

Questions Specific to Kristy, Anna and Misty:

1. What surgeries did you have? Are you happy with the results? How much was removed?

Answered live 18:13

2. What stage were you?

Answered live 18:39

3. Did any of you have lymphoedema as well as lipoedema? If you had lymphoedema, did it help your swelling feet?

Answered Live 18:58

4. Did any of you manage to do all of this (surgery, recovery from the surgery, and maintain a full-time job). I heard the phrase the other day that managing lipoedema is a full-time job.

Answered Live 18:46

5. Did any of you ever find it “all too overwhelming” even just starting your journey? i.e., Vein work to be done; getting used to compression; the thought of surgery; etc. If so, how did you overcome thoughts like “It’s all so daunting” to take the necessary steps forward?

Kristy: The initial diagnosis is a lot to take in all on its own. Tackle one thing at a time don't over think it. Look at the journey as a checklist you can only do 1 thing at a time so take it slow and breathe.

Anna: Yes, I did find it overwhelming-especially being in New Zealand where there is little support from health professionals on this disease, most do not know this disease exists! I started by getting diagnosed via zoom with Dr Lekich. I then found a local MLD who worked with lipoedema patients (there are several websites you can use to find a MLD therapist in your area). I met with my MLD therapist, and we discussed conservative management and came up with a plan for me. I then made a list of dos for pre-op including the tests and ticked items off e.g., leg pump, custom class 2 compression, back up compression garment, MLD sessions, vibration plate. For ladies who live in small states or New Zealand where access to medical professionals is difficult, I would highly recommend coming over to the Gold Coast for a long weekend and get them completed in person, along with a consultation with Dr Lekich and Dr Teo. Take things in small chunks, you have got this!

Misty: Oh, my word... yes!!! It breaks you. But every day I had my “why” in front of me: I did not want to be a disabled wife. My husband deserved the very best that I could be. I deserved the very best I could be. I allowed myself to be angry, and to cry whenever I wanted to. And I tried a bit more every day sometimes whilst cursing and crying. It still took over two years to get me to the gym, and now I love it (just who is this completely new person that I have become?).

6. Has anyone had a hysterectomy surgery & if so, did you feel your lipoedema &/or lymphoedema become worse after this surgery?

Kristy: No, but I do struggle with PCOS, and the hormones do not help at all.

Misty: I have not had a hysterectomy. The surgical procedure cuts through the lymphatic system causing disconnection and some scarring and potential flare of lipoedema or lymphoedema due to blocked flow of the lymphatic system.

Appropriate mld treatments post-op may reduce oedema and promote healing of the lymphatics. Also, significant hormonal changes post procedure can cause flare up of lipoedema.

7. What advice would you give to someone with stage 1 lipoedema?

Kristy: Start conservative treatment asap.

Anna: Start conservative management and if surgery was an option I would consider as would be preventative. I wish I had known in my early 20s would have answered so many questions I had. As I moved into my 30s the disease progressed and started to take over my mobility and simple things such as getting up and down off the ground started to get harder my knees were very restricted by lipoedema growth.

Misty: Get diagnosed properly so you cannot be gas lighted by your doctor. Start conservative treatment immediately especially low inflammatory lifestyle. Do consider surgical treatment if appropriate. Early intervention slows progression. Don't be like me.

8. Do you have any regrets about having the surgery?

Kristy: None, I'd do it 100 times over to feel the way I do now. PAIN FREE!

Anna: My only regret is that I did not know about lipoedema earlier and if I had, I would have had surgery when I was younger and at an earlier stage, it would have put less pressure on my lymphatic system and veins. I would have surgery every year if it could mean I felt this good as I do now post op. Surgery has changed my life and given me my mobility back, I will be forever thankful.

Misty: Nope, none at all. Ever. Our super is not as large as it could have been, our children's inheritance will be smaller. But I am now living my best life and am not a burden to anyone. This is the best thing I have ever done for myself and for my family.

Questions about Conservative Management and Pre-Surgical Requirements

1. Did you have to lose weight before having the surgery safely? How did you manage that?

Answered live 18:31

2. Did you try conservative management or keto before deciding on surgery?

Answered live: 18:31

3. What do you have to do to prevent more lipoedema tissue from developing? How likely is it that people can keep it from recurring, long-term?

