



CANCER'S *hidden aftermath*

It's blooming in the arms and legs of many women (and men) across Australia: lymphoedema, an often unstoppable swelling that causes limbs to bulge in the wake of cancer surgery. Yet new procedures to help are on their way, reports **Catherine Marshall.**

ROBYN METCALF WAS weeks away from a family skiing holiday in the US in 1994 when she noticed a peculiar swelling around her pelvic area and upper thigh. A masseuse in her home city of Sydney tried to drain the fluid, but two weeks later, during the 20-hour plane trip to America, Robyn's leg and foot swelled up so dramatically that she required physiotherapy so she could fit into her ski boot.

Unbeknown to her, Robyn was suffering the onset of secondary lymphoedema, a condition provoked by the routine removal of lymph nodes from her groin during cancer surgery 18 months earlier. The lymph flow in Robyn's leg had been interrupted, causing lymph fluid – which contains inflammatory cells and would ordinarily be flushed from the system – to leak into the surrounding tissue. The die had been cast: Robyn's skin

would gradually deteriorate and the tissue between skin and muscle would turn fatty or fibrotic. Ultimately, she would run the risk of contracting cellulitis, a bacterial infection that requires hospitalisation and intravenous antibiotics, and which can lead to septicaemia.

The diagnosis, when it was delivered by Robyn's surgeon upon her return to Sydney, came as a blow: for the rest of her life she would have to wear expensive, made-to-measure compression garments (often called "sleeves") to prevent further leakage of lymph fluid, undergo regular massage therapy and protect the skin on her affected leg from irritation (sunburn, insect bites, abrasions) lest infection set in.

"I didn't understand that this was forever," recalls the now 63-year-old. "I didn't return to my competition squash and covered my leg whenever possible. I couldn't walk on a sandy beach or feel the cool water over my feet. Swimming at the beach was just too difficult. My

self-esteem took a beating. I tried to keep a positive attitude, but the frustration sometimes overcame me and I finally had to seek treatment for depression.”

As the incidence of cancer in Australia grows, so does the risk of secondary lymphoedema. A study by The National Breast and Ovarian Cancer Centre, now part of Cancer Australia, estimates that 20 per cent of breast, genitourinary, gynaecological and melanoma patients will go on to develop lymphoedema in their legs or arms following the removal of nodes

from the groin or armpit (nodes are removed to determine whether the cancer has spread). Moreover, a small number of Australians will live with the condition for life: sufferers of primary lymphoedema who are either born with an under-developed lymphatic system or who develop the condition during puberty, pregnancy and menopause, or when the body's immune system is compromised.

“It's fairly random [among cancer patients] – the one thing that we know is the larger the number of lymph nodes removed, the more likely that you'll get lymphoedema,” says Dr Helen Mackie, a lymphoedema and rehabilitation specialist at Sydney's Mt Wilga Private Hospital and Macquarie University Cancer Institute (MUCI). “Radiotherapy directly over those lymph nodes will also perhaps increase the likelihood of lymphoedema and also being overweight.”

Despite this, lymphoedema is not always accurately diagnosed by medical professionals – a further tragedy heaped upon the patient's original cancer diagnosis. Yet changes are afoot – MUCI is part of an international study to determine whether early intervention prevents the onset of lymphoedema.

“We now have the capacity to pick up sub-clinical lymphoedema, before there is any clear evidence of swelling,” says Dr Mackie. “If we intervene at that point, hopefully, in the future we can show that the early intervention has prevented people from going on to more severe cases. But there will be a percentage of people who you simply cannot do anything about and

it's really important that people who do get lymphoedema are informed or know that they got it because they had cancer and they had the lymph nodes removed, not because they did something they shouldn't have done. There should not be any guilt attached to lymphoedema.”

For those already beset by the condition, treatment is an endless treadmill of self-

massage and manual lymphatic drainage to augment lymph flow, the strict wearing of compression garments and regular, brisk exercise. And while still in their infancy,

surgical interventions are showing promise: the reconnection of the lymphatic and venous systems by super-microscopic surgeons (a procedure not yet readily available in Australia); lymph node transfers (where healthy nodes from areas such as the shoulder or chest are implanted into the affected area); and liposuction, the modern version of a “de-bulking” operation where the fatty or fibrotic tissue is removed from enlarged limbs.

Poignantly, it was as her own mother was dying of cancer that Tiina Eriksson became aware of Macquarie University Hospital's liposuction treatment program. She was herself in remission from a rare and recurrent form of endometrial cancer that she'd been diagnosed with in 2007, at the age of 43. Suffering severe lymphoedema in one leg, she was a good candidate for the surgery. “I was excited at the prospect of having a more normal-looking leg, but also apprehensive because it was going to be a fairly complicated and expensive process,” she recalls.

Four litres of fat were drained from Tiina's affected leg. Her foot, with its toes resembling “fat little piggies who've had roast beef”, was excluded from the procedure due to the risk of permanent nerve damage. Yet her leg was transformed.

“It's now been just over a year since my surgery and the result is as good as could be expected,” she says. “The shape may not be exactly identical to my healthy leg, but I can now wear any type of pants without feeling self-conscious and can finally fit my calf easily into knee-high boots.”

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While liposuction excises much of the limb's abnormal tissue, it doesn't cure lymphoedema and Tiina must continue wearing compression stockings to prevent the reswelling of her leg.

For Robyn Metcalf, her mismatched legs are no longer a source of shame. She eventually returned to her beloved sport and went back to wearing skirts and shorts. Today, she serves as a role model to others suffering this condition through her support of the recently launched Lymphoedema Action Alliance.

“I hope I can pass on some inspiration for those struggling with the concept in those early dark days,” she says. “Life is for living and it is up to us to be proactive and be the best that we can be.” ■

For more information about lymphoedema, visit actionalliance.org.au and lymphoedema.org.au.

CALL TO ACTION

The Lymphoedema Action Alliance – which was launched recently by former Queensland Premier Anna Bligh, herself a cancer survivor – is comprised of 15 cancer, lymphoedema, academic and women's organisations, and aims to improve access to affordable treatment for lymphoedema patients. At present, compression garments are prohibitively expensive and services for both primary and secondary sufferers of lymphoedema are inconsistent. Moreover, medical complications are costly.

“Cellulitis often requires 48 hours in hospital and a week of follow-up by a community nurse and a GP at least. It's a huge cost to the community,” says Dr Debbie Geyer, who chairs the Lymphoedema Support Group for NSW.

“If we invest earlier, we can reduce that cost – not to mention make people healthier and happier.”

