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Philip Botha

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Mission
 Oncology Buddies informs and inspires all those who have, or are affected by cancer. Oncology Buddies is committed to working with all stakeholders to find solutions aimed at improving the quality, lifestyle, satisfaction, enjoyment and activities of people affected by cancers.

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Philip Botha
 From preparing for death to living in wonder

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WELCOME

by Laurelle Williams

This issue is full of **Power People** who are doing superb advocating and awareness in their own right. Even though this issue highlights the strength and resilience of many, it also shows the sad reality of what cancer patients have to face with medical schemes, public healthcare systems, and life-saving drugs that cost a fortune, all the while trying to defeat mortality. It’s doesn’t seem fair.

The good news though is it seems immunotherapy, pembrolizumab in a particular, is saving many lives as we see in Philip Botha’s story *From preparing for death to living in wonder* as well as Raymond Pleaner’s story *Fighting the good fight*. But one cycle costs R82 000, with most patients needing more than one. Very few people can afford these costs. Raymond Pleaner shares, *“I’m not only advocating for myself but also for those who can’t afford it.”*

Treatment declined by René Botha gives us insight on why medical schemes decline treatment based on evidence-based guidelines, and advocates to take out further insurance, if you’re able to.

We learn more about *Clinical trials*, thanks to Teresa Smit and Debbie Peters while Heleen Feldmann, who has metastatic melanoma cancer, shares *The trial of my life*.

No matter how many articles Bonni Suckling’s writes, tears are shed reading every single one of them. Read *The unspoken long-term side effects of childhood brain cancer*.

Remember we are all advocates, share your knowledge and let’s talk about cancer. **✉**





Cancer Alliance v MEC for Health, Gauteng

While judgement is still underway, Khanyisa Mapipa helps us understand the case of *Cancer Alliance v MEC for Health, Gauteng, and 10 others*.

Section 27(1)(a) of the Constitution provides that everyone has the right to access healthcare services. This right is predicated on the condition that the government has resources available to provide the service.

The affirmation of the limitation on the right to access healthcare is almost as old as our Constitutional dispensation, with the right having been tested at the advent of our democracy in the *Soobramoney* case.

The Constitutional Court created then a precedent that still holds some thirty years later – where the state's resources are constrained, the right to access healthcare services can be

limited, no matter how grim the consequence. A limitation on the availability of a service based on the availability of resources is logical and constitutionally defensible, but what about a limitation of the right when resources aren't only available but earmarked and ring-fenced for the service?

A limitation of this nature must be constitutionally indefensible and yet, it remains a common occurrence in government health facilities with millions of rands returned to National Treasury each year due to underspending by provincial departments of health.

Cancer Alliance take MEC for Health to court

This is exactly what has happened in the case of *Cancer Alliance v MEC for Health, Gauteng and 10 others*. In July 2024, the Cancer Alliance, represented by SECTION27, filed legal proceedings against the MEC for Health and Gauteng Department of Health (GDoH), among others, for failure to provide radiation oncology services to approximately 3 000 patients. This failure persisted for a prolonged period with some patients waiting 18 months to three years for treatment that, in terms of their treatment protocol, they ought to have received within 12 weeks of their tumour resection surgery.

Cancer Alliance asked the court for an order: declaring the respondents' failure to provide radiation oncology services in the public sector unlawful and unconstitutional; directing the respondents' to update the backlog list of patients awaiting radiation; directing the respondents' to provide radiation oncology treatment in the public or the private sector; and interdicting the respondents' from paying, dispersing or otherwise dealing with the R250 million ring-fenced to provide these services.

Cancer Task Team

The facts stretch as far back as July 2020 when Cancer Alliance first brought to the attention of the then Gauteng MEC for Health, Nomathemba Mokgethi, the growing backlog of patients awaiting radiation oncology services. This plea, followed by a few others, were ignored by GDoH until they culminated in protest action in November 2021.

The protest forced government to give the issue attention. In March 2022, the MEC for Health established a Cancer Task Team consisting of members of civil society organisations Cancer Alliance and Treatment Action Campaign, alongside the head of hospital services within GDoH, the head of radiation oncology at each of the two public hospitals that provide radiation oncology in the province (Charlotte Maxeke Johannesburg Academic Hospital and Steve Biko Academic Hospital), and various clinicians working in the public sector.

The Cancer Task Team sat a total of eight times over a period of six months and accomplished nothing. The list of patients awaiting radiation oncology continued to grow, tenders for radiation oncology equipment continued to stall, and GDoH continued to bleed radiation oncology staff.

The absence of progress was not due to a lack of trying on the part of the civil organisations that sat on the task team. Throughout the life of the task team, Cancer Alliance offered several seemingly viable solutions to the problem which were aimed at keeping government funds within government.

Proposed solutions

The solutions included, triaging the patients and prioritising treatment for the sickest; this proposal was shot down by the government citing that due to the length of time patients have had to wait for treatment, everyone was equally the sickest patient.

Another proposal was to run the available radiation oncology machines overnight, offer overtime to staff, and

offer treatment right through the day. This proposal was also shot down and government cited that the type of patients who require services in the public sector rely on public transport and would therefore have to be housed in the hospital overnight and the hospitals simply didn't have enough beds. And so, it continued.

Eventually Cancer Alliance proposed that government outsource the services to the private sector but only for the backlogged patients. The logic was that the hospitals seemingly had enough capacity to deal with new patients and the decreased pressure would allow GDoH to make arrangements to improve equipment and staff numbers. This proposal was accepted by the department, however, they stated that they didn't have money to fund the venture.

A solution found but not achieved

This prompted Cancer Alliance and SECTION27 to reach out to the Gauteng Department of Treasury and following engagements, Provincial Treasury ring-fenced R784 million, to be disbursed in three tranches over three financial years. The first tranche of R250 million was paid over to GDoH in March 2023.

Following this allocation, Cancer Alliance and SECTION27 attempted to continue engagements with the department including providing suggestions on the most efficient and speedy way to deal with the backlog. Cancer Alliance and SECTION27 convened experts from the National Department of Health, National and Provincial Treasury to guide GDoH on how to make emergency procurements, similar to those we saw during the COVID-19 pandemic, without offending procurement principles.

The advice from these entities was ignored. Instead, GDoH opted for a long procurement process that culminated in them awarding a tender for radiation oncology planning services, without the accompanying treatment.

Commencement of litigation

The award of the tender prompted Cancer Alliance to launch the litigation process. As evidenced above, like any reasonable litigant, Cancer Alliance sought to resolve the dispute long

before the matter became litigious. It was left with no option but to approach the court for a resolution to the crisis.

In the court case, Cancer Alliance argued that GDoH had acted unlawfully in failing to provide radiation oncology services to those on the backlog list. In response, the department attested that it had equipment and staff constraints that made it difficult for it to meet its obligations but that it was in the process of hiring further staff and procuring equipment.

Further, Cancer Alliance argued that the decision to award a tender for planning services was unreasonable given that there was no certainty that patients, after receiving planning services, would be provided with treatment. In response, the department argued that it had the capacity to provide treatment internally – something it had failed to do for years – and that it was undergoing yet another tender process to procure privately sourced treatment services.

As the case progressed, it transpired through an affidavit that Cancer Alliance forced the department to file in response, that the department had, in fact, not spent a cent of the first tranche of funds allocated and as a result these funds had been returned to treasury.

It was also revealed that after a year since the tender for radiation oncology planning services was issued, less than 100 patients had received the service. The GDoH was at a grave risk of losing the second tranche of funds which amounted to R261 million. The matter concluded in December 2024 and the parties are awaiting judgment.


The deaths can't be justified

The right to access healthcare services within the government's available resources is a constitutionally protected right. However, as demonstrated by this case, ineptitude and a severe lethargy towards ensuring the realisation of this right is perhaps our biggest problem as a country. It's not possible to say how many people died while awaiting radiation oncology services even when funding for it was made specifically available. Their deaths can't be justified and their deprivation of access to healthcare is constitutionally indefensible. ¹



MEET THE EXPERT

Khanyisa Mapipa is an activist attorney and the Head of the Health Rights Programme at the law centre, SECTION27. Her current areas of expertise include sexual and reproductive health rights, oncology services, migrant health, and emergency medical services.



Treatment declined

René Botha underlines the reasons why medical aids may decline treatments and offers other insurance options to help cover this shortfall.

Following a cancer diagnosis, you often see several specialists within a short amount of time and then get presented with various treatment options. Often, more than one treatment modality will be required for the best chance of treating the disease, either sequentially or sometimes at the same time.

The treatments offered often include surgery, radiotherapy and systemic therapy (chemotherapy, targeted therapy, or immunotherapy).

After all these discussions if, for example, systemic therapy or radiotherapy is recommended, the oncologist's team applies to your medical aid for authorisation while you prepare for the upcoming treatment, but then...the medical aid replies: treatment declined.

