WEEK 2 MEDICINE & THE ARTS – CHILDREN'S VOICES AND HEALING
MY SONG FOR THE LIVING

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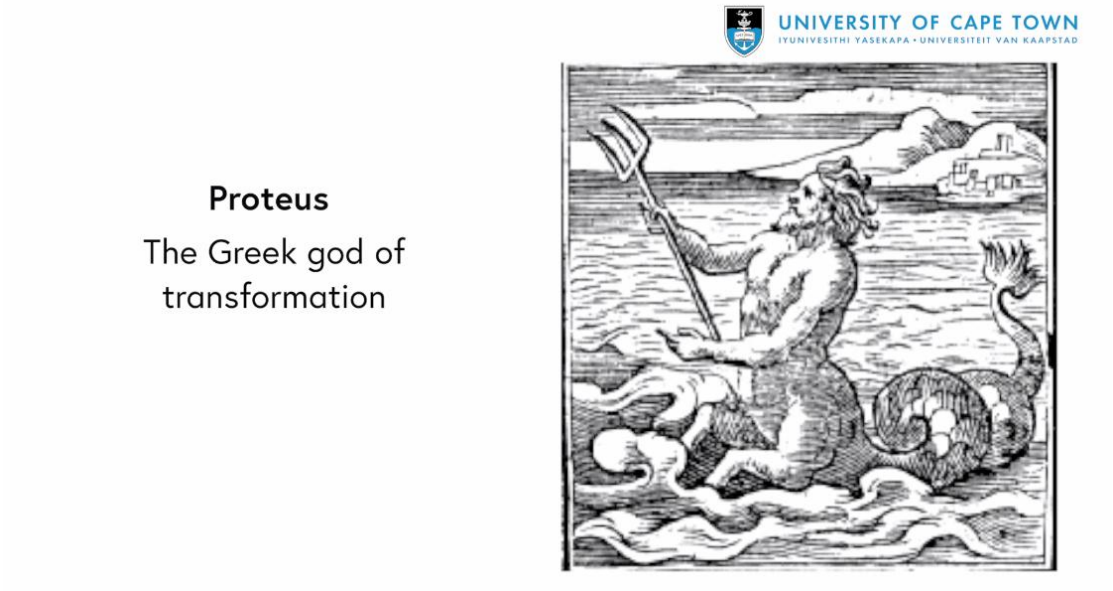
Welcome. My name is Marc Hendricks, and I'm a paediatric oncologist working at the Red Cross War Memorial Children's Hospital in Cape Town, South Africa. I'm also a musician and a songwriter. In this segment, we're going to focus on the intersections between music and healing and look at key concepts in the caring for children with cancer in middle income settings.

The relationship between the arts, in particular music, and medicine is well documented in the medical literature and dates back to the time of William Shakespeare. This has traced a path through history and has touched on almost every medical discipline including neurology, nephrology, and emergency medicine.

And so it's hardly surprising that caring for children requires doctors to navigate the space between art and science. Doctors really become shape shifters, a lot like Proteus, the Greek god of transformation. There really is often more art to medicine than science. And managing the softer relational elements when caring for patients often enhances patients sense of well-being.

