own recovery is feeling the guilt as I watch my loved ones struggling

to come to terms with my diagnosis. My family and friends (including my ex-husband) have boarded my train and are passengers I can only describe as angels. They have put their lives on hold, while travelling on my journey with me. Their support has aided me to get to where I am today, and I am forever thankful.

What my experience has taught me:

Before I was diagnosed, I never even knew what the HPV virus was. It's too late for me to have the vaccination, but I urge anyone who is eligible to please take advantage of the scheme and have the vaccine — it could save your life.

I ask anyone reading this to close your eyes and hear the words, "You have one year to live". What would you do? I was told those words. I never thought it would happen to me, but it did. It is what it is, and I am prepared to beat this with every muscle, emotion and power I have. I will not let cancer define my life. It will not define the person I am or the person I am going to be.

My tips for Australian women about cervical health:

If something doesn't seem right — go and see your doctor, stay up to date with your cervical screening and if you are eligible for the HPV vaccine — get it. It could save your life.



Post
Treatment

4

Life after treatment.

Life after cancer treatment will be different for everyone. It is normal to have feelings of despair.

Cancer treatment can be very physically and emotionally draining, and it is important to take some time for yourself to adjust to the changes in your body and to slowly re-establish a daily routine. Some women feel pressured to return to 'normal life' once given the all clear, but it is important to take the time that you need to adjust.

You will most likely be exhausted or in discomfort from treatment, or you may be anxious about the cancer returning. It can be hard to say what your recovery will look like, as everyone's journey is their own. It may take time to recover from the effects of cancer and treatment, and the road to recovery may not be straightforward. It can be helpful to talk with a psychologist or someone whom you trust about how to cope and move forward.

What if the cancer returns? How will I know?

Your specialist will schedule follow-up appointments for you after your treatment is finished, to ensure your recovery is going smoothly.

During these appointments, your health professional may perform various screening procedures to make sure that the cancer has not come back, such as a Cervical Screening Test, blood test, x-ray, CT or PET scan.

Make sure you let your doctor know, both during and in between appointments, if you are experiencing any symptoms that worry you. After all, even if it turns out to be nothing, it'll put your mind at ease. If you find yourself constantly worrying and anxious or experiencing prolonged periods of sadness, it may also be a good idea to talk to your GP. Depression is quite common amongst cancer survivors.



It is important to seek support early, as your symptoms could escalate if left untreated. Counselling sessions or medication, even for a short period of time, can often help a lot. Medicare rebates are available for up to 10 individual and 10 group therapy sessions, as well as a range of other mental health treatments, with a referral from a GP.



Nanette's Story

Location: QLD
Age at diagnosis: 40s

The beginning of my journey:

The cancer was in a position where it was not able to be easily accessed – high up in the cervix and on the outer edge. I was lucky that the cancer had not spread to any lymph nodes or other areas.

My treatment:

I was thrust into a series of appointments as my surgery was planned. I had my surgery on 9th September 2017; the day after my daughter's wedding. I was in hospital for 6 weeks, and was still in recovery mode 7 months post op, but you know what? I'm OK. I wouldn't wish to have all of this happen, but I can manage it.

Post-treatment:

Unfortunately, my surgery resulted in a lot of internal scar tissue, which has caused chronic pain and discomfort during my recovery. I recently had a surgery to remove some of this scarring and am currently in recovery from this. I can finally walk without limping, which I consider to be a major success!

However, I still have a tight band in my body which was not resolved. I may have to have another surgery in a few months to target this. I did everything right but

still had a cancer develop undetected. Unlucky, I think. My road to recovery has been, and will be a long one, but I am determined to hold on to my positive attitude!

My tips for Australian women about cervical health:

- Have regular CSTs.
- Look after your body – eat well, exercise regularly.
- Listen to your body. If you think something isn't right – keep asking until someone will do the exploration.



