

What about us? The patient perspective

Neil Piller

It's clear that in order to gain an optimal outcome for the patient, we must first undertake a full assessment. Part of this involves an accurate differential diagnosis to ensure that the treatment is targeted and appropriately sequenced, directed towards the problem and the presented condition is the one that the professional is providing the treatment for.

It is extremely important to understand the individual patient issues to achieve this optimal outcome, and just as critical is treating the whole patient; that is to say a holistic approach and not one focusing just on the affected limb. It's easy to enthusiastically focus on making the leg or the arm smaller, and not hear or think about other issues that the patient may believe are important to them; for instance, range of movement, functionality or how the limb feels. This means we need to continue to acknowledge the patient as an individual, as was presented in a previous editorial (Piller, 2014).

This editorial discusses those aspects and two patients, one with secondary arm lymphoedema (Monique Bareham) and the other with primary leg lymphoedema (Jodie Squiers), who give their personal accounts in this editorial about what they believe is important in relation to their condition, the questions we should ask of them, and the questions they should ask of us as clinicians in this partnership towards achieving the best outcome. It's also about what the patient thinks in terms of how that necessary partnership, trust and open communication should be established.

Monique's introduction (MB)

I am the president of the Lymphoedema

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Support Group in South Australia (LSGSA). My severe early-stage lymphoedema developed 10 years ago at the age of 37, while I was undergoing cancer treatment. I was confidently told: 'You won't get lymphoedema because you are young and not overweight. Don't worry about it.' No baseline measurements were taken because 'we do not want to frighten the patient unnecessarily.'

I was assured I could not have lymphoedema, even when I developed painful and distressing swelling in my arm, hand and fingers. I took photos of me pretending to blow up my hand like a balloon by my thumb in an attempt to allay my fears through humour. I'd not been well informed, nor given a clear plan of what to do should it happen and been told that it simply 'would not happen.'

I still hear similar stories. Many are far more frightened of developing lymphoedema than of having a recurrence of cancer. Outside of the 'cancer bubble', patients have similar stories of not feeling listened to by their healthcare professional. Their lymphoedema symptoms are 'brushed under the carpet.'

Jodie's introduction (JS)

I am a committee member of the LSGSA. My life with lymphoedema started at the age of 12 (Lymphoedema Praecox) when I developed localised swelling in my right thigh. This condition went undiagnosed for approximately 8 years, during which time it had spread to the rest of my right leg, most noticeably in my ankle. Had I received a diagnosis earlier, I believe that my lymphoedema would never have progressed to the point that it did. Even after diagnosis, I was not adequately informed about the condition, what I could do and what I needed to do, in order to properly care for

my limb and to prevent the lymphoedema from progressing, or at the very least, slow its progression.

Communication — is it and can it be a two-way conversation?

MB: Strong and trusting two-way communication is the most important aspect for me and has been a key feature when I have experienced the best health outcomes. It is distressing and frustrating when things don't work as hoped, but when communication is good, we can work together to find a way forward. I become more empowered as a patient too — and that has to be a good thing for everyone.

JS: I think the key point here is that medical professionals and therapists need to be open to the fact that we are all different and that there is no 'one size fits all' treatment plan for someone living with lymphoedema. We are all different and will all respond to treatments very differently. Ultimately, if it works for you and makes you feel better about your limb or yourself then it should be used and taken seriously.

Your choice in treatment options — are you offered a choice?

MB: I do not feel that I have always been provided with a great deal of choice and I have not yet found the holistic treatment approach I need and can afford in one place. Because of this, I realised that if I wanted to maintain the quality of life that I wanted, I had to become an expert in terms of my own lymphoedema. It took me many years of dedicated research, treatment sessions and trial-and-error to put together my personal 'toolbox', which includes self-management and therapy with specialised lymphoedema therapists. I am always finding and learning about new approaches as they develop,

or as my condition changes. This is an expensive and exhausting process, so I fully appreciate why many who do not have the capacity to do this may give up. If I am being honest, I do not believe that the patient should have to shoulder as much of it on their own as they currently do.

