

## Living with Lymphoedema

With increasing survivorship of patients post treatment for breast and gynaecological cancer, many subsequently develop lymphoedema as a potential side effect of surgical and radiotherapy treatment. Lymphoedema is chronic protein rich swelling that occurs when the lymphatic load exceeds the body's transport capacity. It can appear in some people during the months or even years after cancer treatment ends. While other studies have reported a sense of disability and poorer quality of life associated with living with lymphoedema, the experience of Singaporeans affected has not been explored in depth and documented. Here, **Ms Elizabeth Chan**, Principal Physiotherapist from KK Women's & Children's Hospital, shares what her research is uncovering about the perceptions of Singapore women on living with lymphoedema.

### **Q: How did you become interested in the study of lymphoedema after cancer treatment?**

I started my encounter with lymphoedema patients through my work as a physiotherapist in KK Women's & Children's Hospital. Patients who underwent surgical removal of lymph nodes and radiotherapy as part of their treatment for gynaecological and breast cancers were at risk of developing lymphoedema. After completing a specialised decongestive manual lymphatic drainage course, I spend most of my time treating these patients. They share candidly yet honestly the many struggles they encounter while coping with the barriers of living with and managing this chronic swelling in Singapore. As their experience have not been documented, I hoped my study will be an advocate and voice for the challenges patients experience and in so, highlight the importance of preventing and detecting lymphoedema early.

### **Q: As a common complication of cancer treatment, what causes lymphoedema?**

The lymphatic system consists of a network of lymphatic vessels and lymph nodes. The vessels carry lymph fluid containing water, waste products and lymphocytes which play an important role in the body's immunity. Surgery and radiotherapy removes and damages the lymphatic system, making it harder for the body to filter any increase in lymph fluid efficiently.

Poor hygiene and skin care, including injuries increase the risk of infection and consequently, increases the probability of developing lymphoedema. Prolonged constriction from tight jewellery and clothing on the affected body part can obstruct lymphatic circulation. Staying in prolonged fixed positions such as standing or sitting for long hours in those who had pelvic lymph nodes removed can also lead to swelling. Other possible contributing factors include increased body weight, extreme heat environment like saunas and flight travel. While these may be possible factors, it is not always possible to pin point the single cause of lymphoedema in most patients. However, early detection and diagnosis is key as early, mild lymphoedema is reversible.

**Q: How does lymphoedema affect patients?**

Lymphoedema presents as chronic swelling on the affected body part. If swelling is prolonged and untreated, it can also lead to skin changes such as thickening of the skin. In breast cancer patients, the arm on the affected side and in gynaecological cancer, the legs are at risk of developing it. Although it may not always be painful, the extra weight and tightness on the limb can increase strain on patients' movements and flexibility. Footwear and clothes are also more difficult to fit. When swelling is obvious, it becomes harder for patients to hide their cancer diagnosis.

**Q: In Singapore, are cancer patients fully aware of the risk of lymphoedema?**

Cancer patients are increasingly aware of lymphoedema through the education done by various healthcare professionals during their cancer journey. In KKH, all patients undergoing lymph node removal surgery in breast or gynaecological cancer treatment are educated on the signs and symptoms of lymphoedema. They are also given tips on how it can be prevented. These patients are followed up for a period of 1-2 years post surgery to monitor for the onset of lymphoedema as well as to repeatedly remind them of the importance of early detection and treatment. However, this is not a standard practice across all the hospitals in Singapore. Because lymphoedema can occur at any time after cancer treatment, those that develop it many years later may have difficulty recalling this information. Generally, the awareness of lymphoedema is lacking.

**Q: In your study, what are the key areas of concern of Singaporean patients having lymphoedema?**

The key concerns highlighted by Singaporean patients include the lifestyle and attire adjustments they have to make to care for or hide their swollen limb and the dilemma of wanting to treat it due to fear of lymphoedema worsening, yet facing time constraints and discomforts to do so.

Patients have had to forgo simple pleasures such as their favourite clothes and shoes. They struggle with finding suitable footwear and clothes to accommodate the asymmetrical and larger limb size, so as to avoid repeated questioning by others. There is a loss of privacy as their cancer diagnosis becomes exposed.

Patients are also afraid that their condition will worsen and undo their efforts if they did not continue with treatment. Treatment is time consuming. Preparation to head out for work or other social activities becomes less simple as they need to set aside time to don their compression garments. Due to the heat from using multilayer bandages or thick compression garments in hot and humid Singapore, patients are also prone to skin irritation and heat rash. And so they struggle to balance the need to comply with treatment and to avoid this discomforts arising from compression therapy.

Overall, patients feel that their life has had to revolve around having and managing lymphoedema. They have had to make several adjustments and change in decisions for the benefit of their swollen limb.

**Q: Is there any future treatment adjuncts to be developed that can better cater to the needs of patients with lymphoedema in managing this lifelong condition?**

Although there has been growing research in the treatment of lymphoedema, decongestive therapy comprising of skin care, exercise, manual lymph drainage and compression therapy remains the most effective. However, many have started to innovate to develop different types of compression garment and therapy options to ease patient's use and to improve compliance. However they are rather costly at the moment.

**Q: What do you suggest the patients to do to lower their risk of developing lymphoedema?**

The following care tips can help minimise the risk of developing lymphoedema

- Skin care - dry and moisturise well daily so as to avoid skin irritation and infection
- Avoid injuries and cuts on the affected limb
- Avoid injections, blood pressure taking, acupuncture and invasive procedures on the affected body part
- Use sunscreen with high sun protection factor to prevent sunburn
- Use insect repellent to minimise insect bites
- Avoid wearing constrictive jewellery or clothes
- Avoid prolonged resting positions e.g. avoid standing for long periods of time if your legs are at risk of swelling
- Avoid extreme heat environment such as sauna, steam bath and hot springs
- Wear compression garments on flights
- Wear well-fitted covered shoes
- Exercise regularly
- Maintain a healthy body weight

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