Maxine's Story

Location: SA
Age at diagnosis: 50s

The beginning of my journey:

Being a woman in the menopause age bracket, I put off going to the doctor with symptoms of bleeding after sex, horrendously heavy periods, spotting continuously for months, back pain and leg pain. I hadn't had a CST for over ten years. When I finally went to the GP about my symptoms and had a CST, the nurse rang me a week after and said that I had to see the doctor today, as my results "weren't good actually" (her exact words). On the 20th of November 2013 (my sister's birthday), I was told that I had cervical cancer.

My long battle with cervical cancer:

My first thought was that I'd have a hysterectomy before Christmas and then it'd all be over, and I could relax. I didn't get an appointment to see the gynaecologist for a colposcopy until December 23rd, as I am a public patient. On the 7th of January 2014, I had a cone biopsy operation and a CT scan.

A week later, I got a phone call saying that the results had unclear margins, so I would need a hysterectomy. I was shopping with my daughter at the time and just burst into tears standing on the sidewalk. Another appointment was made, and my hysterectomy was performed on March 13th with robotic assistance. I got the results from my hysterectomy and they had clear margins. Yay, my family could smile.

On the 10th November I had my next check-up after my hysterectomy, and I had a vault smear test (a screening process where cells are taken from the top of the vagina) done. The doctor did see an area with suspect lesions that they took a biopsy from, so I was back to waiting for test results again. I received a letter in the post saying I had high-grade pre-cancer VIN 3 (Vulva intraepithelial neoplasia, or abnormal cells of the vulva). I was back in limbo again. No one could tell me if it would change to cancer or how long it would take.

This time the doctors decided to do laser surgery on my vagina to remove the precancerous cells. I got the clear margins again. 3 months later, I had a colposcopy and more suspect lesions were visible; a biopsy was taken and came back as high-grade pre-cancer VIN 3 again. This time, they would take away 3cm from the top of my vagina. The results from surgery were clear margins again.

My tips for Australian women about cervical health:

I would say one thing for the older ladies out there, don't presume that your symptoms may be just menopause. Go to your doctor and get yourself checked; it could save your life.

Relationships and sex

Your cancer journey will most likely be stressful and tiring, not only for you, but also for the people around you.

You may find that your relationships with family, friends and colleagues end up feeling strained as a result. It is important to keep in mind that everyone copes with stress differently.

Sometimes an adjustment period and good communication is all that is needed. There are also people you may find that you grow apart from. Cancer is a life-changing learning experience that can result in many changes in your lifestyle, especially in the forms of your values, priorities and attitudes.

Depending on your treatment, you may be asked to refrain from penetrative sex while your body heals. After recovering from cervical cancer, your sexuality may be affected and you may not even feel like having sex. Treatment can alter your body's production of certain hormones that affect your libido. Many women experience vaginal dryness, tightness or pain during penetrative intercourse due to some side effects of treatment.

If this is you, it may be beneficial to have a talk with your doctor on how to manage this. It could also be beneficial to look into the use of a vaginal dilator; a smooth tube-shaped object inserted into the vagina to gently stretch the walls when

the vagina has become narrowed due to treatment. If you are worried about your relationship, there are other ways you and your partner can connect intimately without penetrative sex. Remember that communication is important and will be key during this period of recovery.



If you'd like more information on sex and intimacy post-cancer, check out the Cancer Council Resource 'Sexuality, Intimacy and Cancer: A guide for people with cancer and their partners'.

[Read here](#)



Chelsea's Story

Location: QLD

Age at diagnosis: 20s

My diagnosis:

I was 12 months overdue when I went for my CST in January 2012. I was told that my results were abnormal, and that I needed to see a gynaecologist for further testing. I had a colposcopy and biopsy that confirmed the results of the CST. In order to determine my diagnosis, I had to have a cone biopsy. I was told I had a 1.8cm tumour and that it was cancer. I was devastated and in complete shock. I was hoping I would wake up and realise it had all been a bad dream. I was diagnosed with stage 1b1 adenocarcinoma of the cervix.