JS: In my opinion, unless you have a very good and very well-informed therapist, then no, I don't believe that we are really offered treatment options and/or choices. I think we are largely left to our own devices and left to research the different options and decide what is 'right' for us. I feel there is very much the mentality that lymphoedema is a condition that you just need to live with and 'it is what it is'.

How do you know when a treatment is working (or not)?

MB: I know when my treatment and self-management is working because I can feel it. I'm aware of even the slightest change in my condition. I have an emotional reaction to those changes too; sometimes I am cross with myself because I know I have not been doing all the right things and my arm starts telling me it's not happy. Other times, I am disheartened as, even though I am doing the right things, I still feel very unwell, or my arm starts to swell, or the pain and feeling of woodenness comes back. I personally don't get too hung up on constantly having an L-Dex® (ImpediMed) score, as I believe I already know how my body is travelling. I play a little game with myself that I call 'Guess my L-Dex'. I challenge myself to know what my score is going to be based on what my body is telling me. Mostly, I am correct.

JS: It is 100% a feeling and this is a very hard one to explain. But when my diet is poor, and I don't use my pneumatic compression pump as much or move as much, my body definitely lets me know that it is not happy. My leg feels heavy and starts to ache (even more than it does on a normal day), and if I'm REALLY bad for an extended period of time then I can actually start to feel the changes in my tissue, which starts to feel quite hard.

One of the hardest parts about managing a condition like lymphoedema is that we spend so much time fixing

or working on improving a certain area that by the time we 'fix the problem', so to speak, we find that we have actually created a new problem or moved it to a different area.

A therapist and clinician may have their measurements — volume and circumference, fluid levels and tissue hardness — but what are your measures or views on a good or poor outcome?

MB: We understand that there needs to be measurements but it's not all about the numbers to us. For many, it is all about the 'feeling' and how it impacts on our daily lives. I feel positive on those rare days when I can actually forget that I have lymphoedema. By this, I mean my whole body and arm feels pretty normal. Early on in my first intensive bandaging programme (where I started with an L-Dex of 55), I felt so unwell, my arm was painful and felt like a brick. After several weeks of bandaging, there was a day when I suddenly became aware that I did not feel the pain or heaviness in my right arm. It actually felt the same as the left one. It felt 'normal'. I hadn't had that feeling for months. The relief was so overpowering that I cried.

JS: After finally having undergone surgical liposuction, where I had 3.7 litres of fatty tissue removed from my right leg, I found that my surgical team and treating doctor and I had very different measures of success. They are all about the numbers and the volumes in your leg being symmetrical (and I totally understand that they need a way to measure the success of a surgery); however, as the patient, there is so much more to it than the number. For me, how my leg feels is just as important (if not more important) than the number or how it looks. So while my legs now look very similar (with the exception of my foot and ankle), my right leg still feels terrible and aches daily — for me, my measure of success is all about the feeling and not about the number!

What are the barriers to optimal or prescribed treatment, i.e. time, cost, travel, or lack of a good therapist?

MB: There are many barriers to achieving optimal treatment. There are no subsidies and virtually no public services, so travel

distance and time to get to a therapist may be a factor for some patients, or that there simply is not a therapist to access. Referral pathways and awareness of the condition among healthcare professionals are also major barriers. Even for those fortunate enough to find a GP who is lymphoedema-aware, there may be no-one nearby to refer their patient to or a lack of choice of therapists. This is one of the biggest issues patients face.

When I started on my lymphoedema journey, I did not know what I did not know. Unfortunately, I did not always receive the best advice or treatment and, as I had nothing to compare it to, I followed blindly, even when it felt wrong. This cost me money I could ill afford, which was adding to the stress. I was so frightened of this thing called 'lymphoedema', I lapsed into denial. As time went on, I found a treatment regimen that works for me but this has come at a high emotional and financial cost. If I were to count up how much money/emotional energy, I have spent on garments and treatments that were simply not appropriate, I think I would be like 'wow! Look, I could have gone on holiday!' Consumers should not have to go through all of this to access the health services that they require.

