
INFORMATION FOR MEN DIAGNOSED WITH ANAL CANCER

**THE
BOTTOM
LINE**

GAY MEN, HPV &
ANAL CANCER

THEBOTTOMLINE.ORG.AU

INTRODUCTION

If you have been diagnosed with anal cancer, you are likely be shocked and upset by this news.

This part of the website presents information which we hope will help you to adjust to the diagnosis by explaining the process involved and the treatments used.

It also presents the stories of a number of people who have been through the experience of an anal cancer diagnosis and are still living well with it a number of years afterwards. All the case studies below are from people who are HIV-positive, but it is important to remember that HIV-negative people are also at risk.



EARLY TREATMENT AND REGULAR MONITORING SAVES LIVES.

The experiences of the three men in these stories vary from treatment in the mid-nineties to the late 2000s. No one is pretending that treatments for anal cancer – surgery, chemotherapy and/or radiotherapy – are not very difficult or painful. If surgery is involved, this can be very painful in the post-operative period, may lead to removal of the anus and part of the bowel, and require a temporary or permanent colostomy bag. Treatments for anal cancer are improving though as there is more understanding on how to target cancerous lesions.

Everyone who goes through this process will usually require months for recovery and considerable support as the

treatments are very intrusive in people's lives, they require pain management and understanding or possibly counselling to help people with the psychological stresses involved. Finally, there are details on where to find support to help you through this time. (See 'Getting Support and Services' at www.thebottomline.org.au for more information)

Once a diagnosis of cancer is made (usually following some form of surgical procedure), the person undergoes "Staging". This is a series of blood tests, X rays and scans to establish how far (if any), the cancer has spread. Stage 0 means that there has been no spread at all, Stage 4 means that it has spread throughout the body. Response to treatment is highly dependent on the stage of the cancer. Five year survival for cancers in Stage 0 is nearly 100%, whereas for those in Stage 4, it can be as low as 20%. That's why it's important to get a diagnosis as early as possible.

TREATMENT

To treat anal cancer, you may be referred to the care of a colorectal surgeon who works with a radiation oncologist and/or a medical oncologist to discuss the forms of treatment which are used for it. Apart from at the initial diagnosis stage, surgery is usually the last option, unless the cancer has not spread beyond its original site.

HOW IS ANAL CANCER TREATED?

RADIATION THERAPY

Radiation Therapy is the mainstay in the treatment of anal cancer. The radiation comes as a form of high-energy X-rays that are delivered to the patient to the areas at highest risk for cancer. The radiation is more damaging to cancer cells compared to healthy cells.

Typically radiation for anal cancer is given daily, Monday to Friday, for 5 to 6 weeks.

The radiation is usually aimed at the entire pelvis for the first 2-3 weeks to target any cells in the lymph nodes surrounding the anus.

After this, the radiation is aimed more specifically at the anus in the lower part of the pelvis.

Like X rays, radiation treatments cannot be felt and do not hurt.

Radiation treatment can result in irritation to the skin. This can be quite severe with redness, dryness and breakdown of the skin. Temporary hair loss can also occur. Sometime patients will require a break from treatments to allow the skin to heal.

Other side-effects of radiation therapy can include fatigue, diarrhoea and a lowering of blood counts. Most side-effects get better within a few months of treatment.

Radiation therapy in the abdomen and around the rectum can sometimes cause erection difficulties.

Radiation proctitis is the term used for inflammation of the bowel following radiation treatment. It is very common and typically causes diarrhoea and blood in the stool. It can also make receptive anal sex very uncomfortable for months after the procedure.

Discussion with the radiation oncologist or other medical staff involved in your care should be able to identify ways to minimise these complications.

Intensity-Modulated Radiation Therapy (IMRT) is increasingly used at specialist centres. IMRT involves very careful imaging of the cancer, then using highly targeted, small pulses of X rays to destroy the cancer, but have minimal impact on the surrounding tissues. It is associated with fewer side effects compared to conventional X ray therapy. This is relatively new technology, and is not yet available everywhere. Talk to your doctor about if IMRT is suitable for you and where it is available.