My treatment:

The next step was to discuss treatment with my oncologist. Option 1 was to have a radical hysterectomy. I immediately burst into tears. I knew that a hysterectomy meant that I would not be able to have children. I was devastated and no words can describe how I felt at that moment. I was then told about a second option, which was to have a radical trachelectomy, meaning I could keep my uterus, but would also need to have my pelvic lymph nodes removed.

I had a PET/CT scan, which determined that the cancer was confined to my cervix, which meant that I was a candidate for a radical trachelectomy. On 23 May 2012, I had the radical trachelectomy (removal of my cervix, upper vagina, surrounding tissue) and pelvic lymphadenectomy (removal of pelvic lymph nodes). It was a success!

Post-treatment:

Since then I have continued to have regular check-ups and CSTs with both my oncologist and gynaecologist, and the cancer has not returned. If I had left it longer, I may have had a much more difficult treatment journey. I believe the CST back in January 2012 saved my life.

In December 2017 I learned that I was pregnant. I was so happy. My son Henry was born in July 2018 at 35 weeks. I am so grateful for my oncologist and the treatment I received following my cervical cancer diagnosis. I am one of the lucky ones who is able to live and enjoy life, and experience motherhood.

My tips for Australian women about cervical health:

I share my story so that people value the importance of CSTs and so I can hopefully prevent someone from experiencing what I have.

If the tumour had been greater than 2cm (2 millimetres bigger) I would not have been able to preserve my fertility and would have needed a hysterectomy or worse.

I ask you to encourage the women in your life to have regular CSTs. No one is invincible to cervical cancer... don't think it won't happen to you, like I did.

Fertility

Your ability to have biological children after treatment will depend on the severity of your cancer, and the treatment you received.

Medically induced menopause is a possible side effect of treatment. Various hormone replacement treatments are available to aid in managing symptoms of menopause.

You can ask your health practitioner about the possibility of having eggs or embryos harvested and frozen before your treatment. Ovarian tissue cryopreservation and transplantation is a relatively new procedure involving the removal of ovarian tissue before treatment. This ovarian tissue is then reinserted into ovaries, or grafted into the pelvic area to reverse menopause, and stimulate fertility. However, depending on the stage of your cancer, there may be a risk of transplanting cancer cells with this method, so it is important to have a chat to your doctor about your options.

Fertility preservation procedures can be expensive, and prices are likely to vary in different locations, so be sure to ask around, and talk to your doctor about your financial options.

Surrogacy is an option if you have had a hysterectomy and are unable to carry a child yourself. It is important to research options, as there are many legal issues with surrogacy that you will need to take into consideration. Some people also choose to go down the path of adopting a child in need of a home.



Kate's Story

Location: NSW

Age at diagnosis: 30s

The beginning of my journey:

My wife and I were married in February 2018. Around a year after our wedding, we began our IVF journey with us both getting routine CSTs from our gynaecologists. We were both about twelve months overdue, but neither of us had ever had any gynaecological issues, so I had no concerns. My CST came back with abnormal cells and I required a biopsy.

I had heard this story so many times from friends and other women so I convinced myself that I would be fine. It was on the 2nd of April 2019 that my doctor contacted us via Skype (because her office is about six hours from our home) and had to deliver the news that the biopsy had come back positive for cervical cancer.

My first thoughts:

I was talking to my doctor about whether this would push back our timeline on having children, when my doctor said to me, "Kate, we aren't talking about you having children, we are talking about you surviving." That's when it really sunk in. I began to spiral downward pretty quickly. The thing that no one tells you about cancer is all the waiting around you have to do. Waiting for answers. Waiting for results. Waiting for appointments and phone calls. Those first five days between being diagnosed and being able to speak to a specialist were a bleak hell.

