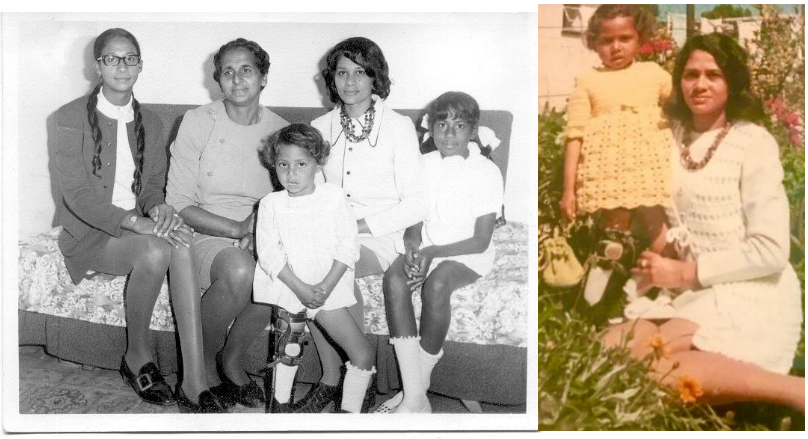
Marlene le Roux contracted polio in 1967
Rural Wellington
Post-Polio 2024

The psychological trauma of a post-polio sufferer before her 12th operation

Marlene Le Roux

As the CEO of Artscape Theatre Centre, one of Cape Town's most iconic performing arts institutions, I believe it is crucial to lead by example in collaboration with wonderful people and partners who share my vision of inclusivity, humanity, empowerment, and excellence, based on the values entrenched in our country's constitution. Art forms with all their diverse genres – visual art, music, theatre, literature, dance – are at the core of our daily business which we execute with great aplomb as a collective and which we celebrate together with our patrons, visitors, local communities, as well as our city, provincial and national leaders.

But then there's my own dance, a genre I've performed for 57 years with great difficulty, it is my own, unique 'pole-io' dance, one which is daily taking its toll on my physical strength and psyche, a dance with a difference for which I honour two exceptional heroes – my mother Tietie (Christina le Roux, née Abrahams) and grandma Christie (Christina Abrahams, née Davy), who accompanied me unselfishly all the way on this journey: My dance with polio characterized by trauma, excruciating and constant pain, exhaustion, depression, rejection, humiliation, despair, discrimination, struggle. This special dance means that I can only use my weak leg with the support of a calliper – a leg brace that has accompanied me all my life as a person living with polio. This disease recently culminated in a full hip replacement to ensure I can still walk independently on my better leg which is my primary support and stronger leg.



Left photo (from left): Marjorie Jacobs (née Abrahams, Christina Abrahams (née Davy), Christina Le Roux (née Abrahams, Ray Kieffer (née Abrahams) with Marlene le Roux in front. Right photo: Marlene with her Tietie.

So, what is polio? When did I contract it and how is it affecting me?

Caused by a virus that mainly affects nerves in the spinal cord or brain stem, polio or poliomyelitis can lead to paralysis of the limbs. It affects your muscles and as we all know, one's entire body is wired by muscles. In Afrikaans, polio is called "kinderverlamming". It can also lead to trouble breathing and sometimes death.

I contracted polio in 1967 at the tender age of three months. My mother and grandmother, both upright, elegant seasonal farm and factory workers from Wellington (near Paarl) , told me years later how doctors at the clinic for black people and so-called persons of colour dismissed their concerns that something was wrong with me. "What do you hotnots know? The child must be teething!" they remembered the white doctor's sayings. And the white doctor at that time could not even administer the basic polio drops. And thus, my journey of multiple operations and long stays in hospital started from a very early stage.'