Kristy: Low carb/ anti-inflammatory diet, keeping active.

Anna: I work with my MLD on a conservative management plan to manage post op recovery and my veins. I am still wearing compression either during the day or evening to aid recovery.

Misty: Every one of us is completely different, and our disease progression is also very different. Eat very low inflammatory foods (for me it is just protein and fat, and easy) for the rest of your life. The condition does not go away just because the fat has been removed. Some people can grow new fat cells. Maintain some degree of conservative treatments for life (compression, mld, diet).

4. At what stage did you decide that the conservative management approach was not sufficient, and you needed surgery? Did you have success with the Conservative Management at all?

Live answered 18:51

5. Did any of you have a problem with cramps before surgery, if so, how did the surgery and recovery and cramps go?

Kristy: Yes, I had severe restless legs prior to surgery other than post op jitters and nerves reactivating touch wood I haven't had any issues with this again.

Anna: I am very active with the gym and used to often get cramps, but they have seemed to calm down by taking magnesium and walking. Post op your muscles feel tight but walking and wriggling your toes helped me relieve this.

Misty: I used very low carb, high fat moderate protein ketogenic lifestyle, salt and magnesium plus adequate hydration to completely get rid of leg cramps, leg pain and ectopic heart beats. All gone!

6. What is a vibration plate?

Kristy: A floor plate/ board that vibrates and creates ripples throughout your body/ muscles and helps with blood flow and movement.

Anna: Vibration plate helped me loosen the lymph fluid in my body and helped my legs feel lighter, my usual routine pre op was vibration plate, leg pump then self MLD. The vibration plate can be used in so many ways e.g. sitting or standing.

Misty: A commonly available exercise machine which vibrates causing muscles to contract when standing on it, or resting feet on it. The vibration stimulates muscle contraction which squeezes the lymphatic system to clear oedema. Walking has the same effect but the vibration plate is purported to be great for people who have difficulty walking, and it is a great tool as an alternative to a sequential compression pump.

7. Misty, when you had vein surgery prior to extraction surgery, was it just a day procedure? Was it painful? Did you recover quickly?

Misty: It was a day procedure for both legs, with revision of one leg during the post-op check-up (no local or gas, just a sting when the veins were treated). It was more uncomfortable than painful, with swelling and quite a lot of bruising. I was able to walk immediately e.g. To the car, accommodation, upstairs (very carefully with swollen, bruised sausage legs). Within a day or two I was going for short walks in the local neighbourhood.

Questions about Surgery

1. What were your must haves pre and post-surgery?

Answered live: 18:33

2. Does anyone know whether surgery will need to be repeated in a few years down the track?

Answered Live 18:47

3. Is this permanent removal or can it come back?

Answered live 18:32

4. What is the difference in the surgery compared to a thigh lift by a plastic surgeon? (I have had 2 x thigh liposuctions and lifts done by plastic surgeon with cut from groin to below knee but my legs are still very big and painful.)

Kristy: no skin removal, no huge incisions. If big and painful possibly an inflammatory issue. I think it would also depend on each individual and also the surgeon.

Anna: The surgery is staged to give your body the best chance of recovery and its focus is pure lipoedema removal. I would recommend surgery if you still have lipoedema present. My understanding is thigh lift is removal of skin and some tissue. Lipoedema extraction is focusing on removing the lipoedema disease.

Misty: A thigh lift involves liposuction with skin excision to pull up the loose skin. Liposuction in preparation for this procedure may not remove all the lipoedema tissue and so you may be left with painful fat which can still progress in lipoedema stage. Dr Lekich & Dr Teo concentrate on removing all of the problem lipoedema tissue from the whole affected area. It cannot be guaranteed that every diseased fat cell is removed because it is impossible to see this without surgically opening the entire area and examining the entire internal surface of the affected limb with a microscope. It is just not possible and not safe. Dr Lekich and Dr Teo spend considerable time to manually feel the tissues to isolate lipoedema tissue for targeted treatment. Conservative treatment must be continued for life after lipoedema extraction surgery to control the disease as some cells may be left. This is a genetic condition which does not go away just because a person has surgery. You would need to ask this question to a doctor specialising in lipoedema treatment (e.g. Dr Lekich or Dr Teo). I would expect that yes, you could still have appropriate lipoedema extraction.