CHEMOTHERAPY

Chemotherapy refers to medications that are usually given intravenously or in pill form.

There are a range of chemotherapy treatments available and sometimes it might be possible to vary the ones used, based on the side-effect profile of the different drugs and your health at the time. The most common combination is mitomycin C and 5 fluorouracil, although a number of other combinations are under trial.

If the cancer is thought to be localised to the anus and pelvis lymph nodes, chemotherapy is often used at the same time as radiation therapy. (See below)

CHEMORADIOTHERAPY

As the name suggests, this is the use of a combination of chemotherapy at the same time as radiation therapy.

Using both together has been shown to reduce the chance of the cancer recurring.

However, some people are unable to tolerate both treatments together and are given the treatments at separate times.

Most people with HIV, who are on antiretrovirals, can tolerate the standard anal cancer treatment regimes. Very rarely, lower doses of chemotherapy or radiation are used, or they are given over a longer time period. Occasionally additional treatments are used to boost the immune system during the time of treatment.

SURGERY

Surgery is often performed to make the initial diagnosis. Under general anaesthetic, the surgeon will remove as much of the cancer as is safe at the time of the procedure.

Often this is all of the cancer, particularly in early cases. The specimen will then be sent to a laboratory for detailed analysis. The term “clear margins” indicates that all the cancer has been removed. However, people still generally receive chemotherapy, in case there has been microscopic spread.

With earlier diagnosis, an increasing number of people are being diagnosed with Superficially Invasive Squamous Cell Cancer (SISCCA). This is the name given to very early cancers. There is some evidence to indicate that surgery alone is all that is necessary in cases of SISCCA. However, more data are required before this approach can be routinely recommended.

Surgery is also sometimes used for relief of symptoms, such as blockage of the bowel, particularly when cancers are large. It can sometimes be quite extensive, including wide removal of the anus, the anal muscles and the creation of a colostomy (where a bowel opening is created on the abdomen, as an alternative route for faecal material).

Surgery may also be performed if the cancer recurs and additional chemotherapy or radiation cannot be given.

WHAT HAPPENS AFTER TREATMENT?

After treatment for anal cancer, patients are usually followed every 3-6 months, sometimes for several years. Sometimes these visits may involve CT scans. The use of High Resolution Anoscopy for the follow up of anal cancer is currently being evaluated, as it potentially offers an opportunity to diagnose recurrences at a much earlier stage.

Anal cancer tumours can take some time to shrink after treatment. There may still be a residual mass for some time after treatment. This does not mean that the treatment didn't work.

If a cancer is going to recur, it will usually do so within 2 years. The longer a person goes without a recurrence, the greater the chance the cancer will never come back.



PERSONAL ACCOUNTS OF LIVING WITH ANAL CANCER

Below are three accounts from people who have had anal cancer about their diagnosis, experience with treatments and medical professionals and the level of support available to help with living with this condition.



MAX'S STORY

“For me, getting a diagnosis of anal cancer was as big a challenge (if not a greater one) than dealing with my first AIDS-defining illness in 1988. It took a great toll on me physically, emotionally and psychologically. I couldn't bury my head in the sand with cancer – I had to learn about it, be treated and recuperate in a similar way that I had to with those earlier illnesses.”

Max has endured a lengthy battle with anal cancer over a fifteen year period (and in truth, still lives with the fear that it might come back again one day). It all began with a diagnosis of HPV-related pre-cancerous changes in 1991. He was referred to a colorectal surgeon who operated to surgically remove the lesions, with the hope that they wouldn't return.

At the time, Max had a low CD 4 count as there were few HIV treatments available. His lowered immunity probably contributed to the return of more cancerous changes, with a diagnosis of carcinoma in situ in 1995. (In situ meant that the cancer had not spread to surrounding cells. This is now called HGAIN - see 'Understanding Anal Cancer Screening Results' at www.thebottomline.org.au for more information. Further surgery was done.