My diagnosis and first round of treatment:

A PET scan and MRI showed that the cancer was a grade 1B1 adenocarcinoma. I had a radical trachelectomy, which in theory, would still allow me to try and carry a pregnancy in the future.

A massive blow:

After the surgery, my oncologist delivered the news that despite what was shown on the PET and MRI scans, the cancer had spread to one of my lymph nodes. Now, 5 rounds of chemotherapy and 28 of radiotherapy later, I am infertile and likely to go through early menopause. I had always wanted to be pregnant and feel that connection with my baby. Knowing I would never get the chance to experience that, crushes me. We were given the chance to complete one round of IVF before my radiotherapy. Because of everything my body has been through, it didn't respond as well to the IVF hormones as we had hoped. We ended up with only one embryo.

Post-treatment:

In three months, I will have tests to see whether I have NED (No Evidence of Disease). I will continue with these tests every three months for five years until doctors will officially tell me I am cancer free. Physically I am recovering well, but mentally I am still struggling. I am grieving for the life I had and the life I had worked hard for. I've started to see a psychologist, and I recommend this for every woman who's dealing with a cancer diagnosis.

My tips for Australian women about cervical health:

#serviceyourcervix and #dontfearthesmear! Don't do what I did, stay up to date with your screenings and know your normal. If something doesn't feel right, talk to your GP, your gynaecologist, your friends. Don't stop talking until you get an answer that you're happy with. Check in with your friends and make sure they're up to date with their cervical screening too. Look after yourself and each other.

Become a part of the cervical cancer survivor community

It can help to know that there are others out there who have gone through similar battles with cancer.

You may find that you are able to talk more freely about your experiences and concerns with other women who understand what you are going through.

It can be a relief knowing you are not alone. ACCF can help you connect with other cancer survivors and provide any further information and support about cancer and life after treatment.



Mel's Story

Location: QLD

Age at diagnosis: 30s

My diagnosis and treatment:

I was diagnosed with cervical cancer adenocarcinoma stage 1b at 31. I had a radical trachelectomy (the removal of my cervix) and lymph nodes removed.

Things I am grateful for:

I had abnormal cells on my cervix in my 20s so I was vigilant with my regular cervical screening. That's why my cancer was caught early, which I'm so grateful for.

Despite having a reconstructed neo-cervix [trachelectomy], I fell pregnant 7 years later with my beautiful miracle baby girl Mia.

What cancer taught me:

Cancer taught me to be kind to my body, make health my number one priority and make the best out of this life by helping other women living with cancer. Today I'm doing a PhD in gynaecological cancers and sharing stories of hope and how to love your body after cancer on girlsrockingcancer.com. Cancer helped me find my purpose! We can't always avoid cancer but we can do a great deal for awareness, prevention, early detection and support.

My tips for Australian women about cervical health:

Listen to your body, find a doctor that your trust and join a tribe that inspires you.

The stories included in this document have been condensed from their original length. If you'd like to read more, head to the Faces of Cervical Cancer on our website by visiting faces.accf.org.au

This booklet was made possible by the generosity and support of ACCF donors and partners. ACCF's Support Program remains dedicated to providing individual support, information and resources to women and their families impacted by a cervical cancer diagnosis. You can ensure the work done through ACCF's Support Program continues to help Australian women by visiting accf.org.au/donate.