Now what?

May you appeal this decision? Are all cancer treatments covered by medical aid? Unfortunately, the answer is no.

It's important for you to understand your specific medical aid cover so that you know what to reasonably

expect your medical aid to pay for. Medical aids have different options, the scheme you select as well as the plan option will determine the funds available under the oncology benefit and the terms and conditions that apply.

Evidence-based guidelines

Once you have been registered for oncology benefits, there are specific evidence-based guidelines that are followed to fund cancer care.

Most medical aids base their guidelines for funding criteria on the recommendations of professional bodies, such as the South African Oncology Consortium (SAOC) and Independent Clinical Oncology Network (ICON) as well as the Council for Medical Schemes (CMS).

The guidelines for funding criteria assess which treatments are clinically appropriate and then divide treatments into different levels or tiers. The first level, or tier, of treatment is the basic standard of care and is available to all patients. These treatments are usually covered in full and are often also referred to as prescribed minimum benefits (PMBs).

In terms of the Medical Schemes Act (131 of 1998), PMBs are a set of specified healthcare benefits that medical schemes should cover by law. This cover includes funding for the diagnostic tests like biopsies and imaging studies, treatment, and ongoing care for the listed conditions.

Not all cancer treatments fall under the PMB classification. Newer drugs, more advanced techniques, and novel treatments may be classified into higher tiers of treatment. While these treatments may be clinically reasonable, they may not be available to all patients.

These higher tiers of treatment aren't included under the PMB classification. This means that the medical aid schemes aren't obligated by law to approve them. Should these treatments be approved, a sublimit may be applied and the treatment may incur a co-payment which you'll be liable for. Depending on the terms and conditions of the scheme and the plan, some of these treatments may even be listed as exclusions. To manage costs, certain medical aid plans only approve PMB level treatments.



Make use of designated service providers

Certain schemes have appointed designated service providers (DSPs) who have contracted to specific rates. These schemes encourage their members to make use of these service providers to lower the costs of treatment.

According to the CMS, funders are legally not permitted to decline treatment at a non-DSP provider. However, the funder may apply a co-payment to the treatment. This would usually be covered in the terms and conditions that you have signed with your medical aid. You should discuss costs with your oncologist before starting treatment to plan ahead.

Reasons for denied treatment

Once a treatment plan is submitted, the first step in the authorisation process is to evaluate if the treatment is clinically appropriate. The next step is to apply the scheme rules regarding the funding criteria.

When you receive a message that authorisation for a specific treatment has been declined, the first step is to

determine the reason for decline. A treatment plan that doesn't match the guidelines may be referred to a medical advisor or external review committee to assess if the treatment is clinically appropriate. These committees include oncologists who assess whether the treatment is appropriate and then advise the scheme on this matter.

Should this review find the treatment to be clinically inappropriate, they may recommend that it be declined. Furthermore, this review may find the treatment to be clinically appropriate, but it may not match the funding criteria and then treatment may still be declined by the scheme itself.

Should the treatment plan be submitted with insufficient clinical details, the case manager may not be able to assess whether the treatment is clinically appropriate or not. In this case, providing the necessary information may be sufficient to support approval of the treatment.

Another reason for declined treatment is that it doesn't meet the funding criteria. This means that the selected plan option doesn't provide cover for this level of treatment. Even if the treatment is clinically appropriate, the treatment may still be declined if it falls into a higher tier. In these cases, an appeal may be made to fund the treatment despite these rules. However, this appeal may not be successful.

In certain cases, higher tier treatment may be approved, but with the condition that only a percentage of the treatment will be funded. The co-payments may be up to 50% of the cost and may add up to large amounts, so it's important to enquire about costs before treatment starts.

ADDITIONAL INSURANCE OPTIONS

Gap cover

Gap cover is an additional insurance that may be purchased in addition to medical aid. The purpose of this insurance is to provide additional financial cover for medical expenses that aren't fully covered by your medical aid.

It's important to be aware that having gap cover doesn't mean that all out-of-pocket expenses will automatically be covered. You need to ensure that you understand your gap cover policy well to know what costs are reasonable for the insurer to cover.

Many gap cover policies allocate a certain amount to oncology costs and may assist to cover some of the additional expenses from co-payments.

Dread disease cover

Dread disease cover is another additional insurance option. Dread disease cover pays out in the event of a dread disease diagnosis, such as cancer.

Different percentages of the insured amount may be paid out depending on the staging of the cancer and the effect on your physical abilities. This insurance is useful in many ways. If you're unable to work for some or all of the duration of your cancer treatment, this pay-out may assist to cover this loss of income. It may also be used to assist in paying for treatment that isn't covered by your medical aid.

When purchasing dread disease cover, read your policy documentation carefully so that you know what you can expect when you claim.

The love-hate of grudge purchases

Medical aid and insurance decisions are often made when you're well. They are the *in case grudge purchase* that you don't really want to pay for when you don't need it. Policy documents may be vague and may not always list exclusions. The finer details of the oncology benefits can't always be documented in full as guidelines change as new evidence becomes available.

Oncology treatments may be very costly and may quickly deplete the allocated benefits available. Understanding which treatments should still be covered in full under these circumstances may make a big financial difference.

Having open discussions with the oncologist regarding treatment plans and expected costs may help you prepare for any associated costs that may not be covered. It may also help to know about any unexpected co-payments to see if any of the amounts should be reprocessed under PMB cover. Also, be sure to check your claim statements regularly to ensure that claims have been paid under the correct benefit. ☒



MEET THE EXPERT

René Botha is a radiotherapist with a special interest in treatment planning. She works in private practice and is based at the Wits University Donald Gordon Medical Centre.

Fighting the good fight

Raymond Pleaner shares the dispute he had with his medical scheme to get immunotherapy treatment approved. Thankfully, the end result was in his favour.



Raymond Pleaner (70) lives in Sandton, Gauteng with his wife, Marcelle. They have three children and nine grandchildren.

In June 2024, Raymond was diagnosed with cancer which was on the cusp of his oesophagus and stomach. He had no symptoms, but it was thanks to the keen eye of his pulmonologist (Raymond has lung issues due to COVID) who noticed something was amiss.

"He noticed I didn't have the energy I normally have and asked how I'm feeling; I was tired. He sent me for an iron test and I have to thank him for thinking out the box. My iron was extremely low, and he booked me in to have a gastroscopy and an endoscopy. This is when the tumour was discovered," Raymond explains.

More scans were done before a consultation with an oncologist. Due to the location of the cancer, a gastrectomy (removal of the entire stomach) was proposed. His intestines would be attached to the remaining part of the oesophagus. However, chemotherapy would be needed first and thereafter.

Declined treatment

The oncologist proposed chemotherapy and a new immunotherapy (pembrolizumab). "Since this was a newer treatment regimen, my medical aid took over a month and half to make a decision. It was sent for review; we got told that the society who reviews it has agreed and 50% of the immunotherapy will be covered and the shortfall will be on us. A week later, it was back under review and then we were told that the medical scheme had declined the three cycles of immunotherapy," Raymond explains. "This made the whole process even more stressful; my medical scheme was making decisions about my life."

Fortunately, Raymond could afford the three cycles of pembrolizumab (which are R82 000 each) and he began

treatment in August 2024, along with chemotherapy which the medical aid approved.

Even though Raymond experienced side effects (fatigue, change in taste, neuropathy), he made a point of getting up every day. Though he notes how his social life dwindled completely.

"We are social people, going out a few nights a week but I was too fatigued. My wife had to go out by herself on many occasions, and we are so used to doing everything together."

Since Raymond was retired, they also had plans of travel but all that was put on hold.

Gastrectomy

Before having surgery, it was noted that there was a significant reduction in the tumour. In November 2024, Raymond underwent a gastrectomy; 17 lymph nodes were also removed as well as a small section of the oesophagus.

"Everything was sent for histology and only one node had a smidge of cancer in. The surgeon said this was unprecedented and would have never happened if I didn't have pembrolizumab," Raymond says.

Due to his stomach been removed, Raymond doesn't produce stomach acid which affects the absorption of the food he eats. After surgery, he had a feeding tube and could only suck ice. Then he slowly moved to clear liquids then soft foods. Since he can only eat small amounts at a time now, he eats six times a day. He also has to have a vitamin B12 injection monthly and avoids fatty foods as well as popcorn and seeds. Another side effect is he now has bile reflux which makes him nauseous. Unfortunately, there is no medication for this. He still consults with a dietitian.

In total, Raymond has lost roughly 17kg since starting treatment and is very self-conscious of his weight, even asking his wife to take the mirrors out the bathroom.

Discussion with medical scheme

Once Raymond recovered from surgery, he had a further two cycles of pembrolizumab in January 2025. The oncologist applied to the medical aid and it was approved and then declined a few days later.