In 1996, however, Max was diagnosed with HPV- related cancer in the peri-anal area. This time, radiotherapy was the course of treatment and he found this to be quite an

assault on the body. "I felt so ill and lacking in energy after each bout of radiotherapy," said Max. "And the worst part was coping with the burns. No matter how hard they try, it is almost impossible for the radiologists not to burn you in a sensitive part of the body like that and the pain is extremely intense, sometimes lasting for a week afterwards."

[Since Max's treatment, there have been advances in radiation therapy with more targeted radiation and much less impact on the surrounding tissue. (See 'Treatment' earlier in this booklet for more information)]

Having thought the worst was over, Max was confronted by the news that the cancer had returned in 2004. The colorectal surgeon advised that radiotherapy was not possible a second time and now the only option was surgery again, only this time it would need to be more extensive, involving skin grafts and a temporary colostomy while the wound healed.

Unfortunately the skin graft surgery failed and Max remained in hospital for five weeks while the doctors worked out what to do next. He had to learn to live with a colostomy which he found very confronting. "It severely affected my self-esteem and my body image. The support from the colostomy nurses though was wonderful. They understood the fear involved and were there for me, every step of the way.

"The most important thing for me to try to avoid at this stage was a colostomy for the rest of my life. The doctors did understand the sexuality factor in this and they were prepared to try to do a skin graft again, although this time they warned me that it would be a very difficult process.

“My skin had been so damaged for previous radiotherapy that it was necessary to graft skin from other parts of my body. The second graft required special preparation in a hyperbaric chamber to try to promote wound healing. Amazingly this worked but the doctors told me the chances of a second operation succeeding were not great.

“In fact, the technique they were using with the skin grafts in this part of the body was so rare that I was the second person in the world to be given it. Of course I went through major fears that it wouldn’t work and I would have to have more invasive surgery.



**THEY UNDERSTOOD THE FEAR INVOLVED
AND WERE THERE FOR ME, EVERY STEP
OF THE WAY.**

“After the surgery I had to remain immobilised in my hospital bed for a week. When the doctors told me that the second skin graft had worked, the stress that lifted off my shoulders was enormous. I could live a relatively normal life again and try to put this behind me.

“While the cancer has not come back since, I still live with the fear that it might recur. I visit my colorectal surgeon still to check on progress and I don’t think I’ve ever forgotten what it was like to get over the biggest battle of my life.”

MAX'S ADVICE ON GETTING SUPPORT:

"It is certainly a good thing to be able to talk to others who have lived with anal cancer. Support groups are still not available. I rang the Cancer Council in my state and was told that, while they would be happy for me to be a part of a group for people with cancer, it would not be solely for those with anal cancer. The group would not be solely for gay men, either.

"Because the fears about anal cancer are often around sexuality concerns, I thought it would be difficult to talk about those issues in a group like that and decided not to take up the offer.



ONE-ON-ONE COUNSELLING WOULD PROBABLY HELP SOMEONE COME TO TERMS WITH A CANCER DIAGNOSIS.

"I found the greatest supports for me came from the medical staff that treated me. I was particularly impressed with the care and compassion shown by the colostomy nurses and the willingness of the doctors to go the extra mile for me, to try fairly radical surgery, was also incredibly heartening.

"One-on-one counselling would probably help someone come to terms with a cancer diagnosis. If they could find a counsellor who understands cancer, that would be very helpful, I think.





STEVE'S STORY

Steve has lived with HIV for about thirty years, having been diagnosed in 1983. He received a diagnosis of anal cancer in 1993 and was treated with multiple courses of chemotherapy and radiotherapy.

"I had the complication of also having bowel cancer intermittently with the anal cancer. I had very few T-cells in the early nineties so I knew there were real risks that both cancers would recur.

"When the doctor said I had to have surgery and a colostomy bag, I accepted it. The cancers were internal as well as in the peri-anal area so there was no choice.

"I have always been a very positive person in my outlook about life. I like to look forward, thinking about the things I haven't done yet, rather than to focus on the limitations that life was presenting to me during that period.

"In eight years I had 12 bouts of cancer and then unfortunately in 2010, the cancer came back with a vengeance. I lost the majority of the peri-anal area due to a tumour the size of a rockmelon in my lower bowel. The pain and fear was overwhelming.