5. I think it was Misty who said she had it (Lipoedema) removed from her stomach. Was this diagnosed easily by Dr Lekich? If so, did this make a drastic difference to back pain?

Answered live: 18:38

6. Did they remove the lipoma's as part of the surgery? If so, are they commonly associated with lipoedema?

Kristy: Although each surgery I had large amounts removed I was lucky to not have any issues with lipomas

Misty: I had already softened my large lipomas on the inner knee and lower back of thigh with low carb, high fat, moderate protein keto way of eating, plus compression wear, mld, sequential compression pump 2x per day so the tissue was soft and easy to remove with liposuction. I do still have a few very small nodules remaining, but these do not cause any issues or pain for me.

7. Did anyone have to have a blood transfusion?

Answered live: 18:40

8. What were your total surgery expenses?

Kristy: \$58,800 for 4 surgeries. Other expenses including accommodation, compression, MLD treatments, lymph press, travel, medication etc put the total cost around \$80,000.

Anna: Around 18-20 k per surgery (NZD) including flights for 2 people/ accommodation/ MLD pre/post op and compression.

Misty: For surgery, approximately \$79,000 for six lipoedema extraction procedures. I chose to have six (not less) because I was becoming mentally and physically exhausted with larger volume extractions and preferred the ease of a few smaller procedures. My age and fitness had some influence on this decision. Plus, we don't have a mortgage or dependent children.

9. Does Medicare cover any of the costs?

Answered Live 18:32

10. Did you have a lot of excess skin?

Answered Live: 18:38

Kristy: I had a total of 18.8 litres removed just from my thighs and bottom due to this I do have excess skin 12 months post my last surgery I will assess if it needs to be removed.

Anna: Between upper fronts and posterior backs I had about 2 inches of loose skin. About 3 months post op my skin retracted nicely. I also found going back to the gym, nightly MLD self-massage with moisturiser as assisted my skin. It's a bit to get used to as my legs used to be rock hard like concrete and now feel soft and you can see muscle definition.

Misty: I am 62 years old, have over 40 years of damage and had a very large lipoedema burden (29 kilo weight loss, 24.5 litres fat removed = another 11 kilo weight loss) so cannot expect the same skin retraction as a younger person with lower stage lipoedema. My calves are pretty darn good with just a little loose skin. I do have residual puffy inner ankle because I did have very large cuffs. But these are not apparent in compression or boots or jeans (yes, I get to wear skinny jeans now!!!). My thighs and butt are reminiscent of a shar-pei and I will be having a 360 degree body lift next week to remedy this.

11. Are you able to talk to any memory you have of the actual surgery experience, if any?

Kristy: First 2 surgeries I was awake for and remember most of them was a pretty cool experience. Second 2 I was asleep and cannot remember anything.

Anna: I wanted to have as less twilight as possible, I was very relaxed and dozed in and out of sleep. Dr Lekich and his surgical team talked me through every step I felt very comfortable and safe. I remember asking if I could listen to music which was accommodated.

Misty: I remember groaning at a bit of pain for my first procedure then absolutely nothing. The next four procedures I was only aware if they needed to turn me (sedation is lightened for safety during turning). I remember during my last procedure that I was half awake at the end during the back of thigh revision and being amazed that I felt absolutely nothing at all. That was quite interesting.

12. Considering you all have had a few surgeries did you establish any routines or traditions with the surgery process?

Kristy: Pre-surgery is a splurge dinner somewhere nice, post DVT is a trip to a Bakery/ Cafe. Otherwise, it's just taking it day by day.

Anna: I would always visit Paddock bakery (2 min drive from hospital) after my DVT check. I also booked an "extra" check-up round day 7 post op just to check I was ok and no seromas before I flew back to New Zealand as I knew it would be difficult to get adequate care in New Zealand.