JS: The biggest barrier for most people living with lymphoedema is quite simply the cost. I am the first person to acknowledge that I am very fortunate to be in a position to care for my lymphoedema very efficiently; however, I am the exception and not the rule. Pumps are expensive, garments are expensive (and need to be replaced regularly), massage sessions are expensive. Overall, it is a very costly condition to have.

Who or what has helped you the most with your condition? Google? Local, national or international support groups?

MB: I think you cannot underestimate the positive benefits to the individual that can be gained by connecting with peers. I have come to use the term 'The Lymphoedema Maze' to describe the world I found myself in once I started to develop symptoms. You can find out more about lymphoedema and how to navigate your way through this maze by speaking with others who live

with it, than anywhere else.

I remember a time when I felt so lonely and isolated that I truly believed I was the only person living with breast cancer-related lymphoedema in my age group. One day, I came across a phone number for the Lymphoedema Support Group of South Australia (LSGSA) and suddenly, I was no longer alone. For me personally, the support group has become my purpose and my passion, as it is the mechanism whereby I am able to launch my advocacy efforts. Being an active member of our group has had a profound positive effect on me. I have access to the most up-to-date information about lymphoedema, which empowers me to be the best expert in my lymphoedema possible. Through this I have been able to learn to live with, and indeed love, my lymphoedema. For others, connecting with peers may mean simply joining in with the odd coffee catch-up, or following a group on Facebook. That's the beauty of peer support, as you can reach out and access them when you are ready, in whatever way is right for you.

JS: Without a doubt, this has to be other people living with lymphoedema and the support groups that exist, both in a formal structure like the LSGSA and informal structures like Facebook groups. These groups are invaluable to our community. Just to know that you are not alone and that there are other people going through the same thing as you, makes living with this condition a little more bearable and a little less lonely.

What do we need to do to go further in improving outcomes for you and other people with lymphoedema?

MB: I guess the best way I can answer this is to describe the care I have experienced, which led to the best outcomes for me. Thinking back on those experiences, it was not only about the actual treatment I received. What was equally important, was the level at which I was able to become involved within the process. The more I am able to be involved in my own treatment, the better my outcomes are. The principles of patient-centred care encourages greater patient 'buy-in'. In my experience, the times where I have truly experienced patient-centred care, I have also experienced far better health outcomes.

In conclusion

MB: I think it's important to remember that everyone with lymphoedema has their own unique pathway. Often it has been a challenging, time-consuming and expensive journey, just to get to the point of assessment and diagnosis. There may have been many tests, incorrect and conflicting advice, or even the sense of complete disregard for the concerns of the consumer. For many, it can take a long time to come to terms with, and adjust to, living with a lifelong chronic condition. Taking good care of your lymphoedema requires diligence — it is time-consuming, expensive, relentless and draining. Sometimes I just don't want to 'lymphoedema' anymore, but I do not have that option and this can be the cause of anxiety and depression.

JS: I feel that it's very important for therapists and healthcare professionals to remember that, as the person living with a condition like lymphoedema, we NEVER get a break! If you go on a diet, for example, you will generally be told to follow the 80/20 rule — be really good and diligent 80% of the time, so that you can indulge 20% of the time. This is NOT a luxury that we can afford! If we were non-compliant, even 10% of the time, this would be extremely detrimental to our affected limb and overall health.

References

Piller NB, Finnane A, Partsch H et al (2014) What's best for our lymphoedema patients? Have we lost the patient as an individual in the quest for good science? *Journal of Lymphoedema* 9(2): 6-10

Journal of Lymphoedema update

We are delighted to announce that the *Journal of Lymphoedema* is now proudly affiliated with the British Lymphology Society, the Canadian Lymphedema Framework and the American Lymphedema Framework Project. We hope to enjoy a fruitful working relationship going forward and aim to continue being the world's number one resource for clinicians involved in the care of people with lymphoedema.

Writing for *Journal of Lymphoedema*

Journal of Lymphoedema welcomes a range of articles relating to the clinical, professional, and educational aspects of lymphoedema. If you have written an article for publication or if you are interested in writing for us and would like to discuss an idea for an article, please contact the editor, Adam Bushby, at abushby@omniamed.com