Glossary

A	
Adenocarcinoma	A cancer that starts in the glandular cells of body, such as the cervix.
Adenosquamous carcinoma	A rare type of cervical cancer that contains both squamous cells and glandular cells. Also called mixed carcinoma.
Anaesthetic	A drug that stops a person from feeling pain during a medical procedure. Local anaesthetic numbs part of the body. General anaesthetic makes a person lose consciousness for a period of time.
Atypia	Slight changes to the cells of the cervix.
B	
Benign	Not cancerous. Also called nonmalignant.
Bilateral salpingo-oophorectomy (BSO)	Surgical removal of the ovaries and fallopian tubes. Removal of one ovary and fallopian tube is called a unilateral salpingo-oophorectomy.
Biopsy	The removal of a small sample of tissue from the body for examination or further testing.
Brachytherapy	A type of radiation therapy in which radioactive material is placed directly into or near cancerous cells.
Blood transfusion	A procedure in which whole blood or parts of blood are put into a patient's bloodstream through a vein.
C	
Cervical Screening Test (CST)	A test that checks the cervix for presence of the HPV virus. The CST has replaced the Pap test.
Cervical canal	The neck of the uterus. The cervical canal joins the uterine cavity to the vagina.
Cervical intraepithelial Neoplasia (CIN)	Abnormal cells found on the surface of the cervix. Now referred to as squamous intraepithelial lesions (SIL).
Cervix	The lower, narrow end of the uterus that forms a canal between the uterus and vagina.
Chemoradiation	Chemoradiation uses a combination of chemotherapy and radiotherapy and is the most common treatment for women with late stage cervical cancer.
Chemotherapy	Chemotherapy is generally recommended for women diagnosed with late stage cancer, where it has spread beyond the cervix. Chemotherapy drugs are most commonly given intravenously, however, some can be administered orally. These drugs aim to kill or slow the growth of cancer cells, while leaving healthy cells as undamaged as possible.
Colposcopy	Examination of the cervix, vulva and vagina from outside the body with a colposcope (a magnifying instrument).
Cone Biopsy	The removal of a cone-shaped piece of abnormal tissue from the cervix. The tissue is checked under a microscope for signs of disease. May be used to check how far pre-cancerous or cancerous cells have spread, or to remove early stage tumours. Also called conization.
CT scan	Computerised Tomography scan. Uses x-ray machines to create a detailed picture of the body.
Cystitis	Inflammation of the bladder lining and urinary tract.
D	
Dilation and curettage (D&C)	A procedure to scrape and remove tissue from the inner lining of the uterus. The cervix is dilated (made larger) and a curette (spoon-shaped instrument) is inserted into the uterus to remove tissue. A tissue sample may then be checked under a microscope for signs of disease, such as infection or cancer. A dilation and curettage may be done after a miscarriage or to treat certain conditions, such as abnormal bleeding.
Discharge	A fluid that comes out of the body.
E	
Ectocervix	The ectocervix is the outer portion of the cervix that projects into the top section of the vagina. It forms a curved surface with the external os in the very middle.
Endocervix	The inner surface of the cervix that forms the cervical canal. The endocervix is lined with cells that make mucus.

Epithelium	A thin layer of tissue that covers organs, glands, and other structures within the body including the cervix.
External os	The external orifice (opening) of the uterus. The external os connects the cervical canal to the vagina.
G	
Genital warts	Small and rough growths of skin on the genitals. Genital warts are a sexually transmitted infection caused by certain types of HPV.
Glandular cells	A type of cell found in the inner surface of the cervix (endocervix).
Grade	A score that describes how similar cancer cells look compared to normal cells and how quickly they may grow.
H	
Human Papillomavirus (HPV)	A group of viruses can cause abnormal cell growth and other changes to cells. Some types of HPV can increase the risk of cervical cancer.
HPV Test	A test that checks for the presence of the Human Papillomavirus (HPV). Also called a Cervical Screening Test.
Hysterectomy	Surgical removal of the uterus. Depending on the type of hysterectomy, other organs such as the fallopian tubes, ovaries and cervix may also be removed.
I	
Internal os	The internal orifice (opening) of the uterus. The internal os connects the uterine cavity to the cervical canal.
Immunotherapy	A type of therapy that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases.
L	
Laparoscopy	Surgery done through small cuts in the abdomen using a viewing instrument called a laparoscope. Also called keyhole surgery.
Laparotomy	A type of open surgery in which a long cut is made in the abdomen to examine and remove internal organs.
Large loop excision of the transformation zone (LLETZ)	A procedure to remove cervical tissue for examination and to treat some precancerous changes of the cervix. Also called loop electrosurgical excision procedure (LEEP).
Laser Therapy	The use of a laser beam to remove tissue and treat some precancerous changes of the cervix.
Lesion	An area of abnormal tissue.
Liquid-based cytology (LBC) test	A test that looks for cervical cell abnormalities if a Cervical Screening Test finds HPV.
Lymphadenectomy	A surgical procedure in which the lymph nodes are removed and a sample of tissue is checked under a microscope for signs of cancer.
Lymphatic system	A network of tissues, capillaries, ducts, vessels and nodes that removes excess fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells.
Lymph nodes	Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.
Lymphoedema	Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes can't drain properly because they have been removed or damaged.
M	
Malignant	Cancerous. Malignant cells can spread (metastasise) to other parts of the body.
Menopause	The time of life when a female's ovaries stop producing hormones and menstrual periods stop.
Metastasis	A cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.
MRI scan	Magnetic Resonance Imaging scan. A type of scan that uses magnetic fields and radio waves to take detailed pictures inside the body.
O	
Oncogenic	Potential to cause cancer.

