

HIV HEALTH SERIES

Balancing act: HIV and cancer

As the HIV population ages there is an increasing risk of other health conditions like cancer, so regular monitoring is even more important. Knowing a lot about HIV doesn't necessarily mean we know everything there is to know about our health.

Some men have routine health checks for prostate, and women breast and cervical cancer; however, you need to check for other cancers which are now becoming more common among people with HIV.

The outlook for many cancers is improving constantly. Early diagnosis and reducing your risk (such as quitting smoking) can help to lessen long-term harm.

This factsheet is based on personal experiences and clinical expertise. It offers information on cancer prevention, monitoring and management, and shares some strategies on dealing with a cancer diagnosis, and enhancing quality of life.

Why the increase in some cancers?¹

Cancers² including anal, vaginal, Hodgkin's lymphoma and liver are higher among people with HIV than the general population. When compared with the general population, the risk of cancer is more than double for men with HIV and approximately 50 percent greater for women with HIV.³

Researchers⁴ have suggested that higher rates of non HIV related cancers in HIV-positive people may be due to a higher rate of co-infection with cancer-causing viruses such as HPV (human papilloma virus)⁵ and hep B or C, weakened immune systems (nearly 80 percent of cancers), and lifestyle factors such as smoking although these links vary among different cancer types.

About 47.6 percent⁶ of people with HIV smoke cigarettes. As people with HIV live longer and continue to smoke, they increase their risk of developing smoking-related cancers.

How can I reduce my chances of getting cancer?

There are three ways to beat cancer: early detection, treatment and healthy lifestyle.

While some risk factors may seem out of your control, like having a family history for cancer, you can still take action.

Talk with your HIV doctor about your cancer risk and what you need to watch for

Ask about tests and screening even if you have no symptoms. These include:

- pap smear for cervical cancer
- anal pap smear for pre-cancerous anal lesions
- mammogram for breast cancer
- screening for bowel cancer
- prostate examination for men over 50 years of age
- oral examination by a dentist every six months
- monitoring for skin cancer.

Know the warning signs and do self-exams

Check for any unusual changes to your body, such as:

- a sore or ulcer that does not heal (look for new growths on your skin or any changes in the size, color, or shape of moles or warts)
- a lump or hardness in the skin, especially in testicles and groin area, and in women's breasts
- sores, swelling or bleeding, white patches, scabs, or cracks inside of your mouth, lips, gums and tongue
- changes in your bowel or bladder habits
- detection of blood in your urine or stool
- a cough or a sore throat that lasts for a long time or coughing up blood
- heartburn or trouble swallowing that does not go away
- a lump in the neck, armpit or anywhere else on the body
- new moles or skin spots, or ones that have changed shape, size or colour, or that bleed
- unusual vaginal discharge or bleeding
- unexplained weight loss.

"IF YOU NOTICE ANY LUMPS OR ANY OTHER CHANGES TALK TO YOUR DOCTOR AND DON'T BE AFRAID TO GET A SECOND OPINION."

— PETER

"WHEN YOU GET AN HIV DIAGNOSIS, THERE ARE CERTAIN THINGS THAT YOU MENTALLY PREPARE FOR AND LEARN ABOUT YOURSELF. I THINK THAT HAS HELPED IN THE WAY I DEALT WITH CANCER."

— STEVEN

You can lower your cancer risk, manage your HIV at the same time, by making healthy choices

Look at other parts of your life in order to reduce stress and improve both quality of life and general health. Lifestyle changes like reducing or avoiding alcohol intake, quitting smoking, eating and resting properly are important. Regular exercise can also lower your risk of some cancers.

Get help and support for quitting smoking

If you quit smoking, you can greatly lower your risk of cancer of the mouth, throat, lungs, stomach, kidneys, liver, pancreas, and bladder. As soon as you stop smoking, your body starts to heal and your cancer risk drops. Ask your doctor or health worker about treatment and counselling to help you quit.

If you are an HIV-positive smoker this is one of the most significant ways to improve your health and reduce your risk of cancer.