This confusion and added stress were the final straw and Raymond along with his financial broker demanded a meeting with his medical scheme. He goes on to say, "What happens to the person who can't afford paying for it, are they left to die? Why are medical aids playing God?"

In the meeting, it was explained that Raymond couldn't have any more chemotherapy and needed to continue with pembrolizumab as it was effective.

The meeting resulted in the medical scheme paying for one of the cycles Raymond had in January as an apology for the computer glitch that said his treatment was approved, and they agreed to cover 75% of a further six cycles. Raymond is currently undergoing these treatments.

"I'm not only advocating for myself but also for those who can't afford it. Before we walked out, one of the representatives asked if she could hug me."

Looking forward with gratitude

Raymond and his wife are grateful for all the support they received from their children, friends, and family and are looking forward to picking up their social life. "I've got a whole new digestive system and I need to give it a chance to recover," Raymond says. Though, he is happy that he can now eat a small chop when he goes out for dinner. ☺

MEET OUR EDITOR



Laurelle Williams is the editor at Word for Word Media. She graduated from AFDA with a Bachelor of Arts Honours Degree in Live Performance. She has a love for storytelling and sharing emotions through the power of words. Write to editor@buddiesforlife.co.za

The pitfalls of bed rest

Megan McLoskey unpacks how prolonged periods of bed rest causes muscle mass loss and offers guidance to achieve a smoother recovery.

During a cancer journey, you may spend prolonged periods of bed rest at home or in a hospital, either while undergoing medical procedures, recovering from illness, or awaiting various forms of treatment.

Prolonged periods of lying in bed can lead to a substantial loss of skeletal muscle mass due to inactivity, a condition known as muscle atrophy. Muscle loss and decreased strength can begin within just a few days of lying in a bed. Additionally, bed rest results in significant changes in skeletal muscle metabolism associated with a reduced resting metabolic rate, impaired glucose tolerance, increased fat storage, and potential hormonal imbalances.

Bed rest is not only linked to muscle atrophy but can also lead to other complications, including blood clots, constipation, pressure sores, depression, weakened bones, and stiff joints.

Ways to reduce muscle mass loss

To minimise the effects of prolonged bed rest and muscle mass loss, a multi-disciplinary team approach to treatment is recommended. This typically includes a physiotherapist, biokineticist, occupational therapist, dietitian, doctor, and nurse.

Research has shown that a personalised early rehabilitation programme significantly enhances functional capacity and muscle strength outcomes in individuals.

A COMPREHENSIVE TREATMENT PROGRAMME SHOULD INCLUDE:

Preventative measures

Pressure sore prevention (through frequent rolling and turning in bed), deep vein thrombosis prevention, and contracture prevention (passive/active joint range of motion) are essential to maintain overall health and prevent further complications.

Breathing exercises

Although breathing exercises alone can't completely prevent muscle atrophy during bed rest, they are essential for maintaining lung function. Proper breathing helps ensure adequate oxygen delivery to

If you have been prescribed bed rest by your healthcare team, it's essential that you stay in bed and rest. There are various measures that can be taken to assist your recovery process and not lose muscle mass.

the body, which can indirectly support muscle health and function during periods of limited movement. This is particularly important for reducing the risk of complications, such as pneumonia caused by shallow breathing during extended inactivity.

Bed exercises

To prevent muscle atrophy during bed rest, you should engage in gentle exercises, such as leg lifts, ankle rotations, arm raises, and isometric muscle contractions. These activities target various muscle groups while you remain in bed, helping to preserve muscle strength and function despite limited mobility. A physiotherapist plays a crucial role in this part of your treatment journey.

Nourishing your body


A dietitian plays a crucial role in the medical management team by providing guidance on the appropriate diet and supplements to help reduce muscle atrophy and enhance muscle mass. Dietary adjustments may involve the intake of protein or essential amino acids, which can acutely stimulate muscle protein synthesis in a dose-dependent manner. Therefore, increasing the overall protein or amino acid content of your diet has been suggested as a strategy to mitigate muscle loss during periods of inactivity.

Functional engagement

The length of time spent on bed rest is directly related to the extent of functional decline in various activities. This includes activities of daily living, such as washing, dressing, grooming, mobilising, transfers, and community skills like cooking, cleaning, and driving; and participation in social activities.

Prolonged bed rest can significantly impact independence and overall quality of life. Therefore, a key aspect of early rehabilitation includes occupational therapy through gentle functional engagement in the above-mentioned skills. This approach not only helps improve muscle strength but also preserves independence and enhances functional outcomes after discharge.

Prep for a smoother recovery

Prolonged bed rest, whether due to illness, recovery, or treatment, can significantly impact muscle strength, functional abilities, and overall quality of life. A multi-disciplinary approach that includes early rehabilitation, personalised exercise programmes, proper nutrition, and breathing exercises is essential to minimise the adverse effects of inactivity. By addressing the physical, functional, and emotional challenges associated with extended bed rest, you can achieve a smoother recovery and an improved quality of life. 

MEET THE EXPERT



Megan McLoskey is an occupational therapist with a specialist interest in lymphoedema management and cancer rehabilitation. She is currently working in private practice in Bedfordview and at Life Fourways Hospital. She is qualified in Lymphoedema Assessment and Treatment.



From preparing for death to living in wonder

Philip Botha was preparing for death until his medical aid approved a new immunotherapy drug to treat his bladder cancer. He shares his phenomenal story with us.

Philip Botha (60) lives in Randburg, Gauteng with his wife. They have two adult children and three grandchildren.

In May 2023, when Philip first encountered signs of bladder cancer: blood in urine, frequent and burning urination, and loss of appetite, he was on a holiday in Zanzibar, and spent five days in the hotel room while the rest of his family were on the beach.

Once Philip was back home, he stalled in making an appointment with his GP. "You don't really want to face the truth," he says.

Once at the GP, a protein urine test was done, and Philip was referred to a urologist, with his GP telling him to not take this lightly. A scan was ordered which identified a tumour in the bladder and Philip was then booked in hospital for a biopsy and scope.

"I was expecting it to be cancer from what the GP said, and family members have passed away from cancer, my mom – leukaemia, my dad – stomach, and my sister – lung," Philip says. "My whole life I always thought I would get cancer."

The proposed treatment was to surgically remove the whole bladder, leaving Philip living with a urostomy pouch for the rest of his life. Philip wasn't happy with this course of treatment and took time to go for a second opinion. "I didn't want to live with a bag for the rest of my life. I needed to look at all of my options," Philip explains.



Change of treatment

After seeing an oncologist, Philip was told that the cancer is serious, but he doesn't have to have surgery and that her aim with chemotherapy was full recovery. She also referred him to a new urologist who became part of his cancer care team. "I would rather have five good quality years of living than living with a urostomy bag forever," Philip adds.

In October 2023, chemotherapy commenced. The side effects were fatigue and nausea. "I'm a carpenter and have my own business so work couldn't stop," Philip explains.

Unsuccessful treatment

In May 2024, once chemotherapy was completed, Philip went for an MRI scan and unfortunately chemotherapy didn't work; the tumour had grown in size and had spread to lymph nodes. One ureter from his kidney to bladder was completely blocked by the tumour so that kidney wasn't functional. At this time, Philip only had 30ml space left in his bladder which meant he constantly went to the bathroom. "I noted how many times I went; 38 times a day," Philip says.

"I saw the urologist and I asked him to not sugar-coat the news; he told me that I have three to six months to live. My wife was in tears and I didn't know what to do," Philip says. "Another patient overheard this and asked if he could pray with us, which he did. His name was Len which was my father's name. To me this was reassurance from God."

Preparing for death

Philip was referred to a palliative care doctor. By this time, he was in excruciating pain as he couldn't urinate due to blood clots in his urethra. "The palliative doctor rushed me to hospital and a catheter was inserted which relieved the pain. I was in hospital for four days; my family and friends came and said goodbye. My minister was even there, and I asked him to bury me, which he agreed to"

Philip went into palliative care at home, spending four to five hours in bed a day. He looked at options of where he would die. He wanted to die at home but then reconsidered as it would be too traumatic for his family. He found a tranquil hospice where he was comfortable to die at and that his

medical aid would pay for. He asked the urologist to explain how he was going to die, and it was explained it would be from kidney failure. The palliative care team reassured him that they would be by his side and make it painless.

Surprise immunotherapy approval

Philip went to see the palliative care doctor and to his surprise she told him that his medical aid had approved pembrolizumab, an immunotherapy drug.

Philip knew about pembrolizumab as his friend in the USA who had lung cancer had told him about it. Though, when hearing the price (R82 000 per one treatment) and that the chance of his medical aid covering it was slim, Philip knew he wouldn't even be able to cover the co-payments, if the medical aid covered 50%. The nest-egg money he had, he wanted to keep, ensuring his wife could survive when he passed away. So, he chose the chemotherapy route.

