

## *Psychology and Lipoedema*



*by Dr Femke Leathes*

My role is to meet with Anne's patients before (and if they would like to, also on another occasion later on in their surgery journey), to support them as they go forward. Having surgery is a big decision, and it's important patients have the space to process that confidentially. There are many aspects that pose psychological challenges, including anxiety around the surgery, hopes and fears around the outcomes, concerns about coping in recovery – taking time off work, dealing with pain, not being able to look after family. Many patients can experience feelings of guilt – feeling they are prioritising themselves over others and spending money on themselves that could have been used for other things. There are even challenges around being able to leave lipoedema behind, and adapting to life without it – it takes some getting used to!

After patients have met with Anne for the first time and booked in for surgery, I contact them (usually by email) to arrange a time for our appointment. We do everything remotely over Skype – we're very aware most of Anne's patients don't live anywhere near Birmingham! – so this is one less thing they have to travel for, and it makes it easier to fit into busy schedules, which we know tend to get even busier in the run up to surgery of course. Having met, I ask ladies if they are happy for me to get in touch a couple of weeks after their surgery just to see how they are. We often have a good chat over email about the surgery and the recovery (with often a good deal of humour thrown in – content of which may not always be appropriate to share on the website!). Patients know they can get in touch at any time and arrange a follow-up appointment should they like to do so. There is no right or wrong as to when is a good time for that. Some ladies like to do it soon after the first surgery to debrief, others like to schedule it for just before the second surgery to help prepare, and others still like to wait until right at the end to reflect on what they have achieved and what they are going to be doing (and feeling) in the new exciting chapter ahead of them.

I wonder if I could share some of my reflections from my work with Anne's patients. I've been very privileged to be part of Anne's team working with ladies with lipoedema for two years now. Not nearly so long as Anne! But long enough to learn something about how this very difficult condition affects people.

When I first knew I would be working with Anne, I did what any clinical psychologist would do, and consulted the research. Or, at least I tried to. There isn't much – yet. What there was, suggested that people who suffer from lipoedema are more prone to mental health problems such as depression, anxiety and low self-esteem. The limited number of studies available talked about reductions in quality of life which we know of course has a big impact on mood. What I discovered when I began meeting Anne's patients however, was that this isn't the full picture by a long way. Although there is an understandable amount of emotional challenge involved in living with lipoedema (which of course has its consequences), the degree of strength and resilience in the ladies I have met is extremely high. These are qualities that I think have been neglected in the research, and indeed are so rarely recognised 'out loud' to those people suffering themselves. I hope I can go some way in this blog to start to undo that omission and help Anne's patients realise and, dare I say, feel proud of what they have achieved – not just after surgery, but before they've even got to theatre.

I won't need to tell anyone suffering from lipoedema what an incredibly difficult condition it is to cope with psychologically. Don't get me wrong, it's not the only physically-demonstrable health condition in the world (nor the only one with difficult psychological consequences), but it IS one of the very few which is misunderstood and critically, *misattributed*. It's worse than people simply not understanding; as anyone suffering from lipoedema will tell you, it's that people misattribute it to poor lifestyle choices. In other words – what they're thinking (and sometimes what they actually say) is *"you aren't looking after yourself properly and it's **your fault** you're like that"*. That simply isn't the case with many other visible health conditions, for which sufferers may well be noticed, but are more likely to receive responses that are understanding, empathetic and kind. Lipoedema then, is a double whammy. Most ladies I have spoken to have been told umpteen times by family, friends, even health professionals to lose weight, eat less, exercise more. They have spent years, if not decades, living with a condition they have been told is their own fault and under their own control, but not being able to change it despite often extreme efforts to do so. And all the while being judged for it. How can that not affect one's self-esteem?

Then there are the other aspects to having lipoedema. The pain. The immobility. The practical constraints. Things that most people take for granted such as going for a walk, buying a new pair of jeans (or buying jeans full stop), running in the park with their children, letting the dog jump up on their legs, putting on shorts on a hot day to feel cool – these are major considerations for anyone with lipoedema, and often they are simply not possible. There is sometimes a very sobering moment in my appointments with Anne's patients, when we talk about what they are looking forward to after surgery, if indeed they dare allow themselves to think beyond it. Many ladies have said simply this: *"I am looking forward to being able to wear a pair of wellies and go walking in the rain"*. Wow. This is the basic stuff of life, and it's something many sufferers have had to live without for a very long time. Life is hampered in so many ways by lipoedema. How can that not affect how you feel?

When I meet with Anne's patients, it's usually a month or so before their first surgery. In many ways I know ladies feel at this stage that they are at the beginning of a long haul. Surgery (usually plural) and recovery lies ahead. Most people understandably want to blink and wake up right at the end of the whole lot. But these ladies are not at the beginning; they are at the final chapter. What they have gone through to get to that point is actually the hard part. The years of judgements, pain, discomfort, restrictions, trying to change things but coming up against brick walls every time. And yet every single patient I have spoken with, is there because they have never given up. Despite what they have been told, despite feeling low, despite often great troubles with self-esteem, they have kept hold of who they really are, kept the belief that there must be an answer, and valued themselves enough to find it. That takes something. And that's what I mean by strength and resilience. A real privilege for us all on Anne's team to be a small part of that journey with them.

I am reminded often of something in my work with Anne's patients which I would like to share in closing. Derived from a prayer, I will share the agnostic version here:

*Give me the serenity to accept that which I cannot change; the strength to change that which I can..... and the wisdom to know the difference.*

Want to know what that looks like in real life? Meet Anne's patients.