"The surgeons said that this time, it was extensive reconstructive surgery to my arse. It was extreme surgery to the abdominal area. I would require a lot of skin grafts from my legs (and there wasn't that much there, in the first place!).

"The doctors told me that I had a one in four chance of surviving. 'Well you'd better tell the other three people they're not going to make it' was my reply.

“After the involvement of 30 surgeons, including plastic surgeons, I came through the operation. I spent eight months in hospital and a further eight months in recovery. I have so many stitches all over my body I look like a cabbage patch doll.

“None of this has stopped me living out my life plans, though. I have been studying towards a Certificate V1 and Diploma in Aged Care and I intend to go back to work once I’m able.



MY ADVICE TO OTHERS WHO MIGHT BE DIAGNOSED WITH EARLY OR LATE STAGE CANCERS IS NOT TO PUT OFF ANYTHING.

“My advice to others who might be diagnosed with early or late stage cancers is not to put off anything. I had so many friends with cancer tell me not to do chemotherapy as it was so toxic and because they stuck to that, they are not here now. I wish they had, I miss them.

“You have to be up for the challenges life presents you. I have such a strong will to stay alive, such good support from family friends, RDNS nurses and medical staff, that I knew I could survive this.”

STEVE'S ADVICE ON GETTING SUPPORT:

"I can't say that the cancer support group I went to in Adelaide worked for me. They were all heterosexual, mainly older men and they didn't have anal cancer. I didn't feel comfortable and only went there once.

"My greatest support I got was from my circle of friends. I include surgeons, specialists and nurses as friends as well. I have been through so much with them by my side that they feel like friends to me.

"I did try cognitive behavioural therapy to help me with a few self-esteem issues when I first got a colostomy bag and after so many operations on my body. It did help me start to find some inner strength, to realise that you have to find the greatest support from within yourself.



MY GREATEST SUPPORT I GOT WAS FROM MY CIRCLE OF FRIENDS.

"You need to nurture yourself when you have so many health problems going on. I regularly receive massages, reflexology, go to natural therapists and I have to meditate a lot. This kind of self-care is essential."





DAVID'S STORY

In 2003, David moved to Newcastle with his partner of 14 years. Everything was working well for him at the time. After experiencing a few AIDS-defining illnesses earlier, he now had the virus under control. His only problem was a persistent anal wart that seemed to be growing all the time.

“My GP there was a female and I was too embarrassed to drop my trousers to let her have a look at it. So I left it and when she finally got to see the problem, she said that I had left it too long and now had anal cancer. Who would have thought a wart might lead to cancer? I now had anal cancer. As a gay man, I knew this would be very hard to deal with.

The GP referred him to the local hospital. “The doctor there said I needed to have radical radiotherapy and chemotherapy to try to control the cancer. I sat in the Radiation Clinic in Newcastle, sitting and thinking about what this therapy was going to do to my T-cells-which I had fought so hard to increase over the years.

“I couldn't cope with the idea of chemotherapy or radiotherapy and I ran from the appointment out of fear. Later I went back to the surgeon and he agreed that he would try surgery instead. Little did I know this would be a four year saga. I had numerous surgeries, and each time it was incredibly difficult to keep a positive attitude, with all the pain after the operations, the stitches and problems keeping the wound clean when you went to the toilet.

“In 2007 we moved back to Sydney and I thought that if the cancer caused me more problems, there probably would be more experienced doctors used to dealing with HIV there. This was true but I still often felt that I was on my own, that few others had been through this 'rare' cancer and that doctors were not quite sure about it.

"When the cancer came back, I went to an oncologist who said I would need chemotherapy and radiotherapy together. The chemotherapy would last for six weeks and be a combination of pills and a drip in hospital. The side-effects would include low energy levels, loss of appetite, and generally feeling poorly and it could last up to seven weeks.

"The radiation however, was to be a much greater challenge. It would last for thirty days. I really wasn't well prepared for what would happen to me. When the procedure was about to start, the nurse said to me, 'You know we are treating you whole pelvis, back and front, including your thighs?'