"I was so confused when I heard it was approved. I went back to the oncologist and asked her if it was true and she said yes, the medical aid was willing to pay 100% of six treatments. It turns out that the oncologist's assistant motivated my need for pembrolizumab once chemotherapy was unsuccessful and sent it off to the medical aid."

Within that week, May 2024, Philip had his first IV pembrolizumab treatment. Thereafter the remaining five were every third week. An MRI was done after the six sessions and the tumour had shrunk by 75%.

A new motivation was sent in and another six cycles were approved by the medical aid, which started in October 2024. When an MRI was done in January 2025, there was no sign of the tumour.

Third time's a charm

Philip had the catheter removed in February 2025 (which he says is like heaven) and is urinating normally. "I saw an improvement in the colour of my urine after week three on the new drug." He adds that he is feeling on top of the world and is in full recovery.

Philip is waiting to find out if maintenance therapy is needed and the next steps. His concern is that if more pembrolizumab is needed that his medical aid will not continue paying for it.

Philip says after this ordeal, he has seen the hand of God clearly through friends and strangers, as on two occasions payment for pembrolizumab were offered. "Four school friends of mine put R2 million together when they heard I couldn't afford pembrolizumab. However, I couldn't accept it. Then my wife's client, who doesn't even know me, also offered to pay for treatment but I wasn't comfortable with that either," Philip explains.

Third time's a charm, Philip could accept that his medical aid would pay for treatment. He bought the oncologist's assistant a gift, hugged her, and thanked her for saving his life.

"Throughout this my perception of God has changed. He feels so near and it's such a peaceful place to be in with Him." ☒

Photos by Mandy Steenkamp Photography | Follow @mandysteenkampphotography

MEET OUR EDITOR ↑



Laurelle Williams is the editor at Word for Word Media. She graduated from AFDA with a Bachelor of Arts Honours Degree in Live Performance. She has a love for storytelling and sharing emotions through the power of words. Write to editor@buddiesforlife.co.za

How is bladder cancer diagnosed?

Dr Daleen Geldenhuys lists the various diagnostic tests that may be done to diagnose bladder cancer.

The diagnosis of any cancer starts with acting on abnormal symptoms and reporting those to your general practitioner.

Bladder cancer symptoms

Haematuria (blood in urine), even if only at the end of urination should be investigated. Occasionally only staining of the undergarment may be the only blood seen. Bladder infections, bacterial or even bilharzia infections, can also present with bleeding but in general, that should also be reported to the primary care physician.

Bladder and pelvic pain or discomfort and being aware of your bladder all the time is suspicious. Pain may radiate to the flanks and not be central. Suprapubic pain (pain in the lower abdomen, above the pubic bone and below the belly button) may be a sign of local extension of the tumour. Invasion of the complex nerve system around the bladder neck may cause incontinence but may also cause urinary retention (unable to pass urine despite a large volume of urine in the bladder).

Voiding symptoms, the feeling of not being able to empty your bladder, with residual urine only emptying if you change position, indicates a non-compliant, non-contractile organ. Irritative voiding, such as urge incontinence appear in about a third of patients.

Bladder cancer may involve other organs, such as the prostate and the rectum that lies directly behind it in men or the cervix and vagina in women. Pain or difficulty passing stool, may also be a sign. Often the blood in the urine disappears for a week or so and may make you think that all is well. Don't ignore it.

Symptoms such as fatigue, weight loss, and no appetite are usually signs of advanced or metastatic disease and denotes a poor prognosis. In rare cases, patients may have constitutional symptoms due to kidney failure caused by bilateral ureteral obstruction.

Causes of bladder cancer

This includes a number of different causes. Chemical exposure, such as smoking, the main cause, including secondary smoke, opium users, and occupational exposure to pathogens.

At risk occupations are metal workers, painters, rubber industry workers, leather workers, textile and electrical workers, miners, cement workers, transport operators, excavating-machine operators, and jobs that involve manufacture of carpets, paints, plastics, and industrial chemicals that include benzene, polyaromatic hydrocarbons, and diesel exhausts.

Diagnostic evaluation

Bedside evaluation with a urine dipstick as well as observation of macroscopic blood seen in the urine sample. This should be sent for microscopy, culture, and even cytology if the clinician suspects a non-benign diagnosis.

Cystoscopy (a procedure to examine the inside of the bladder and urethra) is the initial procedure for both the diagnosis and management of urothelial malignancy. Cystoscopy is used to establish the diagnosis, assess whether or not muscle invasion is present, and provide initial therapy for non-muscle invasive lesions.

Urine cytology (test that examines urine samples for abnormal cells) is widely used in combination with cystoscopy to assess for the presence of carcinoma in situ and to evaluate for the presence of upper urinary tract lesions.

Tissue biopsy of the lesions in the bladder or if more advanced, lymph nodes or other organs involved. This allows better characterisation of the tumour and also specifies whether the tumour is transitional carcinoma, squamous carcinoma, or infiltrative from direct extension from e.g. colonic or prostatic origin.

CT scan is the preferred imaging procedure to assess the local extent of disease and to further examine the renal pelvis and ureters.

MRI scan of the pelvis will assist to see if the tumour is localised or invasive into the bladder muscle.

FDG PET-CT scan is only useful for metastatic workup as the bladder fills with the tracer very quickly and will mask disease in the bladder.

Remember, diagnosis depends on early detection of this cancer. As there are no screening programmes, even for patients at risk, the key factor in making the diagnosis is prompt reporting from the patient and high level of suspicion from the general practitioner. ☒



MEET THE EXPERT



Dr Daleen Geldenhuys is a specialist physician and medical oncologist who works at West Rand Oncology Centre at Flora Clinic and the ICON Unit at Johannesburg Surgical Hospital. She treats patients with all types of cancer and enjoys clinical research, and is a member of SASMO, SASTECS, ESMO and ENETS.

Image by freepik.com

The role of a haematology case manager

Jacki Van Niekerk details what a haematology case manager does and their role in the haematology cancer journey.

Before we look at the role of a haematology case manager, let's differentiate between the two different types of case managers.

Clinical case manager: These are typically trained/registered nurses or medical officers. In our haematology clinic, we employ a medical officer who assists the doctors in managing and co-ordinating patient care, guiding them through their treatment journey. This specialised role is essential for improving the quality of life of patients, streamlining care processes, and ensuring the most effective use of healthcare resources.

Non-clinical case manager/medical aid liaison officer: A breed of elite professionals who advocate for patients by ensuring they receive the best evidence-based medication from funders (who often resist covering certain chemotherapies) as prescribed by the haematologists. They also assist with chronic application forms, pharmacy co-payments/payments (for private-paying patients), and hospital queries when required.

Additionally, they work closely with pharmaceutical representatives from various companies that manufacture haematology treatments and products.

Who does a haematology case manager work for?

A haematology case manager typically works either for a medical practice or a medical aid/insurance company, depending on the setting.

In a medical practice: The case manager is often employed directly by the healthcare provider or specialist clinic. In this setting, they work closely with haematologists, nurses, and other members of the healthcare team to co-ordinate patient care within the practice.

The goal is to ensure that patients with blood disorders (anaemia, leukaemia, lymphoma, sickle cell disease, and other haematological conditions) receive optimal care, manage costs effectively, and navigate complex treatment protocols.

AREA OF EXPERTISE

Haematology case managers require a strong background in both haematology and case management. Areas of expertise include:

Understanding complex haematological conditions

A deep understanding of blood-related diseases, including rare conditions like myelodysplastic syndromes, haemophilia, leukopenia, and various types of cancers affecting blood and bone marrow (leukaemia and lymphoma).

Treatment protocols

Ongoing understanding of evolving treatment regimens, including chemotherapy, blood transfusions, stem cell therapies, immunotherapy, and other advanced treatments.

Navigating insurance and medical aid systems

Proficiency in navigating complex healthcare policies to ensure that patients receive covered treatments and services, thus reducing out-of-pocket expenses.

Liaising with patients

Haematology case managers serve as a bridge between the patient, healthcare providers, and the medical system. Our role is to ease the patient's journey by offering both emotional and practical support.

Personalised care co-ordination

One of the primary responsibilities is to ensure that the medical aid approval process is completed within a three- to five-day turnaround time and that urgent treatment requests are handled within 48 hours.

Patient education and emotional support

Blood disorders can be complex, and patients may feel overwhelmed by their diagnosis and treatment. We have a psycho-social therapist who addresses the emotional well-being of newly diagnosed patients, as well as any patient or family member requiring emotional support during this difficult journey. Our medical officer or doctors also educate patients about treatment plans and side effects.



Liaison between healthcare providers

In the treatment of complex blood disorders, patients often see multiple specialists. Haematology case managers act as the liaison between these healthcare providers, ensuring that everyone involved in the patient's care is aligned. In our practice, we co-ordinate communication between our haematologists, pharmacists, and hospital staff.