P	
Palliative care	Care given to patients facing an advanced disease or terminal diagnosis, with the goal of reducing pain or discomfort and improving quality of life.
Pap Test	A test used to detect cell changes in the cervix. Replaced by the Cervical Screening Test.
PET scan	Positron Emission Tomography scan. A procedure in which a small amount of radioactive glucose (sugar) is injected into a person. A scanner is used to make detailed pictures of areas inside the body. Cancer cells will absorb more of the glucose solution, appearing brighter in the scan.
Precancerous	A term used to describe a condition that may become cancerous.
Prognosis	The expected outcome of a person's disease.
R	
Radiation therapy	The use of targeted radiation to kill or damage cancer cells so they cannot grow or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.
Radical hysterectomy	Surgical removal of the uterus, cervix and part of the vagina.
S	
Screening	Checking for specific diseases in people before any symptoms appear, through an organised program.
Speculum	An instrument used to hold open the walls of the vagina so the cervix can be examined.
Spinal tap	A procedure in which a thin needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give drugs. Also called lumbar puncture.
Squamous cell	A type of cell found in the outer surface of the cervix (ectocervix).
Squamous cell carcinoma	A cancer that starts in the squamous cells of the body, such as those found in the outer surface of the cervix.
Squamous intraepithelial lesion (SIL)	Abnormal growth of squamous cells on the surface of the cervix. Changes may be low grade (LSIL) or high grade (HSIL). In the past, SIL was referred to as cervical intraepithelial neoplasia (CIN).
Staging	Tests performed to determine how far a cancer has spread.
T	
Test of cure	Testing performed 12 months after treatment for a high-grade abnormality, and annually thereafter until the patient receives a negative test result on two consecutive occasions. Following this, a patient should return to five-yearly screening.
Total hysterectomy	Surgical removal of the uterus and cervix.
Trachelectomy	Surgical removal of the cervix and upper part of the vagina, with the uterus and ovaries remaining in place.
Transformation zone	Area of the cervix where the squamous and glandular cells meet. The most common site for abnormal cells to develop in the cervix.
Tumor	An abnormal growth of tissue. Tumors may be benign (not cancer) or malignant (cancer).
U	
Uterus	A hollow, muscular organ in a female's lower abdomen where a fetus (developing baby) grows during pregnancy. Also called the womb.
V	
Vagina	The passage leading from the vulva to the uterus in females. Also called the birth canal.
Vaginal stenosis	A condition in which the vagina becomes narrower and shorter. Often caused by radiation therapy to the pelvis or from some types of surgery.
Vulva	The external female genital organs.
Vulva intraepithelial neoplasia	Abnormal cells are found on the surface of the vulvar skin. These abnormal cells may become cancerous and spread into nearby tissue.
W	
Womb	See uterus.