PROTEUS – GREEK GOD OF TRANSFORMATION



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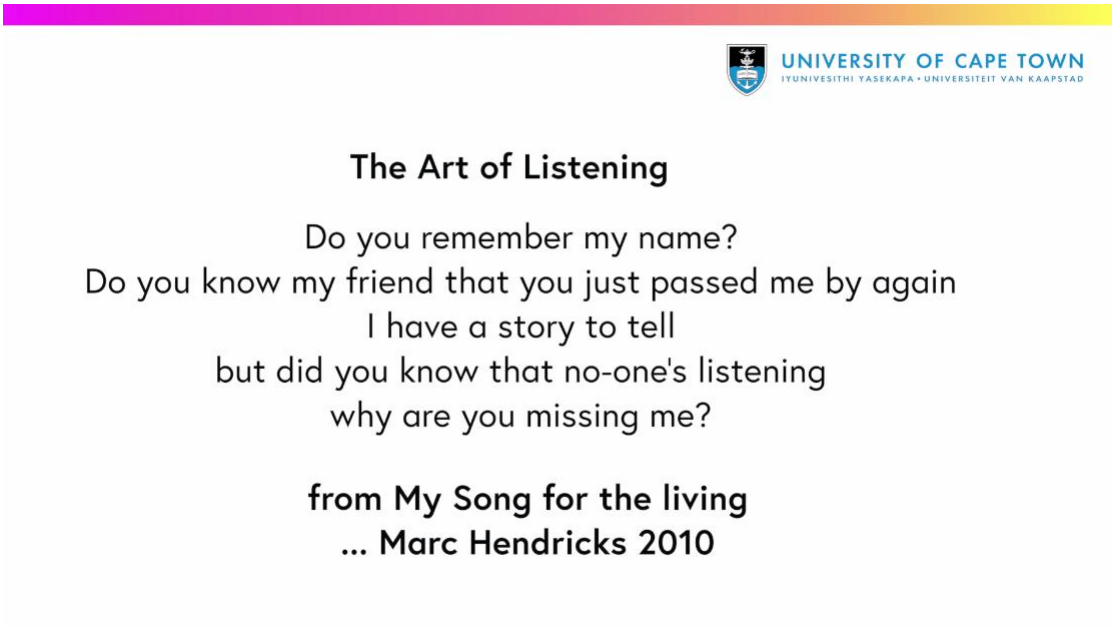
The first step in relating is listening.

This excerpt is taken from a song entitled, "My Song for the Living," which was performed in a musical production hosted by the hospital. The production called Uhambo, which is the Xhosa word for the journey, traces the journey of parents and their unwell child from the country to Red Cross to seek help.

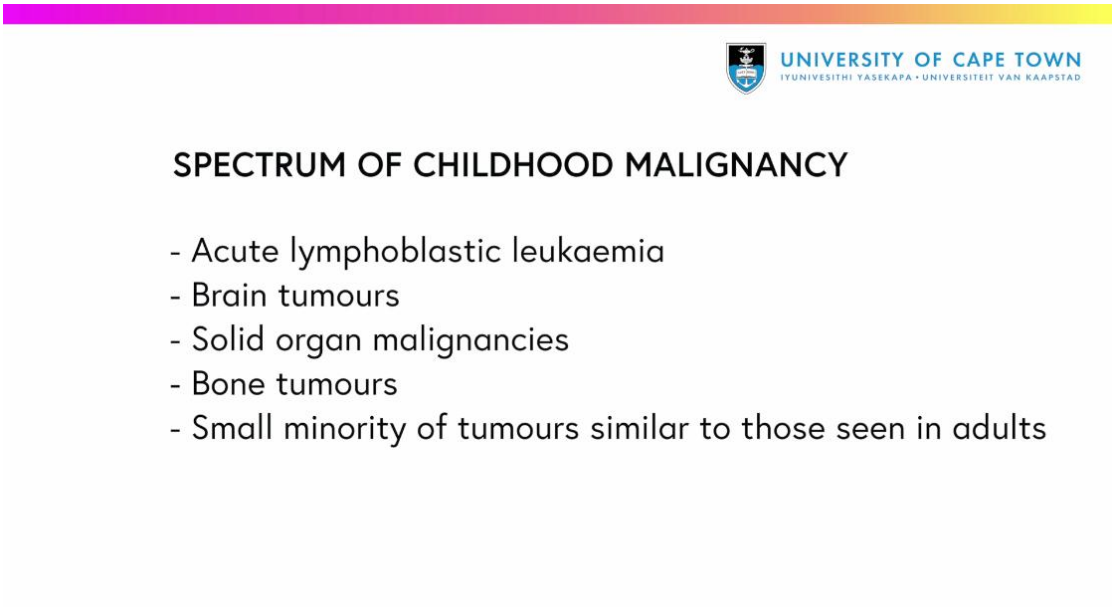
EXCERPT – MY SONG FOR THE LIVING



The song is about a child's plea to be seen, heard, and recognised. Often too easily, and usually inadvertently, the voices of children are marginalised. In the discussions between doctors and parents. And younger pre-verbal children and children with special needs are particularly at risk.