Financial and logistical support


For patients with medical aid or insurance, haematology case managers work to ensure that treatments are covered under their plan, managing any claims, authorisations, or disputes with medical aid schemes. We also assist patients in navigating the financial aspects of their care, offering guidance on accessing support or funding.

Patient journey

The patient journey for individuals with haematological disorders is often long and complex. A haematology case manager is there to guide the patient through each stage, providing essential support throughout their treatment. Our medical officer and doctors cover the following stages:

- Diagnosis and initial care
- Treatment and monitoring
- Recovery and long-term management
- End-of-life care

A crucial member of the team

A haematology case manager is a crucial member of the healthcare team for patients dealing with blood disorders. Whether working within a medical practice or alongside medical aid schemes, haematology case managers play an indispensable role in improving patient outcomes and enhancing the overall healthcare experience. 

MEET THE EXPERT



Jacki Van Niekerk's medical career started when she joined a medical aid administration company in 1998. She joined Constantiaberg Haematology in November 2010 as a medical receptionist. Fifteen years later, she is the haematology case manager at the same practice.

Image by freepik.com

New hope in PARP inhibitors

Dr Trudy Smith shares how advancements in genetics and targeted therapies, such as PARP inhibitors, are reshaping the landscape of ovarian cancer.



Ovarian cancer is one of the most challenging malignancies to diagnose and treat, due in part to the lack of early symptoms and effective screening methods. By the time many women are diagnosed, the disease has often progressed to an advanced stage, which reduces the likelihood of successful treatment.

However, with advancements in genetics and targeted therapies, there is increasing hope for patients, especially those with BRCA1/2 mutations or homologous recombination deficiency (HRD). These breakthroughs are reshaping the landscape of ovarian cancer diagnostics, treatment, and maintenance therapies.

Diagnostic approaches: The role of BRCA and HRD

Early detection remains a major obstacle, primarily because it's often asymptomatic until it has reached an advanced stage. Traditional diagnostic techniques like imaging (ultrasound, CT scans) and blood tests (CA-125 marker) often fall short in identifying the disease early.

However, there is growing recognition of the importance of genetic testing in diagnosing and managing ovarian cancer. Two key genetic factors have gained attention in ovarian cancer diagnosis and treatment: BRCA1/2 mutations and HRD.

BRCA1/2 mutations

BRCA1 and BRCA2 are tumour suppressor genes that help repair damaged DNA. Mutations in these genes, particularly BRCA1/2, significantly increase the risk of ovarian and breast cancers. Women with these mutations have a lifetime risk of developing ovarian cancer that is much higher than the general population, with estimates suggesting a risk of 15–40% for BRCA1 mutations and 10–20% for BRCA2 mutations.

Testing for BRCA1/2 mutations is now a routine part of the diagnostic process. If a woman tests positive for a BRCA1/2 mutation, she can be offered targeted

therapies, including poly ADP-ribose polymerase (PARP) inhibitors, which are designed to exploit the DNA repair weaknesses in cancer cells caused by these mutations.

Homologous recombination deficiency (HRD)

In addition to BRCA mutations, HRD refers to a broader category of genetic defects that impair the DNA repair mechanism in cancer cells. HRD encompasses not just BRCA mutations but also other genetic alterations that affect the homologous recombination repair pathway. Testing for HRD is becoming increasingly important in ovarian cancer, as it helps identify patients who may benefit from specific therapies like PARP inhibitors.

HRD testing can be done through a variety of methods, including gene expression profiling and mutational analysis, providing valuable insight into the molecular landscape of the tumour. This information is crucial for tailoring treatment strategies and predicting the likelihood of a good therapeutic response.

Challenges of late diagnosis and relapse

Despite advances in genetic testing, ovarian cancer remains difficult to diagnose early. Most women are diagnosed only after the cancer has spread to other parts of the abdomen, leading to more complex and less favourable outcomes.

The symptoms, such as bloating, abdominal pain, and changes in bowel habits, are often vague and can be mistaken for other less serious conditions. As a result, a significant percentage of women are diagnosed at later stages, where the cancer has already spread beyond the ovaries, complicating treatment options.

Even when diagnosed and treated early, ovarian cancer has a high relapse rate. Studies show that approximately 70% of patients with advanced-stage ovarian cancer will experience a recurrence within five years. The recurrence is often more difficult to treat, as the cancer may develop resistance to initial chemotherapy treatments, and the disease can become more aggressive.

PARP inhibitors in maintenance treatment

One of the most promising advancements is the use of PARP inhibitors, particularly for patients with BRCA1/2 mutations or HRD. PARP inhibitors work by blocking the PARP enzyme, which helps repair single-strand breaks in DNA. In cancer cells with BRCA mutations or HRD, DNA repair mechanisms are already compromised, and inhibiting PARP leads to the accumulation of DNA damage, ultimately causing cancer cell death.

PARP inhibitors are used as maintenance therapy following initial treatment to prolong progression-free survival (PFS). Maintenance treatment refers to the use of a drug to prevent the cancer from returning after initial chemotherapy or surgery. For patients with BRCA mutations or HRD, PARP inhibitors can significantly delay relapse and improve overall survival.

The advent of PARP inhibitors has transformed the management of ovarian cancer, offering patients with specific genetic profiles the opportunity for longer remission periods and a better quality of life.

As research continues, the use of PARP inhibitors is expanding, with ongoing studies exploring their role in combination with other therapies and their potential to treat other cancers with similar genetic defects.^[8]

MEET THE EXPERT



Dr Trudy Smith is a gynaecology oncologist at Wits Donald Gordon Medical Centre and a senior lecturer at the University of Witwatersrand. She has a keen interest in teaching postgraduates and undergraduates.

Finding strength in community

Jacqui O'Sullivan shares a glimpse of her ongoing battle with ovarian cancer and how her community is pulling her through.

Jacqui O'Sullivan lives in Johannesburg, Gauteng with her husband and two sons.

The past five months have been a whirlwind; an unexpected, life-altering journey that I never saw coming. It began with subtle yet persistent symptoms: weight gain, bloating, and pain in my left groin that lingered for 18 months. Like many women, I chalked it up to perimenopause. The pain worsened, and despite two visits to a gynaecologist, I was reassured that everything seemed fine.

But my GP refused to accept that. He pushed for a sonar scan, which confirmed his suspicions. A CT scan and series of tests followed. Then came the early call. No doctor ever calls at 06:45 with good news. My CA-125 marker, which should have been around 35, was a staggering 4368. Ovarian cancer was confirmed.

What followed was a flurry of tests, scans, and preparations for major surgery. In October 2024, I underwent a radical hysterectomy, omentectomy (removal of the fatty layer of tissue that surrounds the abdominal organs), and lymphadenectomy, removing 26 lymph nodes.

Stage 3 advanced ovarian cancer was a terrifying diagnosis, yet there was relief that it hadn't spread further. Five weeks later, a chemo port was inserted.

The power of advocacy and community

If there's one lesson I've learned, it's the importance of having a doctor who will fight for you. I firmly believe that my GP's insistence for further testing saved my life. Ovarian cancer is known as the silent killer because symptoms often appear too late. The GP's advocacy meant that I caught this at Stage 3 instead of Stage 4, and for that, I'll always be enormously grateful.

Beyond medical intervention, what has truly carried me through are my people. My incredible family, rock-solid friends, and unwavering support system. They have held my hand, made me laugh when I needed it most, and quite literally put food on the table when I didn't have the energy to cook.

Two friends helped me choose a wig in advance of the inevitable hair loss.

My friends, current and former colleagues showed up with meals, flowers, and care packages filled with chemo-friendly goodies and consistent messages of support and love. These acts remind me that I'm never alone in this fight, even on the bleaker days.

The unexpected camaraderie in the chemo room

I've come to appreciate the unique environment of the chemo room. It's a space where backgrounds, careers, and social statuses fade into insignificance. No one cares what you do for a living, only how you're feeling and what you're fighting. Some days, the room is quiet, filled with resting patients. Other days, it's lively, filled with shared jokes and mutual encouragement.

The nurses are nothing short of angels, greeting each patient by name and creating a sense of familiarity in a deeply unfamiliar situation. There's an unspoken camaraderie, moments of disappointment when someone's bloodwork isn't strong enough for treatment, and moments of celebration when another reaches a milestone.

A battle against the body

People often ask, "Are you feeling better?" The truth is, no. With each session, the fatigue deepens, the side effects intensify, and my body weakens. I've gone from someone who juggled countless daily tasks to someone who considers a short grocery run an achievement.

The swelling, nausea, headaches, mouth sores, and sleepless nights from cortisone have all become part of my new reality. But oddly enough, knowing these symptoms are normal is comforting, as it means treatment is working.