A dietitian and your doctor can help you plan a healthy diet

A healthy diet means eating less fatty, salty and high sugar foods. Eat more fresh fruit and vegetables, complex carbohydrates (whole grains, breads, rice, pasta, cereals, vegetables, fruits, beans, nuts and seeds), low-fat foods, high-fibre foods, and an adequate amount of protein.

A healthy diet can lower your risk of cancer of the breast, prostate, stomach, colon, and rectum.

Protect yourself from the sun and be aware of new growths on your skin or any changes in the size, color, or shape of moles

Remember to wear sunscreen that is rated SPF15 or higher, a hat, sunglasses and clothing to protect yourself from the sun.

Reducing drugs or alcohol intake can improve your health and lower your chances of cancer

Drugs are not a direct cancer risk, but they can damage your immune system and make it harder to stay healthy with HIV.

Reducing your alcohol intake can lower your risk of mouth, throat, liver and breast cancer (in women).

Your immune system can play an important role in the prevention of some cancers

Research points to the importance of keeping your CD4 cell counts above 250 with ARV (antiretrovirals) to keep your immune system strong.

A strong immune system is your best protection against many types of cancer.

Protect yourself from other viruses like hep A, B and C

Get vaccinated for hep A and B if testing shows no evidence of previous infection and/or protection, and test for hep C. Hep C can be more serious and progress faster in people with HIV, so testing and regular monitoring (if you have it) are even more important.

Protecting yourself from other viruses like hep A, B and C will not only protect your liver from damage, but also lessen the risk of cancer.

How can I manage a cancer diagnosis?

For many, like Peter, cancer can be unexpected:

Peter: Cancer comes on so quickly and you don't have time to prepare. If you notice any lumps or any other changes talk to your doctor and don't be afraid to get a second opinion. You need to be vigilant and trust your instincts.

"THE FIRST COUPLE OF MONTHS YOU'RE NOT WELL ENOUGH TO DO ANYTHING, BUT LATER ON YOU NEED ANOTHER INTEREST TO TAKE YOUR MIND OFF CANCER. I AM LEARNING A NEW LANGUAGE." — JENNY

"THERE WAS A TURNING POINT THROUGH THE THERAPY TO MAKE A GO OF IT AND LIVE A HEALTHY LIFE. ADJUSTING TO YOUR DIAGNOSIS MAY TAKE TIME." — RICHARD

People react to their diagnosis differently. John found it difficult to take in his diagnosis immediately and got the support he needed from the Cancer Helpline (13 11 20):

John: It's hard to think straight when you first hear 'you have cancer'. There was little time between my diagnosis and the day treatments began. I wanted someone to talk to. You build up all these questions in your head and you need answers.

People also learn to deal with cancer in their own way through support of others, getting information and taking control of life changes. Like HIV, cancer encourages people to focus on what is important in life. One approach to managing cancer is to decide first what your priorities are.

A priority for Ben was to set up short term and long term goals that gave him the motivation to live:

Ben: I needed to develop reasons to carry on living. For me, that was finding a job I really wanted to do. Now I teach kindergarten kids. Because I'm not doing it five days a week, I have the energy to put myself into it. I'm now living the life I really want to live rather than plodding along. I'd suddenly transformed my whole way of looking at life and everything fell into place.

Having cancer does not mean losing hope. However, your expectations and hopes may change as treatment progresses. It is about looking for ways to get through a difficult time and where to focus your energies to move forward.

An HIV diagnosis prepared the way for Steven to deal with the challenges of cancer:

Steven: When you get an HIV diagnosis, there are certain things that you mentally prepare for and learn about yourself. I think that has helped in the way I dealt with cancer. Our experiences make us stronger. You just have to accept it and deal with it and then move on in small steps.

While Jenny explains, learning a new skill helped to keep a positive attitude and active mind:

Jenny: I keep my mind active. If you don't have a goal or motivation your mind becomes lazy. The first couple of months you're not well enough to do anything, but later on you need another interest to take your mind off cancer. I am learning a new language.