Lack of support and empathy

During the dark days of Apartheid no one would ask the mother, the granny or supporters about their feelings of looking after a child with a disability. When I contracted polio the doctor actually blamed Tietie and Ma Christie for "neglecting" me. The doctors' attitude towards them was: Deal with it. He claime that she would not live long and a priest was called. From a tender age I encountered the invisibility of how you as a patient can be treated as an object. Ma, Tietie, my aunty Tietie Maai and neighbours would on a regular basis travel to Princess Alice Home in Retreat, the only orthopaedic hospital in Cape Town at the time. That meant getting up at 4am, asking the neighbours to abba me (carry me on their backs) like an Olympic relay , as we had no car, to catch a train at 6am and three more trains to get to Princess Alice Hospital, we waited in a smelly waiting room to encounter doctors and students in white coats who didn't ask anyone: How are you? How do you feel? How does the child feel? And at that time, you had to lower your eyes. You couldn't just look at the whites in their eyes. Then the objectivization started: Measurements, me undressing, with no privacy, and further discussions. During these sessions I started to learn to transport myself to another world. When my time was up, the doctors would go for tea, and in silence, these angels of mine, totally dehumanised, would have to take two trains to get to Cape Town Station again, sharing one pie with gravy cut in four pieces. And then off to Wellington. Then the relay to get home would start again, and all these angels would lose a day's wages. There were no unions in those days, no rights at all.

I got my first calliper (supportive orthopaedic device)—a heavy structure—when I was 2 years old, along with heavy boots. Oh, so ugly! Again, no one told you how to walk with these devices. It was fall and get up. You carried an entire 2 kg on your leg. But we all decided to carry on, and my angels: *Marlientjie* is going to make this work.

She can stand and walk although *mank* (crippled). My name was Mank Marlientjie (little cripple Marlene). For me it was a term of endearment, as my Verlate Kloof, *polonie-dorp* community and my beloved family rallied around me. But there was no psychological support, it was a matter of "adapt or die." But there was always sadness in my Tietie's and Ma's eyes. They never expected that this would happen to me and them.

Operation after operation – sheer torture

Then, the operations started. My first was when I was only 5 years old. The doctors decided I would be their pilot to lengthen my left polio leg, which was shorter than the right one.

They drilled four very long screws right through my leg with a mechanism attached to it to be able to turn the bone every morning (the scars and holes are still visible). Again, no one explained the enormity of the operations to my angels or me.

Every morning for nearly three months, I would scream like a mad person when the white coats entered the room to start with the procedures of turning the screws, no one holding my hand as my family was too far, no painkillers! Discussions after discussions, leaving me in the care of the nuns at Princess Alice Home, who were also not the kindest. I stayed in this hospital for a whole year! Sometimes, the family could stay with friends on the Cape Flats so that they could visit me. As a child, how I longed to be with my family. Here I learned to cope and to navigate my life. Remember, black and kids of colour were treated differently. I survived, but I parked this experience just to cope. Subsequently, I had 11 more operations, each one with no psychological support.

I started navigating my life as a polio survivor by being fully involved in church activities, music activities and wonderful friendships. I was only accepted at a mainstream school after my Tietie protested on her own for the school to accept me irrespective of my physical disability. And the school stepped up. Everybody helped me up and down the steps, carrying my bags. The entire community became activists without actually knowing it. They just practised inclusion on so many levels. Kudus to Wellington! I even swam in the Berg River – glorious days – amid my usual operations and fittings. Gradually it became more bearable as I told my granny and Tietie that I had accepted my disability; it was not their fault. Living in a house without electricity, especially in winter, was my most difficult time as a polio sufferer. You don't have blood circulation, no number of warm socks will warm your polio leg. Wellington has extreme weather conditions: ice cold in winter with snow on the surrounding mountains , and up to 40 °C in summer. My granny used to take bricks, put them on the coal stove and wrap them in cloth to keep my leg warm. Till today, I still use hot water bottles.

UWC accepted their first person with disabilities in 1986 after UCT rejected me. Again, my Tietie made history by giving UCT the middle finger after hiring a car at great cost to go and enrol me at UCT, just to find out you needed a permit as a black/so-called coloured person and at that time disabled singers were not welcome to study opera anyway. Thank the universe, my life changed as UWC took in their first person with disabilities. There I had a full life as a student: dancing, protesting, marching, lectures and everyday student activities. Throughout my growing years, I developed my life's motto: *Die lewe skuld jou niks* (life owes you nothing). I accepted myself and I made sure I was an activist as a teacher. In the beginning the kids would call me names but then they stopped and just saw me as their music teacher, and so I became so privileged to travel through South Africa by just being me that people around me became comfortable with my disability.