So let's for a moment focus on the science. We live in an area where 70% of children can be cured from their disease. This comes with the combination of multi-agent chemotherapy, radiotherapy, and surgery. But also means that 30% of children will not be cured and will eventually die from their disease.

Thankfully, childhood cancer is rare. US data reports an incidence of about 150 cases per million children under the age of 15 years. In South Africa, we report about half as many cases. And that discrepancy may be accounted for by under-reporting, by differences in epidemiology, and by children die from other diseases like malaria, tuberculosis, and HIV/AIDS.



Acute lymphoblastic leukaemia comprises about a third of childhood malignancies. The brain tumours, which are a complex and heterogeneous group of tumours, make up the next third. Solid organ malignancies, which can arise from any organ in the body, but rarely the lung or gut in children, comprise the last group. Bone tumours arise in pre-adolescents and adolescents-- and then a small minority of tumours similar to those seen in adults.

Previously, we mentioned that the outcome for childhood cancer has improved dramatically over the last 30 years. So what accounts for this improvement? Firstly, and most importantly, the collaborative efforts of international trial groups to ask and answer important questions around childhood cancer and treatment, the establishment of academic paediatric oncology units, the development of multi-agent chemotherapy, better diagnostic facilities and health infrastructure, better radiotherapy and surgical techniques, and better support of care for intensive strategies, like stem cell transplantation, have all contributed to the progress made over the last four decades.

So the outcomes are very positive, but is there a catch? We know that invasive and intensive treatments like chemotherapy and radiotherapy can induce long-term health problems-- depression, anxiety, insomnia, diabetes, and hypertension, problems with learning, growth faltering, and also developmental problems.

We also know that the social context impacts usually on outcomes in terms of where the families abandon treatment and also in terms of relapse rates for cancer. And what about epidemiology? Well, we know, for example, that cancers like Burkitt lymphoma are 100 times more common in Central Africa than they are in the developed world. And this is a huge impact in terms of health economics and those who are planning health services in addition to patient outcomes.

So let's telescope down into the consultation room and appreciate how issues of language, culture, socioeconomics, education, and religion impact on the conversation between the doctor and the patient when speaking about cancer. If one does not focus

on these issues, the doctor runs the risk of narrowly missing important issues for the patient-- questions like, who is my patient, what is important to them, what are their real fears and concerns, how does the cancer diagnosis fits into their lives, and how are we going to find a way through this together?

An important part of the discussion with parents is about the family. Every child belongs to a family and has a context within that family. And so understanding the architecture of the family is pivotal to understanding the child. Concepts like parental relationships, parenting styles, parental anxieties, finances, and sibling structure are all key to providing comprehensive care for the child with cancer.

Similarly, the educational environment is critical. Children suffer stigmatisation, absenteeism. They become isolated and disconnected from their peers. This is especially important for children who have issues around their body image-- those who lose hair, who have surgical scars, who need assistive devices to move, and for those who have to have amputations.

In any paediatric environment, often the most anxiety provoking conversations centre around diagnosis treatment, and for some children, around death and dying. These conversations need to be managed in an age-appropriate and sensitive manner. Often, the time arises when treatment no longer is an option for patients, and we shift from treatment to the appreciation of time. Sometimes the enjoyment of time in its most unencumbered way can be our most useful teacher and our most gentle healer.