References

Australian Government. HPV (Human papillomavirus) [Internet]. Department of Health; 2019 [updated 2020 Feb 12; cited 2019 Sep 18]. Available from: <https://www.health.gov.au/health-topics/hpv-human-papillomavirus>

Australian Government. National Cervical Screening Program [Internet]. Department of Health; 2019 [cited 2019 Sep 18]. Available from: <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-screening-1>

Cancer Council. Understanding Cervical Cancer: A guide for women with cancer, their families and friends [booklet]. Sydney, NSW, Australia: Cancer Council; 2019

Cancer Institute NSW. Cervical Screening NSW [Internet]. Cancer Institute NSW; 2019 [cited 2019 Sep 18]. Available from: <https://www.cancer.nsw.gov.au/cervical-screening-nsw> Faces of HPV and Cervical Cancer: A Book of Hope. Upper Marlboro, Maryland, USA: Cervivor; 2014. Available from: <https://cervivor.org/wp-content/uploads/2015/10/cervivor-faces.pdf>

National Institutes of Health. NCI Dictionary of Cancer Terms [Internet]. National Cancer Institute; 2020 [cited 2020 Mar 9]. Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms>

Ovarian Cancer Australia. Resilience Kit: For women living with ovarian cancer [booklet]. Melbourne, VIC, Australia: Ovarian Cancer Australia; 2018

Understanding HPV [Internet]. Seqirus Australia; 2018 [cited 2020 Mar 10]. Available from: <https://www.hpv.com.au>

Appendix



FOR WOMEN

Women's Comfort Checklist

For a more comfortable cervical screening experience

Cervical Screening is one of the best defenses against cervical cancer and is essential for women between the ages of 25 and 74, who have ever been sexually active. This list was developed to help ensure a comfortable screening experience. It aims to educate and empower women by; providing advice on how to best prepare for screening and by explaining what women can expect from their health professional(s).

Simple steps to ensure your comfort:

Make an appointment:

Make an appointment with your doctor or reproductive health clinic at a time that suits you. Additionally sign up for cervical screening reminders at www.accf.org.au/getthetext

Prepare by doing the following;

- Review information on Cervical Screening so you know what to expect www.accf.org.au/cervical-health/prevention
- Wear loose comfortable clothing - you will be asked to remove clothing from waist down.
- Empty your bladder before you arrive at the clinic or ask to use the "ladies" when you arrive.
- Try to stay as relaxed as possible – this will help minimize any discomfort. For example try to take some long slow and deep breaths to maintain a sense of calm.

Expect the following from your health professional:

- An option to have a support person present eg. relative/friend/clinic nurse.
- Privacy to undress and dress.
- A sheet to drape across your stomach and thighs to minimize exposure and ensure your modesty.
- Easy to understand instructions during the procedure and reassurance. You can ask the doctor/health professional questions and ask him/her to stop at anytime.
- Sterilised medical instruments (presented at a comfortable temperature) - to take a sample.

Completion:

- Further privacy to dress & provision of tissues, sanitary pads and handwashing facilities - if needed.
- If you need any personal assurance feel free to ask whether your genitalia / reproductive organs appear normal.
- Feel free to ask when & how your results will be advised (generally provided within two weeks). Don't hesitate to call your healthcare provider to check on your results should you be concerned.
- If any abnormalities are detected, your health professional will advise of further examination options.
- Ensure your contact details are up to date and sign up for "Get the Text" FREE reminder service at www.accf.org.au

Proudly developed by the ACCF Checklist Medical Panel and endorsed by the Australian Women's Health Network

For information about the Comfort Checklist please visit www.accf.org.au/cervical-health/prevention/comfort-checklist or call 1300 727 630 (within Australia) or (07) 3177 1099



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