The need to move my body, despite feeling poorly is a struggle. To boost circulation and lymphatic system I use my trusty rebounder. Even just a few minutes make a huge difference.

Gratitude amidst the struggle

I've always loved my work; however, cancer feels like my full-time job, one I never applied for but must see through.

As I get closer to completing chemotherapy, I think more about the risk of recurrence, but I know I have a team of experts who have my back no matter what happens.

Through the exhaustion, pain, and uncertainty, I remain deeply grateful. Grateful for the unwavering support of my husband, whose dark humour keeps me smiling. Grateful for my employer that has given me the gift of time with a medical sabbatical to focus on healing. Grateful for my friends, who check in, who lift me up, who simply sit with me when I need company. Grateful for my community, who remind me every day that I'm not alone in this fight.

Life isn't always a highlight reel; it's filled with challenges, detours, and moments of deep struggle. But if there's one thing I've learned, it's that community is everything. When you surround yourself with the right people, those who lift you up with no expectation of reciprocity or gain, you can weather even the darkest storms. ☒



The trial of my life

Heleen Feldmann shares her current experience of being on a drug trial for advanced melanoma cancer.



Heleen Feldmann (44) lives in Johannesburg, Gauteng with her husband and three adult children.

As a child, I always thought people in their forties were so old then I reached my forties. Little did I know my current age would be a life-saver.

Melanoma diagnosis

In 2024, I discovered a mole on my back as my gym clothes would scratch it. By October, it was just a bother, and I made an appointment at a dermatologist. Keeping in mind I don't have many moles on my body. After so many follow-up calls, I forced the dermatologist to tell me on the phone; it was malignant.

By November I was booked for surgery to remove it. The surgeon did a scan before the operation; it had moved to my lymph node under my arm. A surgery that was meant to be a mole extraction turned into five operation cuts and extractions. All the extractions were sent away and came back positive. At this time, it was Stage 3 melanoma cancer.

Lung surgery

I met with a medical oncologist who ordered a PET scan; the melanoma spread to my right lung. In December, a cardiothoracic surgeon removed the cancer from my lung. It was now Stage 4 metastatic melanoma cancer.

I got this mode

I was shocked but went into *I-got-this* mode, telling close family and friends and making plans to pay for treatment as my entry level medical plan wasn't going to suffice. It barely covered the operations that followed in such quick succession.

Clinical drug trial

The medical oncologist saved the day again and set up an appointment with another oncologist who was involved in a drug trial. This was a lifeline and I was approved onto the trial. For the first time, my age was a benefit – being 44 (deemed young now) with no underlying or other medical conditions, it was a green light.

This trial is at no cost to me as it covers all treatment and scans. It was explained that it's a Phase 3 blind trial – there is a chance that I would receive either a new drug or another drug that is already approved in SA. All this means is that I'm getting immunotherapy. These treatments are once every 21 days, the base is it boosts my own immune system to fight the cancer in my body. Thus far I've had two treatments and the side effects are most confusing. Everyone tells you immunotherapy side effects are minimum; I beg to differ.

Between the constant headaches, muscle pain, and nausea, there is just enough energy left to balance your personal and work life and will to get out of bed. Plus, small little bumps that appear all over your skin, yet these are all bearable.

The pros and cons

This trial lasts for a year and then five years of follow-up appointments. The part that makes me uneasy is that I can't take any additional supplements or medications as it will interfere with the result of the drug. This concerns me as there are many supplements and medications that people use to assist in recovery or recurrence that could hamper the qualification to the trial. The moment you aren't adhering, you're off the trial. I was warned about this when I took antibiotics for an infection on a surgery wound that wouldn't heal.

Also, if cancer is found anywhere in your body again, you're immediately off the trial. No questions asked. With not too much certainty of what can be done after that.

Trials allows medication that is unaffordable or not always available to give me a second chance. However, the cancer isn't mine, it belongs to the pharmaceutical company that is paying for me to be on the trial.

A rocky road

Sure, it's a journey as it's constantly referred to, but for me it's a rocky road coming down Mount Everest and all I can do is hold on and not lose my mind. This is month four and I'm sure there will be more ups and downs. Still just taking it day by day.

Cancer isn't about the disease to me. It's about the change and impact it's having on me as a person. I will fight to beat the disease, but I'll never be the same person after this. ☒

Visit [oncologybuddies.com](https://www.oncologybuddies.com) to read more of Heleen's journaling of going through melanoma treatment.

Clinical trials

Teresa Smit and Debbie Peters inform us of what clinical trials not only offer patients but healthcare staff too.



Clinical trials are a unique opportunity to get state-of-the-art treatment for free. They give patients access to new products and give healthcare staff valuable experience with these products.

A clinical trial is not experimental in the sense that we do not know what to expect. Clinical trials available at oncology sites are mostly phase 2 and 3 studies, meaning by this time the pharmaceutical company knows the drug is safe and effective.

As cancer patients are a vulnerable population, placebos (fake medical treatment that looks and is given like real treatment but has no therapeutic benefit) alone can't be used in cancer trials. Patients should either receive the current standard of care or the new investigational product. Placebos can be used in combination with one of the above.

How to get onto a clinical trial?

It's quite tricky to get onto a clinical trial. There are usually 20 to 40 inclusion and exclusion criteria to comply with to be eligible. Some are straightforward (to be older than 18 years) and others are more complicated (like liver function or the biological type of the tumour). There is usually nothing the patient can do to increase his/her chances of being eligible for a trial.

A patient can't be forced to take part in a trial and should be given time to think it over and discuss it with family and friends. They should also be allowed enough time to ask questions. Before any procedures on the trial can start, an

Informed Consent Form should be signed by the patient.

This document gives all the information of the trial to the patient regarding treatment, timelines, adverse events, etc. It also shows the patient willingly agreed to be part of the trial.

Patients are allowed to withdraw from the trial at any time. Even after treatment has started. Signing the informed consent doesn't bind them to complete the treatment. However, once a patient decides to take part in a clinical trial, it's essential to be compliant with the treatment, tests, and questionnaires (if applicable). Patients can be removed from a trial if they are not compliant.

Screening period

Studies usually allow a 28-day screening period to show eligibility. During this time, baseline tests are done like vitals, height, weight, ECG, blood tests, CT-scans, MRI, bone scans, and confirmation of tumour biology (among others).

If one or more of the inclusion/exclusion criteria doesn't comply, it means that the patient will not be able to take part in the trial. If all criteria are eligible, the patient can be randomised to the trial.

Patients are often concerned with the 28-day screening period, as being diagnosed with cancer is distressing and patients want to commence treatment as soon as possible. Trial patients are very carefully selected, and if the benefit of treatment doesn't exceed the risk of waiting, they would

not be considered for a trial.


The patient's medical history and chronic medication are all taken into consideration during the screening period. Usually, the patients should carry on with their chronic medication as prescribed, as long as the trial team is informed of them. If there are drugs that are contra-indicated (very seldom), replacements would be considered together with the patient's treating specialist for that condition.

It's very important to not experiment with traditional remedies, over-the-counter supplements, and other wonder drugs while on a clinical trial (a multivitamin is acceptable). Many supplements (like green tea) impact the metabolism of medication in your body. This can make the trial medication less effective or more toxic.

Who covers the cost?

The sponsor company of the clinical trial pays for all the activities requested for the trial (consultations, treatment, blood tests, scans, and a travel allowance).

Over-the-counter medication (like scripts for nausea, pain, etc) isn't paid for by the sponsor company.

Oncology sites have to be registered and selected to be allocated clinical trials. 

Available trials can be found at clinicaltrials.gov

MEET THE EXPERT



Teresa Smit is the research manager at The Medical Oncology Centre of Rosebank. She trained in oncology pharmacy and completed her master's degree in 2019 (MPharm). She is involved in the Research Unit with investigator-initiated studies, as well as overseeing the sponsored clinical trial unit.

Debbie Peters is the study coordinator at The Medical Oncology Centre of Rosebank. She qualified in medical technology and then branched into clinical research. She has 30 years' experience in the fields of infectious diseases, and since 2021, oncology.



MEET THE EXPERT

Image by freepik.com

The unspoken long-term side effects of childhood brain cancer

With May being Brain Cancer Awareness Month, Bonni Suckling highlights the effects of brain cancer treatment and how the journey never really ends.



When my son, Jed, was diagnosed with brain cancer, I learned that the aftermath of cancer treatment is an ongoing challenge, faced outside the sterile walls of a hospital and within the everyday world where the trauma of treatment isn't always visible.

Writing an article about the long-term side effects for educational purposes proved difficult, as Jed only survived for three years. *Disclaimer: I would have taken on ALL the long-term side effects for one more day with my son.*

The physical toll

Radiation and chemotherapy prolonged my child's life, but they also left lasting physical reminders. Doctors warn about potential side effects, but they rarely talk about the aftermath of patchy hair loss from high doses of radiation—not just during treatment, but sometimes permanently. Perhaps patchy baldness is the least of their concerns.