Dealing with insecurities and challenges

But over the years I also had to work hard on my insecurities. You always give 150 percent to show you are capable irrespective of your disabilities. From my childhood days I was involved in numerous accidents where the calliper just broke or my leg would give in as I was walking.

These incidents were very traumatic, but I just had to cope, get up and go on.

I survived a brain tumour and had two beautiful children by caesarean birth. The youngest, a son, was born with cerebral palsy, a disability that caused his death at the young age of 15. Subsequently I had a hysterectomy, followed by another big operation to pull my muscles together which had collapsed. Shortly after that I was in a near fatal car accident. Then Covid-19 followed.

Post-polio symptoms and deterioration

I also had to deal with the horror of post-polio symptoms. I usually have endless energy, but recently these symptoms started getting more severe. I first thought I was having a very long menopause: I got tired easily, my muscles started feeling stiffer than usual, I struggled getting out of bed, I needed more warm baths just to defrost my legs and now my entire body. My hands are weak and daily I have excruciating pain in my knee.

I tried to dance it off, got busier just to ignore the thought that my right leg – my beautiful trophy leg that I am so proud to show off – was also giving in. My childhood trauma , which I have locked away just to survive was creeping back. I was forced to go and see an orthopaedic surgeon due to the pain. At the moment, I also have osteoporosis and arthritis and my worst nightmare has come true: the ball of my hip has shifted, my hip had no more cup left. For nearly 57 years I have overloaded the right leg with a calliper weighing 2.5 kg by now, from living my life like all people do, climbing Table Mountain, working and walking daily at my lifeline which is Artscape. The specialist's diagnosis was clear: I have no option but to undergo a full hip replacement on my trophy leg. The physiotherapist who was absolutely amazing, could not relieve the pain anymore.

I decided, before I go for the operation, I would do it my way. I first finalised with the amazing Artscape team what we still needed to do for 2024. Being on the world panel of the Musical Theatre Now Competition, a world competition for new musicals, theatre and opera works, I had to execute these duties while in a wheelchair. And slowly I became so down. I felt scared that I was going to lose my independence. I got nightmares of the leg lengthening procedures of my childhood. I came to realise I was racing against the clock.

I then realized I should go and see a psychologist before the operation as I wasn't the *Marlientjie* from the scheme with no resources anymore, I had to take charge. On 9 July we launched the Artscape Women's Humanity Festival without any makeup as I needed to shower three times with a bacterial gel against infection.

I gave the polio and post-polio leg a good time dancing and singing and was surrounded by the most passionate people without anyone really knowing I was preparing myself for my biggest life challenge, just like an Olympian.

Getting ready for the hip replacement

The next day, on 10 July, I reported to Panorama Hospital at 6am feeling apprehensive. My biggest concerns were: Will my bones be brittle? Will the surgeon be able to fit the prosthesis, the ball, the cup properly. All these thoughts went through my mind. As they pushed me through to the operating theatre, I was again the small *Marlientjie* with so many uncertainties, so many fears. This time around the doctors reassured me. Then the worst nightmare awaited after a gruelling total hip replacement:

I am allergic to most painkillers. So, it was back to MIND OVER MATTER: Only Panados for me. And my faith will pull me through.

Marlene undergoing surgery at Panorama Hospital

Rehabilitation process

On the third day I decided: Come on, put on your red lipstick, get your walker and start your journey of showing how privileged you are to have the best doctors, support of family and friends, interfaith communities praying for you, a devoted partner, a supportive workplace. Above all, the privilege of being able to go to Oasis Rehabilitation Centre's 24-hour care of excellence. I made new friends at Panorama Hospital and at Oasis.