Maintain your daily routine as close to normal as possible

Living day-to-day may be a challenge and everyday is likely to be different. Many find it useful to think about one achievable step at a time. Do as much as you can – sometimes this may be less than you are used to. Do not be hard on yourself if you cannot achieve your goals.

For Kevin, it was important to focus on what he could do:

Kevin: I set myself tasks. I'd make my bed and sometimes it would take me a day to change the sheets or half a day to do the washing. I was always determined that I wouldn't let it beat me. I set little goals everyday and I achieved those goals even if it took me the whole day to do it.

For others, like Jason, work (its achievements and routines) were integral to recovery:

Jason: I stayed at work – it was so important for me to keep my routine. It was a matter of thinking about how? Like, the hospital staff where I had my treatment visited me at work and did my dressings. They came in three times a week. Managing my health and recovery was a struggle, but I achieved it. My focus is on 'what do I need to do to get well', not on how sick I am.

Identify your support networks

Sharing a cancer diagnosis is not easy. For many, peer support, support from family, friends and/or social worker or psychologist during and after treatment play a key role in coping with the difficult parts of treatment and post-treatment recovery.

Friends and family will be looking for ways to support you, and may want direction from you on how to respond.

Neville explains the importance of setting boundaries and limits:

Neville: You don't have to share every detail about your diagnosis with everyone. I established an email list and sent a message asking people not to ring. I couldn't talk and repeating myself was exhausting. So, I sent an email once a week and kept friends posted. That reassures them that you're okay. Email updates helped me tremendously and were my preferred means of communication. I managed to turn the updates into comic stories.

As with HIV, knowing other people in a similar situation can give you ideas about how to deal with the challenges and issues you may encounter.

For many, there are other priorities earlier on in diagnosis and treatment, which are about caring for self and maintaining a regime of health. For some, like Phillip, support groups become more beneficial during post-treatment recovery:

Phillip: You are coping with medication and the dietary changes that help you to manage the side effects. Also, you are trying to include exercise in your daily routine. It's a balancing act. That can be hard if you are feeling really nauseous or have got diarrhoea. Going to a support group wasn't a consideration during the early stages of treatment. It was more beneficial during my recovery.

Because people can experience depression and anxiety, it is important to have access to mental health care during treatment and post-treatment recovery, if needed.

Talking to a counsellor helped Richard to adjust to his cancer diagnosis:

Richard: There was a turning point through the therapy to make a go of it and live a healthy life. You have to be in the right psychological state and physically up to it. Adjusting to your diagnosis may take time. It's a life turn around, and it changes your whole attitude. You need someone to talk to.

Support may also come in the form of financial and travel assistance or help with shopping or doing your housework (see 'Where can I get information and support?' on the back page of this factsheet.)

Treatment is different for each person

Being prepared and understanding what chemotherapy and radiation therapy are can help lessen some of the stress surrounding your treatment. Talking to your oncologist, HIV doctor or nurse about how to prepare for side effects during and after treatment can be useful. With planning and support, the impact of side effects can be reduced. The Cancer Council Australia website has fact sheets on understanding treatments and managing side effects (see www.cancer.org.au).

Responses to cancer treatment vary from person to person, because of this it is difficult to know how you will react.

Taking one day at a time helped Roger to find his way through treatment:

Roger: If you start to think about what you're going to feel like on Friday and it's only Monday, you're going to talk yourself out of going for treatment. Don't see how long you have got to go before treatment is over. Step through the days individually.

Be an active participant in your treatment decisions and in your recovery 'journey'.

Ask questions, especially if you are unsure or unclear and feel you need more information on the aim of treatment.

- Is it to cure, control, prevent the spread of cancer or recurrence or relieve symptoms?
- Can side effects be prevented or controlled; are they temporary or permanent?

And remember, pain management is always available.

Finishing treatment brought Neville a sense of achievement:

Neville: Radiotherapy was the hardest thing I've ever had to do physically and emotionally, but it taught me that you can do it, particularly if you've got the right help and support. If I'd been able to look at this process in advance, I probably would have said no.