Then there are the steroids, particularly dexamethasone, which can cause rapid weight gain, mood swings, and an insatiable appetite. I remember wanting to make a shirt that read, "My son is not a brat, he is on dexamethasone for brain cancer." He was fat from eating; his moon face was just another side effect. His skin was full of stretch marks—did people think I was overfeeding my son?

The judgment from other parents, teachers, and even strangers can be relentless. They saw my son acting out

but didn't understand the chemical hurricane raging inside him.

The social struggles

For many childhood cancer survivors, returning to school presents new difficulties. Kids can be cruel, and a child who looks different, walks differently, or struggles academically due to treatment-related brain damage often faces exclusion.

Bullying is one of the silent side effects no one warns you about. Some children face cruel whispers, stares, and outright exclusion from kids who do not understand their experience. Even well-meaning family and friends do not always grasp the full extent of the struggles your child faces. The expectation is often that everything is going to be okay and that your child will bounce back. People fail to acknowledge the cognitive and emotional toll cancer takes—not everyone, but some.

Developmental and cognitive challenges

Radiation and chemotherapy don't just target cancer cells; they affect everything, including brain development. Many parents find themselves navigating unexpected learning disabilities, memory problems, and even slowed physical growth.

Doctors' priority is often survival, but they don't always have the time to explain that your child might struggle

with basic math, have difficulty concentrating, or fail to keep up with their peers.

For some, hormonal imbalances caused by treatment mean they grow at a much slower or faster rate than other kids their age, leading to yet another layer of emotional distress.

Trigger alert: *Apple Cider Vinegar* series

As if the daily struggles weren't enough, parents of childhood cancer survivors were blindsided by Netflix's *Apple Cider Vinegar*, a series in which the protagonist fakes brain cancer for attention. Belle Gibson's story felt like a slap in the face.

Watching someone trivialise an illness that took so much from our children was infuriating. For survivors, it was a painful reminder of their trauma, and for parents, it was a gut-wrenching realisation that some people will never understand the reality of what we live through.

A call for awareness and compassion

Surviving brain cancer is about more than just overcoming the disease; it's about navigating the unseen, lifelong challenges that follow. Parents are left piecing together support systems, advocating for accommodations in schools, and helping their children build confidence in a world that often doesn't understand them.

JB and Katherine

To fully write this article from a place of understanding, I reached out to parents whose children are long-term survivors. One of them is Judith Botha (JB), whose daughter Katherine had surgery and radiation for a schwannoma brain tumour.

JB shaved Katherine's hair off for surgery, and radiation later caused bald spots. This affected Katherine's confidence. But the hardest part of dealing with a child with a brain tumour, she told me, is that it's an invisible cancer. People see Katherine, and she looks healthy—her hair has grown back—but she is delayed academically.

Due to the type of treatment she had, she is overweight, and people forget that not all cancer can be seen. Katherine also wears glasses, and children can be mean. She was bullied at school, forcing JB to home-school her in those early years. Now, she has settled into a school that caters to her special needs. Though her eyesight is very poor, and she struggles to grasp concepts quickly, JB is so proud of her daughter and grateful that she is alive. Being a single mother, JB has been fiercely protective of her children—they are her world.


Bridgette and Ian

Another parent I spoke to is my dear friend Bridgette, whom I met in 2018 through the brain tumour community. Her son, Ian, was diagnosed with the same nasty tumour as my son (an aggressive anaplastic astrocytoma) at just 14 months old. Doctors gave him only months to live. But Ian defied the odds. He is eight years old now; a miracle, a child who continues to rewrite the statistics that tried to define his fate. I hope Jed is watching over Ian and keeping that cancer away.

Bridgette told me that Ian is bullied and teased. Children have called him a monster because of his squint. At first, he thought they were just playing, but as he has grown older, he understands now; they are being cruel. He dreads school so much that he sometimes urinates out of fear. He hides away, spending much of his time alone, his small heart carrying more pain than any child ever should.

Children throw sand at him. They exclude him. They do not see him for the incredible, resilient soul that he is. Ian is a sad little boy, trapped in a world that does not understand the silent scars of his brain tumour.

We cherish him. We love him. And we wish, more than anything, that we could take away his pain. ☒



POSSIBLE WARNING SIGNS of a Brain Tumour

Brain tumours kill more children than any other type of cancer. EARLIER DIAGNOSES CAN IMPROVE THE OUTCOME - saving lives and reducing long-term disability. A brain tumour is a growth of abnormal cells in the brain. It can be benign (slow growing) or malignant (fast growing). Understanding the brain tumour symptoms may lead to an earlier diagnosis and a better chance of a positive outcome.

- Abnormal Head position or Eye movements
- Balance and Coordination problems or Dizziness
- Changes in Behaviour or Mood (especially tiredness)
- Confusion and/or Memory loss
- Difficulty with Speech and Hearing
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Grey is the ribbon for Brain Cancer Awareness
- wear it in May for the children in treatment, the survivors carrying unseen scars, and those who will always be remembered.

#GoGreyInMay

MEET THE EXPERT



Bonni Suckling is the founder of Rainbows and Smiles Foundation. In 2022, she completed her Paediatric Post Grad Diploma, a testament to her dedication to improving paediatric healthcare. She has played a pivotal role in establishing paediatric palliative care support groups, offering solace and guidance to families. She is also a gym instructor and endurance athlete.

Image by freepik.com

Your tongue health

Melanie Wright explores tongue health and what it reveals about your well-being, as well as signs of tongue cancer.

Your tongue plays a crucial role in daily life; helping with speaking, tasting, chewing, and swallowing. But have you ever considered how your tongue's health reflects your overall well-being? Changes in colour, texture, or appearance can be early signs of health conditions, including cancer.

Understanding the normal anatomy of the tongue

The tongue is a muscular organ covered with a mucous membrane and is divided into different regions that serve a unique function:

Dorsum (top surface): This area is covered with tiny structures called papillae, which house taste buds and assist in manipulating food.

Ventral surface (underside): The underside of the tongue is smooth, rich in blood vessels, and more sensitive, making it prone to injury or infection.

Lingual frenulum: A small tissue fold beneath the tongue that helps with its movement and plays a role in speech.

Intrinsic and extrinsic muscles: The intrinsic muscles allow the tongue to change shape for functions like speaking and swallowing, while the extrinsic muscles attach it to nearby structures, facilitating movement in various directions.

Healthy tongue appearance

A healthy tongue typically presents itself in a pink or light reddish shade, with a thin, white layer that can be removed through regular cleaning. The tongue's surface should feel slightly textured due to small papillae, which are responsible for the sense of taste. Any sudden changes in the tongue's colour, texture, or the presence of long-lasting sores could point to a potential health issue that needs medical attention.

Warning signs to monitor

Regular self-examinations of your tongue can be an early warning system for health issues. Key signs to look out for include:

Persistent red or white patches: These could be signs of irritation or infection, and in some cases, may indicate early stages of precancerous or cancerous changes.

Sores or ulcers that persist: If a sore or ulcer remains for more than two weeks without healing, it should be evaluated by a healthcare provider.

Lumps or areas of thickened tissue: Any unexplained lump or unusual thickening in the tongue can potentially be an early indicator of oral cancer.

Pain or a burning sensation: Chronic discomfort or a burning feeling on the tongue might suggest an underlying infection or another medical condition.

Changes in texture or coating: An unusually thick coating, a hairy appearance, or noticeable cracks on the tongue could be linked to infections, inadequate oral hygiene, or nutritional deficiencies.

Other unusual symptoms: These may include persistent sore throat, feeling as though something is stuck in your throat, numbness of the tongue, difficulty or pain while chewing or swallowing, or a change in your voice.

Tongue cancer: risk factors and early detection

Tongue cancer is a serious condition that can initially appear as a sore, lump, or colour change on the tongue. Early stages may go unnoticed, and it can sometimes be discovered only during a routine check-up. The tongue extends from the mouth into the throat, and early detection of abnormalities is vital. If you notice any suspicious changes, it's essential to consult a dentist, oral health specialist, or an ear, nose and throat surgeon right away.

Two main types of tongue cancer:

- **Oral tongue cancer:** Found at the front part of the tongue; this type is often visible and can be diagnosed earlier.
- **Oropharyngeal tongue cancer:** This occurs toward the back of the tongue and is more difficult to detect. Often diagnosed later when it has spread to nearby lymph nodes.

Key risk factors

Tobacco and alcohol use: Smoking and excessive alcohol consumption are significant contributors to the development of tongue cancer.

Human papillomavirus (HPV): Certain strains of HPV are linked to the development of oral cancers.

Age: Individuals over the age of 45 have a higher risk, usually due to long-term exposure to known risk factors.