Misty: I have a "liposuction plan" word document table in which I pre-plan and book every flight, accommodation, cat boarding, car parking, car hire, post-op mld treatment, any follow-up appointments etc. It is all planned out months in advance. My procedures were mostly around 8 weeks apart so post-op care ran straight into pre-op care.

13. Has the surgery caused any issues you didn't expect? For example, any hormonal problems?

Kristy: Body dysmorphia, such an instant change takes a lot of getting used to.

Anna: No hormone issues so far. I am finding my legs feel so light and I have so much more energy to be active and I was active prior to surgery too but things are so much easier.

Misty: I only have a multitude of positive effects from the surgery e.g. Joy when I wake up every day. Pride in the completely new person that I see in the mirror. Great love for my adorable, skinny legs.

Questions about Recovery

1. What was your recovery like and how long did it take? Also, what was the most surprising aspect post-surgery?

Answered Live 18:17

2. Do you have any sense on how long it will take to fully recover and whether you will need to always wear compression?

Answered Live 18:22

3. How long does swelling last and what are your tips to reduce the swelling and speed up recovery?

Kristy: Swelling lasts for months but can be minimised and controlled with compression, mld and diet.

Anna: It was different with all 4 of my surgeries. Usually, whole limb for 2-3 weeks then it lessens/ 6 months post op I still had a bit of swelling where I had really fibrotic areas, I worked with my MLD on a care plan to manage the swelling and used items such as a ribbed pad between my skin and compression to assist shifting the fluid, leg pump also helped with speeding up mobbing fluid. Tips for swelling – after surgery wriggle your hands and feet/ankles as much as you can to get blood flowing. Take small walks when you can e.g. I always did a few laps of the apartment every time I went to the bathroom and built myself up. You get very tired so I would usually wake up, have a little walk, shower, put on fresh compression and self MLD, nap and repeat. By day 3 for 3 of my surgeries I was able to walk round the block comfortably.

Misty: I had very little swelling after the first week because I wore my own custom class 2 compression which had been adjusted for my expected post-op sizing. This held everything very firm. I also wore Jobst farrow wraps (firm) over the class 2 which provided even more support and prevented swelling. For buttocks I wore smaller 2xu bike shorts over my class 2s plus the farrow wraps to prevent backflow into my lower legs. My diet remained very low carb, high fat, moderate protein keto with added electrolytes. By week 6 I had lost the minor residual post-op swelling. Only then could I see the true shape and size of the treated area.

4. Kristy, how are you coping with looking after your children whilst in recovery?

Answered live: 18:30

5. How long do you HAVE to have off work (in a sedentary job)?

Kristy: After this surgery I will have had 8 weeks off I work a lifestyle roster.

Anna: I work in an office at a desk and took 1-2 weeks off per surgery (this included my travel over from NZ). For my first week back at work I would work from home on my laptop with a laptop table in bed so I could elevate my legs. I took regular breaks to get walking and MLD. By weeks 3 and 4 I was back in the office 3 days per week.

Misty: I would recommend a minimum of 2 weeks to allow for best recovery so that you can keep your legs elevated, allow yourself time to mobilise well, get back to safe driving and just to heal. These are significant operations which do affect your body and healing.

6. Can you shower and toilet on your own (post-surgery)?

Kristy: Yes, you are fully mobile directly after surgery it just takes a lot of energy those first few days. It's best to have someone with you.

Anna: First 3 days I found it very important to have your support person to assist you even if this is just getting you to the seat. It is very common to feel lightheaded and faint, so you need to get up slowly and walk slowly. My top bathroom tips are – roll a towel round the toilet seat or hire a toilet chair to assist you to go to the bathroom because it makes sitting on a hard plastic seat much easier. I also found a peri peri bottle very helpful to feel fresh and clean. When showering, make sure you have some electrolytes prior to going into the shower and ensure the water temp is not too

hot, sit on your shower chair and let the water run down you. I often found the first shower very exhausting so got my support person to wash my hair for me. First shower after surgery feels amazing.

Misty: I had my carer nearby for the first few days, and always within hearing distance for the first week. I used a shower chair for the first week or so depending upon the procedure.