Exercise can help with treatment side effects and improve your cancer recovery

The nutritional and physical activity needs of most people with cancer change during different phases of treatment and post-treatment recovery. Regular, moderate physical activity can help you cope with cancer and the side effects of treatment such as fatigue.

Physical activity can boost your immune system, improve cardiovascular fitness, muscle strength and self esteem. It can also reduce anxiety and depression which are known to cause fatigue. Unless there are particular reasons why you should not exercise, try to do some exercise everyday. This will help your body as you recover from cancer and cancer treatment.

A dietitian can help you to manage dietary changes during treatment

Weight loss happens during chemo and radiation therapy, because people lose their appetite and/or feel nauseated. A dietitian or your doctor can help you plan a healthy diet.

Jenny found a dietitian can also help you cope with dietary changes that will support your treatment:

Jenny: My nutritionist was wonderful. She not only gave me recipes for economical meals, but also an idea of what's good to eat and how to deal with side effects. I am more aware of my diet and that's a very positive thing because previously I didn't treat my body well. I have changed my attitude and found a balance in my life.

Discuss the use of complementary therapies with your doctor

Complementary therapies may work alongside medical treatments and some have improved quality of life or reduced pain. There is no evidence that these therapies can cure or prevent cancer. Some of these therapies have not been tested for side effects and may interact with HIV or cancer treatments. There are many different paths to take with complementary therapies so talk to your doctor.

Cancer and HIV: a summary

- Because people with HIV are more susceptible to cancer ask your doctor about your cancer risk and what you need to watch for.
- If you are at risk (e.g. smoke, have a family history of cancer or are over fifty) include cancer testing/screening in your routine health checks.
- Treatment can be more effective when cancer is found early. Know the warning signs and do self-exams. If you notice any changes to your body or mouth, talk to your doctor or dentist right away.
- A strong immune system is your best protection against many types of cancer. Keep your CD4 counts above 250 with ARV (antiretrovirals). Look at other parts of your life to improve not only your general health, but also your immune system (e.g. reduce your alcohol intake or quit smoking).
- Protect yourself from other viruses like hep A, B and C. Get vaccinated for hep A and B if testing shows no evidence of previous infection and/or protection, and test for hep C. This will not only protect your liver from damage, but also decrease the risk of cancer.
- Regular exercise can lower your risk of getting some types of cancer. Talk to a physiotherapist, your doctor or a fitness trainer at your local gym. See also ACON's Healthy Life + and services offered by Positive Central.
- You can reduce your risk of some cancers (breast, prostate, stomach, colon and rectum) with a healthy diet.

If you are diagnosed with cancer:

- Exercise and good nutrition can also help with treatment side effects and improve cancer recovery. A dietitian or your doctor can help you plan a healthy diet.
- Talk to your doctor, especially if you feel you need more information on your diagnosis and the aim of treatment. Prepare your questions beforehand or take a friend for support.
- Ask questions and get support. For example, you might want to talk to a counsellor or social worker about how to deal with your diagnosis and manage treatment side effects or contact Centrelink to find out what financial support is available while you are on treatment and during post-treatment recovery.
- Peer support, support from family, friends and /or social worker during and after treatment can play a key role in coping with diagnosis, and difficult parts of treatment and recovery. Support can also help you to adhere to your treatment regime and plan.
 - Identify people in your life who will be a good source of support
 - Joining a support group can provide structure and the opportunity to talk about experiences and to learn from others. For many, this is more useful during post-treatment recovery.
- Maintain your daily routine as close to normal as possible. Do as much as you can – sometimes this may be less than you are used to.

Where can I get information and support?