Poor oral hygiene: Inadequate dental care, especially in those who smoke or drink alcohol, may increase the risk of developing tongue cancer.

Weakened immune system: A compromised immune system, whether from an existing illness or as a result of medications, can heighten the risk of cancer.

Maintaining tongue health during cancer treatment

Cancer treatments, such as chemotherapy and radiation, can impact the mouth and tongue, causing dryness, ulcers, infections, and taste changes. Here are tips to help maintain tongue health during treatment.

Practice good oral hygiene: Brush at least twice a day, floss daily, and use a tongue scraper to remove bacteria and debris. During treatment, you may experience oral mucositis (painful sores in the mouth) or xerostomia (dry mouth). Rinsing with a saltwater solution can help soothe irritation and prevent infections. Fungal infections, such as thrush, can also occur, so it's important to speak with your healthcare team about appropriate treatments.

Stay hydrated: Sipping water regularly can help alleviate the discomfort of dry mouth and make swallowing easier, especially if you're also dealing with changes in taste.


Avoid irritants: Spicy, acidic, or rough-textured foods can worsen mouth sores or increase sensitivity in the mouth and tongue. Opt for soft, mild foods to reduce irritation.

Visit your dental professional regularly: Regular dental check-ups during cancer treatment are essential. Your dentist can help you manage symptoms like mouth sores, dry mouth, or taste changes, and provide guidance on how to care for your mouth throughout the treatment process.

Consult your healthcare team: If you experience persistent pain, swelling, or signs of infection in your mouth, don't hesitate to contact your oncologist or dentist. They can help guide you in managing symptoms and preventing complications, such as infections or mucositis.

Taking proactive steps can help protect your oral health and improve comfort during cancer treatment.

Take care of your tongue

Your tongue is a window into your overall health and paying attention to changes can help with early detection of serious conditions, including cancer. Regular dental check-ups, good oral hygiene, and knowing when to seek medical advice can make a significant difference. Your oral health is too important to ignore, if you notice any persistent changes, schedule a check-up with your healthcare professional today. 

MEET THE EXPERT



Melanie Wright is an oral hygienist and is currently working at a specialised prosthodontic practice alongside Dr Michael and Dr van der Linde; they all function as an integral part of the Morningside Head and Neck Oncology Team.

Cross-species cancer research

Andrew Robson explores how cancer studies in animals contribute to understanding and treating human cancers.

Cancer is a universal challenge that affects humans and animals alike. While often seen as a human disease, cancer also impacts pets and wildlife. This shared vulnerability has opened doors to research benefiting both veterinary and human medicine. By studying cancer in animals, scientists gain insights that drive innovations in diagnosis and treatment across species.

Cancer as a shared disease among animals and humans

Cancer occurs in nearly all species, with mechanisms that are strikingly similar. African wildlife, for example, faces significant cancer challenges. Giraffes in South Africa are affected by sarcoids, a type of skin tumour linked to bovine papillomavirus (BPV). Cape mountain zebras and sable antelopes have also been found with similar growths, underscoring the virus's impact across species. These findings are particularly relevant as humans are similarly affected by papillomaviruses, which are linked to cervical and other cancers.

Meanwhile, Tasmanian devils in Australia contend with transmissible cancers, such as devil facial tumour disease, offering additional insights into cancer's mechanisms of transmission and immune evasion.

But mother nature is a fierce, resilient force and certain animals exhibit remarkable resistance or even immunity to cancer, offering fascinating insights into potential protective mechanisms. For instance, naked mole-rats, known for their exceptional longevity, rarely develop cancer due to a unique mechanism involving high-molecular-weight hyaluronan, which prevents cells from overcrowding and forming tumours.

Similarly, some whale species, such as bowhead whales, display resistance to cancer despite their large body size and long lifespans. This phenomenon, often referred to as Peto's paradox, may be attributed to enhanced DNA repair mechanisms and additional tumour suppressor genes. Studying these species provides valuable clues that could inform innovative cancer prevention and treatment strategies in humans.

These cases highlight the ecological and biological reach of cancer. The shared factors influencing cancer, such as carcinogens, genetic mutations, and aging, make animals invaluable in understanding the disease and developing therapies.

The contribution of man's best friend to cancer treatments

While the understanding of cancer in wild populations is still evolving, dogs continue to play a crucial role in cancer research due to their natural development of tumours similar to those in humans. Unlike laboratory mice bred for specific cancers, dogs offer real-world models for disease progression and treatment responses. Their lifespans of 10-15 years, compared to the human lifespan of 80+ years, allow researchers to evaluate therapies over shorter periods.

One notable breakthrough is the canine melanoma vaccine. Originally developed to treat dogs with advanced melanoma, this immunotherapy has inspired similar approaches in human medicine.

Additionally, research into canine lymphoma has significantly enhanced the understanding of drug resistance and contributed to the development of improved chemotherapy protocols for humans. Drugs such as chlorambucil, cyclophosphamide, L-asparaginase, vincristine, and prednisone have all benefited from canine studies.


For instance, chlorambucil dosing and side effect management have been refined, while cyclophosphamide dosing schedules and combination therapies have been optimised. L-asparaginase administration methods have been improved for human leukaemia and lymphoma treatments, and vincristine

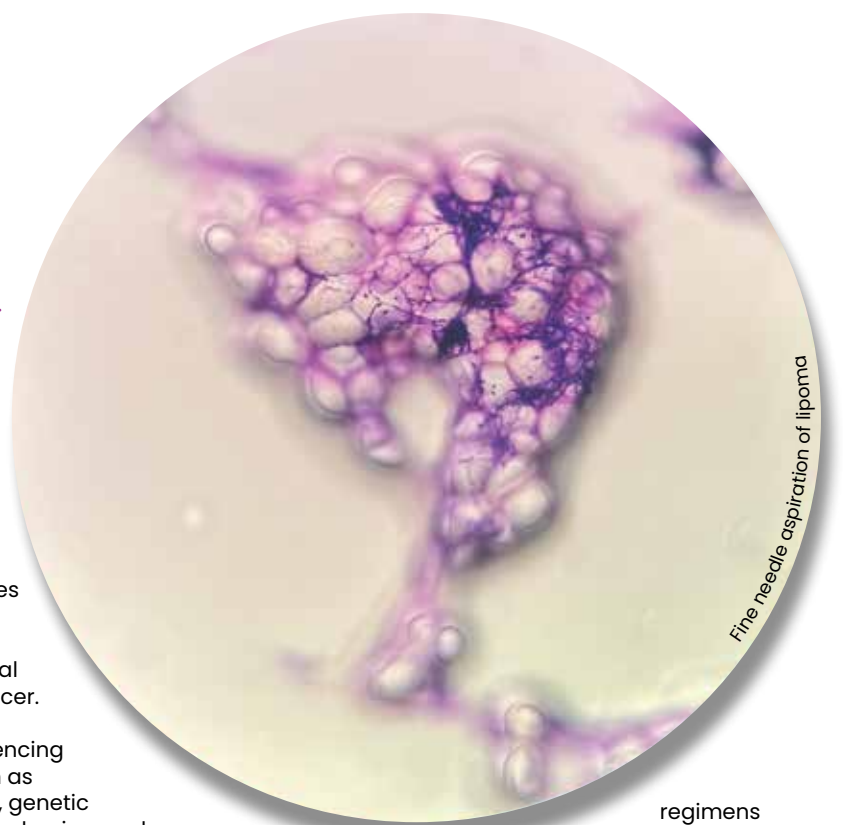
regimens have been fine-tuned to reduce resistance in human patients.

Moreover, prednisone has been better utilised in combination therapies, enhancing outcomes for human lymphoma patients. Studies of osteosarcoma and soft tissue sarcomas in dogs have also guided advancements in limb-sparing surgeries and bone cancer treatments for children facing similar cancers. These contributions from veterinary research have had a profound impact on human oncology, offering new insights and improving treatment protocols.

The One Health perspective

The *One Health* concept highlights the interconnectedness of human, animal, and environmental health, making it particularly relevant in cancer research. Shared exposures to carcinogens, such as industrial pollutants, drug residues in water, and second-hand smoke, provide valuable opportunities to develop prevention strategies that benefit all species.

Cross-species cancer research reinforces the idea that studying cancer in animals not only enhances the understanding of the disease but also leads to improved health outcomes for humans, pets, and wildlife alike. As we continue to advance cancer research, it's essential that we uphold the highest standards of animal welfare, recognising our responsibility as custodians to ensure ethical practices that benefit both scientific progress and the well-being of all species. 



Fine needle aspiration of lipoma

MEET THE EXPERT



Dr Andrew Robson, a veterinarian based in Mpumalanga, holds a Master of Science Degree and has a special interest in companion animal health and well-being. Passionate about improving pet health and fostering the human-animal bond, he is also a proud dog dad.