"No I didn't. I realised that not only would the radiation burns affect my anal area, they would also burn my dick! No one had warned me about this.

[Since David's treatment, there have been advances in radiation therapy with more targeted radiation and much less impact on the surrounding tissue. (See 'Treatment' earlier in this booklet for more information)]

"The pain I experienced from the burns was awful. It started after about 10 days and I was throwing up from a combination of both therapies. The worst of it was I had to continue with the radiotherapy while I was feeling so bad. Each time, I wondered how I could get through more and more pain each time.

"The nurse consoled me that, while the pain was going to be bad, they did have good painkillers to help me. I also had to remember that these burns will heal and everything will be normal again.

"I had to keep remembering this when the sores on my penis became so red and inflamed, I couldn't recognise it anymore. The anal area was just as bad. Going to the

toilet was a nightmare every time. I learnt how to clean myself in the toilet using a Tupperware bowl inside the toilet bowl-and just dabbing lukewarm salty water, not wiping the raw skin. Toilet paper had to be dye and perfume-free and I never used soap in that area.

"I had not been told about the next challenge that confronted me. The radiotherapy caused fibrosis of the penis, a thickening of the arteries at its base and this lead to erectile dysfunction.

"This made me angry. I still wanted a sex life. I started to take my frustration out on my partner a bit and I blamed the radiologist for not telling me about this side-effect. I went back to him and he explained how that they had to be this hard on the body to stop the cancer spreading.

"Eventually I found a doctor who analysed what was going on for me. I had become depressed after this trauma and my body was 'out of whack'. I'd always fought against using antidepressants but he said if I used them for six months, it should help. And it did. Slowly I got back to my old self, my sex life returned to normal and I felt happy again. And, after three years, I am still cancer-free.



**SLOWLY I GOT BACK TO MY OLD SELF,
MY SEX LIFE RETURNED TO NORMAL
AND I FELT HAPPY AGAIN.**

DAVID'S ADVICE ON GETTING SUPPORT:

"Unfortunately I went through my experience with anal cancer feeling quite alone. I wasn't introduced to other people with anal cancer and the information I received from my treating doctors often left out very important details.

"In recent times I have been in contact with some very knowledgeable doctors in Sydney, who know a lot about anal cancer. They have made me realise that my experience has been shared by others and have given me great support.



THEY HAVE MADE ME REALISE THAT MY EXPERIENCE HAS BEEN SHARED BY OTHERS AND HAVE GIVEN ME GREAT SUPPORT.

"My advice about seeing doctors about any symptoms of anal cancer is to write down your questions before you go to see them. Ask as many questions as you need and don't be embarrassed about anything. Take a friend along if you think that would help. If you don't like what the doctor is telling you, it's always possible to get a second opinion. You need to feel cared for by your doctor – if you don't, find another one.

"I have been lucky to have the support of a loving partner who has helped me enormously through such a trying time. I am concerned though that there are currently no support groups for people with anal cancer to enable people to share their stories and deal with their fears. I hope these are set up soon because anal cancer isn't going away."

SUPPORT & SERVICES

This section provides contact details and referrals to organisations for support and more information. This includes information specific to anal cancer, as well as organisations that provide services to people who have had or been affected by cancer more broadly. It also provides details of organisations that provide services and information to gay men and HIV-positive people. Not all of these organisations will have experience with anal cancer specifically.

A sexual health service or GP that sees a lot of gay men may be helpful if you have questions or concerns. You can also talk to them about screening options and vaccination for HPV. You can search for these sexual health services and GPs in your area at www.thedramadownunder.info/clinics/.

For gay men diagnosed with anal cancer, access to therapeutic groups has been more difficult as the numbers of people presenting at any one time with anal cancer tends to be small and people are not always willing to discuss their issues in a group.

Due to the relatively small number of people presenting at any one time with anal cancer, there may not yet be specific support groups or activities for anal cancer in your area. Many gay men with anal cancer may also find it difficult to discuss their issues in broader support settings because of sensitivities around the condition, sexuality or HIV status.