- **Cancer Council Helpline 13 11 20** Information and support for the cost of a local call anywhere in Australia. Contact the Helpline for: information including free written material on specific cancers; support services, which may include counselling, financial assistance and accommodation for people living in regional NSW; information on chemotherapy, surgery and radiation therapy and someone confidential and professional to talk to about what you are going through.
- **Cancer Council Australia** website (with links to state and territory Cancer Councils) www.cancer.org.au
- **Multicultural HIV and Hepatitis C Service** offers support and information for people living with hepatitis C and HIV. Ph (02) 9515 5030 or 1800 108 098 (regional NSW) or visit www.multiculturalhivhepc.net.au
- **Positive Life NSW** is a community organisation representing the interests of people with HIV in New South Wales. Positive Life provides information, educational resources, advocacy and referral. Ph (02) 9361 6011 or Freecall 1800 245 677 (NSW only) or visit www.positivelife.org.au
- **Healthy Life + (ACON)** offers weekly health seminars, individualised training programs and free gym membership. Contact ACON's HIV Men's Health Promotion Team or Women & Families Project. Ph (02) 9206 2000, email hivliving@acon.org.au or family@acon.org.au
- **Positive Central** offers counselling, social work, physio-therapy, exercise programs, occupational therapy, equipment loan, nutritional advice and groups. Ph (02) 9395 0444 or email positivecentral@sswahs.nsw.gov.au
- **HIV Community Team** offers community-based health services for people with HIV. Ph (02) 8305 3800 or email hivcommunityteam@sesiahs.health.nsw.gov.au

Transport, care at home, meals on wheels

- **Community Support Network (CSN)** ACON provides assistance to help HIV positive people with cleaning, cooking, shopping and transport to medical appointments. All CSN services are FREE. Ph (02) 9206 2038 or Freecall 1800 063 060, Hearing Impaired (02) 9283 2088 or email csn@acon.org.au
- **Community Transport** exists in most towns and suburbs. Ask your health worker for information.
- **Community Care (HACC)** exists in most towns and suburbs. They provide transport services to medical appointments, meals on wheels, care at home and help with household tasks. Ask your health worker for information.

Community Health Centres

Community Health Centres exist in most towns and suburbs. They provide different services, including counselling, crisis support and information on local health and welfare agencies. Look in your White Pages under Community Health Centres.

Food and nutrition

Accredited Practicing Dietitians (APDs) work in hospitals and community health centres where there is usually no charge for their services. Alternatively, private practitioners are listed in the Yellow Pages. For information on healthy eating and referral to local dietitians phone Dietitians Association of Australia 6282 9798 or 1300 658 196 or visit www.daa.asn.au

- **Albion Street Centre** for dietary needs. Ph (02) 9332 9600 or freecall 1800 451 600.
- **Food Distribution Network** is a not-for-profit community co-operative offering home delivery of boxes of fresh fruit and vegetables (or both). Eligibility is based on health grounds, not financial. If you wish to become a member of the cooperative phone (02) 9699 1614 or email fdn@ihug.com.au

Alcohol & Other Drug Services

- **NSW Health Services** have a number of Drug and Alcohol Clinics set up around the state offering confidential advice, assessment, treatment and referral for people who have concerns about their use of drugs and alcohol. The services are free. Ph: Alcohol & Drug Information Services (ADIS) on (02) 9361 2111 or 1800 422 599, or contact your local hospital or community health centre who will also be able to advise you on your nearest clinic.
- **nomorebutts.org.au** website provides information on quit smoking treatments and programs for HIV-positive smokers.
- **Quitline 13 QUIT** is a confidential telephone-based service designed to help smokers quit smoking and is funded by the Cancer Institute NSW. Quitline 13 QUIT operates seven days a week from Mon to Fri 7.00am–11.00pm, Sat, Sun and Public Holidays 9.00am–5.00pm. Ph 137 848.

Financial assistance

- **Bobby Goldsmith Foundation (BGF)** provides practical, financial and emotional support to people living with HIV. Ph (02) 9283 8666/ freecall 1800 651 011, email bgf@bgf.org.au or visit www.bgf.org.au
- **Centrelink** for more information on Newstart or other financial assistance. Ph 13 2850 or visit www.centrelink.gov.au and click on 'A–Z'.
- **Welfare Rights Centre** provides free advice and advocacy if you need help dealing with Centrelink. Ph (02) 9211 5300 or Freecall 1800 226 028; TTY 02 9211 0238 or visit www.welfarerights.org.au

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Participant names have been changed.

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