

CANCER Awareness Week **REHAB** 7th-13th September 2020

no one should miss out



“One in three people get cancer. More and more survive. But people are unfairly missing out on optimal recovery programmes due to a lack of awareness!”

A word from Lou James (MNZM), Founder PINC&STEEL International, cancer rehabilitation advocate and champion since 2005.

“I’m Lou James and I’ve been working in the field of cancer rehabilitation for over fifteen years. As a physiotherapist, I saw first-hand the physical and emotional toll cancer had on people and was utterly shocked at the lack of rehabilitative support they received. My experience working as a musculoskeletal physiotherapist with top athletes was in stark contrast to my experience working with cancer patients and survivors. The unfairness was astounding! The disease, the harsh treatment side-effects and the gaping hole in the quality of care patients received were the driving forces behind my commitment to oncology rehabilitation.

The Challenge

The biggest challenge is to reduce the enormous discrepancy between the provisions of medical rehabilitation services for general physical impairments compared with the provision for people affected by cancer.

Hundreds of millions of dollars are spent on drugs to help prevent and treat cancer. The number of people living longer and surviving cancer is growing, however these people are often living with long-term side effects of the disease and treatment (both physical and emotional), which make them feel they haven’t ‘beaten’ cancer at all.

Side effects may be visible during or very soon after treatment, or they may take months and years to become apparent. And many of these side effects can significantly affect quality of life. The number of cancer survivors world-wide is estimated to be approximately 25 million. Current research indicates that in some areas only 5% of cancer patients and survivors are being referred to rehabilitation!

The Lack of Awareness

Hospitals do not send stroke patients or joint replacement patients home without a detailed plan to help them regain as much of their normal functioning as possible. These people are routinely referred for rehabilitation. Yet, cancer patients are routinely discharged with little or no guidance on how to deal with the impairments that remain after their treatment is done!

'Rehabilitation' has never been a part of the traditional patient pathway for oncology patients, and this is one of the biggest reasons behind why getting support from the medical fraternity, hospital boards and other cancer charities is such a huge challenge. It's easy to underestimate the long-term consequences of cancer and its treatment. The primary focus of oncology medical professionals is to eliminate or control disease by suppressing cancer cell growth or directly removing the tumour. These treatments are increasingly successful, but they also damage 'normal' tissue. While oncology specialists seek the best possible outcomes, i.e. the absence of any residual cancer - this does not mean that meaningful emotional and functional recovery is complete.

Many of our healthcare systems do not have the means to effectively assess post treatment functional impairment - and there is a real lack of awareness about rehabilitation services. Consequently, patients and their family members remain in the dark.

The current low profile of long-term consequences of cancer and its treatment means affected people are reluctant to report their ongoing issues, particularly when they feel so grateful to be free of cancer. I believe that revealing the scale of the problem allows people experiencing these issues to understand they are not alone, and I hope it will encourage them to seek the support they need.

The Lack of Understanding

Over the past 15 years I have spent countless hours speaking in front of different medical, charitable and public groups to raise the awareness of cancer rehabilitation and to advocate for the needs of people affected by cancer. The more I speak, the more I see change in individuals' understanding about the benefits of specialised cancer rehabilitation. But we need more voices - we need yours!

Unfortunately, even in our advocacy role to elicit change and reduce barriers for cancer patients, oncology rehab clinicians regularly come across roadblocks. This mainly occurs because of historical divisions between public health care versus private and community healthcare which have been traditionally treated as 'lesser' and sometimes as 'counterproductive'.

Cancer is a very emotive topic. There are many alternative therapies that the medical profession will rightly not endorse because they are not supported by sound evidence or research. Oncology physiotherapy rehabilitation is not one of those! It does not lack sound evidence. Physiotherapists and occupational therapists providing cancer rehabilitation use evidence based best practice to determine their input and oncology rehab supports the whole patient, not just their cancer. They help patients to increase their strength, range of motion, functional status, physical activity levels, manage their fatigue and pain and educate them how to maximize their own recovery. Surely patients should have a right to choose cancer rehabilitation? Isn't it inhumane to leave people who have experienced cancer not even knowing about services that offer them meaningful help?!

The Impact of Disconnected Medical Practices

One thing cancer patients often experience is disconnected medical support. Usually the process of diagnosis alone shuffles them through multiple medical professionals (and a whirlwind of information). Surgical approaches are often handled by different teams to radiation and chemotherapy treatments. Whilst every effort is made to share expertise - the immediate goal is eradicating cancer. GPs may well be in the loop, but they are not necessarily cancer experts. So at what stage does a patient receive dedicated rehabilitation advice? Sadly, it's often, never.

I regularly get phone calls and emails from patients saying,

"Why didn't my doctor tell me about this service?"

"I wish I had started seeing a physiotherapist earlier, if only I had known..."

There are growing numbers of trained cancer rehabilitation health professionals and they have the skills and experience to potentially support hundreds more patients - preventing significant unnecessary disability across populations! There is the capacity, these clinicians are ready and waiting BUT more people need to know about it!

Understanding the Role of an Oncology Rehabilitation Physiotherapist

Cancer is not one disease, there are hundreds of different types of cancer and every patient is affected in different ways. The role of an oncology rehabilitation physiotherapist is to prescribe individualised rehabilitation dependent on the type of cancer, age, fitness level, stage of recovery, type of cancer treatment and the side effects, guided by the patients goals.

Many cancer patients experience pain, fear, debilitating fatigue and loss of body confidence as well as reduction in their joint mobility, muscle strength and stamina. Even side effects such as incontinence can often be improved through physical therapy - if only people knew!

Oncology or cancer rehabilitation physiotherapists are experts in restoring movement and function to people affected by cancer. However, it doesn't stop there. There is also strong evidence supporting rehabilitation and exercise not only help people physically but also emotionally and socially.

Opportunities to screen for and treat impairments in cancer patients begin shortly after diagnosis and continue even years after the completion of cancer treatment. Our care continuum includes prehabilitation (interventions designed to increase function prior to surgery or treatment), rehabilitation during acute cancer care, rehabilitation after acute cancer care and rehabilitation of patients with cancer as a chronic condition (advanced cancer). Ongoing education throughout cancer treatment is vital to heighten the patient's awareness of the potential late effects from treatment and to promote a proactive approach to their diagnosis and treatment. In addition, physiotherapists work to reinforce health-promoting behaviours such as exercise, weight control and physical activity.

The World Health Organization (WHO) defines health as "not merely the absence of disease, but a state of complete physical, mental and social well-being". Our role is to support cancer recovery and actively facilitate rehabilitation and physical activity programs - crucial for the health and well-being of cancer sufferers.

How You Can Help

Over the past decade, there has been a compelling and growing body of research showing that rehabilitation should be part of the clinical pathway for cancer patients. Together, oncology rehabilitation health care professionals are helping more and more people but there is still an enormous discrepancy in the numbers suffering from side effects of cancer treatment and those being referred to rehabilitation.

I need you to spread the word.

I need you to ask your loved ones who've experienced cancer if they are getting the rehabilitation they need... in fact, if they are getting any rehabilitation support at all!

If they are not - I want you to tell them about it.

Secondly, join our [Cancer Rehab Awareness Week Campaign](#). Spread the word in your community. The more people who understand that cancer rehab can help them, and is available, the greater the potential to support people to live their best life after a cancer diagnosis.

Now's the time. Together, let's spread the word.



Lou James (MNZM)