Earlier in this booklet, three men who have survived anal cancer wrote about their experiences. They wrote about how important it was to have supportive friendship networks, both to provide help when they were enduring difficult treatments and in providing emotional support through what some see as a stigmatising condition.

USEFUL WEBSITES ON HPV AND ANAL CANCER

There are a range of useful Australian and international websites for further information on HPV and anal cancer at www.thebottomline.org.au.

CANCER COUNCILS

Cancer Council Australia
www.cancer.org.au (with links to local Cancers Council websites in each state and territory)
Helpline: 13 11 20

The helpline may also be able to connect you to someone who has had a similar cancer experience.

State and territory Cancer Councils also offer online, phone and face-to face support, groups and other information programs.

Cancer Connections - online support groups, forums and blogs (with links to state and territory Cancer Council support programs)
www.cancerconnections.com.au

**AIDS COUNCILS, LGBT
HEALTH & PEOPLE LIVING
WITH HIV ORGANISATIONS**

ACT

AIDS Action Council of the ACT
www.aidsaction.org.au
Phone: (02) 6257 2855

NEW SOUTH WALES

ACON

www.acon.org.au
Sydney: (02) 9206 2000
Freecall: 1800 083 060
Northern Rivers: (02) 6622 1555
Hunter: (02) 4927 6808
Illawarra: (02) 4226 1163

Positive Life NSW
www.positivelife.org.au
Phone: (02) 9206 2177

NORTHERN TERRITORY

Northern Territory AIDS
and Hepatitis C Council
www.ntahc.org.au
Darwin: (08) 8944 7777
Alice Springs: (08) 8953 3172

SOUTH AUSTRALIA

Gay Men's Health SA
(Relationships Australia SA)
www.gmhsa.org.au
Phone: (08) 8245 8112
Freecall: 1800 671 582

Positive Life SA
www.hivsa.org.au
Phone: (08) 8293 3700
Country callers: 1300 854 887

QUEENSLAND

Queensland AIDS Council
www.quac.org.au
Brisbane: (07) 3017 1777
Freecall: 1800 177 434
Cairns: (07) 4041 5451
Freecall: 1800 884 401

Queensland Positive People
www.qpp.net.au
Phone: 07 3013 5555
Free call: 1800 636 241

Positive Directions
www.positivedirections.org.au
Brisbane: (07) 3900 8000
Free call: 1800 422 313
Gold Coast: (07) 5576 8366
Sunshine Coast: (07) 5441 1222
Townsville: (07) 4721 1384
Cairns: (07) 4051 1028

TASMANIA

Tasmanian Council on AIDS,
Hepatitis & Related Diseases
www.tascahrd.org.au
Phone: (03) 6234 1242
Hepatitis Infoline: 1300 437 222

VICTORIA

Victorian AIDS Council
www.vac.org.au
Phone: (03) 9865 6700
Positive Living Centre:
(03) 9863 0444
Living Positive Victoria
www.livingpositivevictoria.org.au
Phone: (03) 9863 8733

WESTERN AUSTRALIA

WA AIDS Council
www.waaid.com
Phone: (08) 9482 0000

LGBTI COUNSELLING

AIDS Councils and LGBT
Health Organisations around
Australia offer counselling for
people with HIV and gay men,
regardless of HIV status. Those
that do not have these services
in-house can usually provide
referrals to appropriate
gay-friendly and HIV-friendly
counselling services.

QLife
(National online and telephone
counselling and referral service
for people of diverse sex,
genders and sexualities)
www qlife.org.au
Free call: 1800 184 527

**NATIONAL HIV
ORGANISATIONS**

Australian Federation of AIDS
Organisations (AFAO):
www.afao.org.au
Phone: (02) 9557 9399

National Association for
People Living with HIV
Australia (NAPWHA):
www.napwha.org.au
Phone: (02) 8568 0300
Free call: 1800 259 666

WWW.THEBOTTOMLINE.ORG.AU



**Australian Federation
of AIDS Organisations**

napwha national association of
people with HIV australia

Australian Federation of AIDS Organisations

PO Box 51 Newtown NSW 2042

www.afao.org.au

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