Marlene with staff at the Oasis Rehabilitation Centre. Top right photo: (from left) Dr Ivan Meyer (Western Cape MEC for Agriculture), Marlene le Roux, Lizzie Brynard-Brill (Manager of Oasis Care Centre)

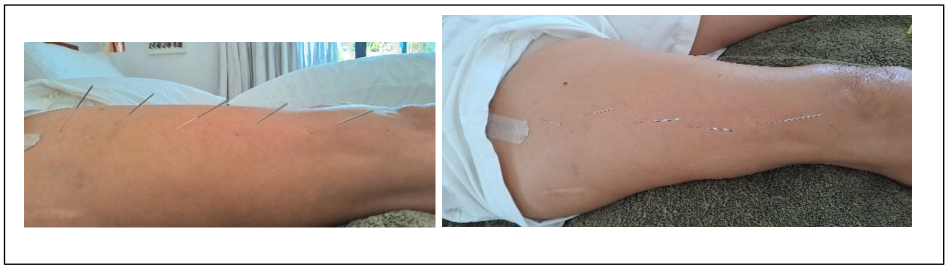
Home Physiotherapy

The physiotherapist is the medical extension and motivator of the healing proses after surgery. It is extremely important that the communication between the physiotherapist and surgeon is ongoing. The aim of physiotherapy in rehabilitation is to restore as much normal function as possible to the muscular, skeletal (bones and joints) and nervous systems, to assist the patient with reaching the most physical as possible This means getting sufficient strength, control and flexibility in these systems through targeted exercises and hands-on techniques. In the case of a hip replacement this role is vital. I realized once again how lucky I was to be able to afford the much-needed medical support.

The hip is a ball-and-socket joint and a total hip replacement means both sides of the joint (the ball and socket) are replaced with a prosthesis. This procedure carries additional risks in the case of someone who has suffered from polio because of osteoarthritis, gluteal weakness (the muscles that control the hip) and changes in joint alignment. When successful, however, a total hip replacement improves both function and quality of life.

Again, I realise how lucky I am with all the support and love I've received during this period from the physiotherapist from Tucker and Conradie Therapists. Yes, being me while in extreme pain watching the opening of the 7th Administration of the GNU from my hospital bed, I heard that the president made persons with disabilities just a side issue. I took pen to paper and wrote an open letter to the president to give suggestions of how to actively make visible the lives of persons with disabilities. At 6am that morning I was on the radio. And the entire week I worked from my bed. However bad your situation, it is important that you continue to make a difference, no matter what.

Tucker and Conradie physiotherapist



With my special home caregiver Jean Bailey

Conclusion

Why am I writing this article about my 12th operation as a post-polio sufferer? For the simple reason that I want government to realise that without the proper support and resources, post-polio sufferers are doomed! Not everybody is as privileged and empowered as I am. I have a good job and earn a decent salary which means I am empowered, I can get all the help and support that I need to assist me all the way. The government grant will not help you. Government must provide the necessary resources for my fellow post-polio sufferers so that all of us can continue to live a dignified life. It is their duty and responsibility! The campaign about polio should not just focus on the eradication of polio, but also on the provision of proper treatment and support for post-polio symptoms that continue after polio treatment.

Yet, my motto is still: *Die lewe skuld jou niks* (life owes you nothing). My non-polio trophy leg is now bionic. Before I could walk on my own without assistance, now I'm dancing with crutches, for the rest of my life. My appeal to all is therefore: know your post-polio status, vaccinate your child with the polio drops, empower yourself, turn your polio devices into stilettos. Live your life!

Thank You

I want to express my deep gratitude for the unwavering love and support I have received from my family, friends, associates and colleagues during this difficult period. Their encouragement and compassion have been like a beacon of light in the darkness, giving me hope and strength when I needed it most. The kind words, thoughtful gestures, and genuine concern shown to me have truly touched my heart and made a significant impact on my well-being. I am profoundly thankful for the incredible people in my life who have stood by me, and I will always remember their generosity and kindness.

With heartfelt gratitude and appreciation, thank you.

I have an uplifting collage of pictures showing supporters visiting, but the phone calls and the messages I received are also important.

Die lewe skuld jou niks. Your biggest wealth in life is people.

Marlene with husband and full-time caregiver Prof Eddy van Der Borght

Turn your calliper and crutches into stilettos and live your life! I'm doing it!