

Lipoedema UK

Annual Conference and Workshop 2016

Surgical Solutions Simplified

Report by Amy Fetzer



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Surgical interventions for lipoedema can be a confusing minefield, with few surgeons competent in treating the condition and confusion over which credible surgeon is suitable for which type of patient, if at all. The 2016 Lipoedema UK Annual conference helped to provide clarity.

The three-day event brought together many of the world's leading lipoedema surgeons; health care professionals and therapists, along with patients and campaigners. Allied health care professionals attended the first day, whilst days two and three were for members of Lipoedema UK. Members typically comprise of a mix of patients and health care professionals such as lymphoedema nurses and therapists.

The focus this year was on surgical interventions for lipoedema, but also included sessions on the latest genetic research, compression, diet and cognitive behavioural therapy. There were also nurse and surgeon consultations and practical sessions of yoga and aqua therapy.

Liposuction who's who

With only a handful of medical specialists expert in using liposuction to treat lipoedema, respected surgeons Professor Wilfried Schmeller, Anne Dancey and Dr Harry Voesten clarified their varying patient criteria, techniques and outcomes for treating lipoedema. Unfortunately, Scottish surgeon Mr Alex Munnoch had an accident prior to the conference had to cancel at short notice so his techniques for NHS patients with lipo-lymphoedema were not covered.

Early stage options

Professor Wilfried Schmeller and his Hanse-Klinik team from Lubeck in Germany explained that their expertise is treating stage 1 and 2 lipoedema patients under local anaesthetic using tumescent liposuction. The Hanse-Klinik's goal is to bring the disproportion caused by lipoedema back into proportion, thereby improving mobility and limb function. By improving the limb shape and size (often involving 3-4 surgeries), the staging of the lipoedema is reduced.

Professor Schmeller also presented the findings from his peer-reviewed study which found that liposuction can have lasting impacts on reducing pain as well as volume.

Later stage options

Surgeon Miss Anne Dancey focuses on mid to later stage lipoedema patients using liposuction. Birmingham-based, Anne Dancey's technique of using general anaesthetic allows her to treat larger areas, and most of her patients are stage 3 and 4 patients.

Liposuction can be effective in helping to manage lipoedema, but surgery must be undertaken with a surgeon skilled in treating lipoedema patients for the best chance of success. Anne Dancey highlighted new credentialing

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criteria due to come in force next year which would help patients to find out how much experience surgeons have in treating lipoedema patients.

Dr Harry Voesten, from the Netherlands, provided hope for late stage patients whose lipoedema is having a major impact on their life and mobility. His surgery focuses on giving patients back functionality, often transforming patients from being wheelchair bound to being able to walk again. His goal is not to create beautiful limbs, but functional ones that could dramatically improve his patient's quality of life.

There was also a presentation on pre/post-operative care and compression from Anne Dancey's nurse specialist Julie Cuneen and a joint presentation on working with your GP and local clinic from Dr Dirk Pilat of the Royal College of GPs and our Nurse Consultants Mary Warrilow and Kris Jones from Lymphcare UK.

Dr Vaughan Keeley also discussed the surprising and encouraging results that he had achieved through bariatric surgery in reducing limb volume and improving quality of life. Though he stressed the need for his case study findings to be scientifically assessed.

Groundbreaking standard of care

Away from a surgical focus, early diagnosis and conservative treatments are a key component of lipoedema care. But few medical practitioners know how to diagnose or which treatments should be offered, and how a treatment programme should be structured.

In Holland, a groundbreaking Dutch standard of care provides these much-needed answers. One of its key architects, Dr Robert Damstra outlined the standard, which was compiled to give medical professionals a clear pathway for diagnosis and treatment of lipoedema. The standard has helped ensure that integrated lipoedema treatments are now part of free healthcare funding in Holland.

This means that Dutch patients should now be able to access a holistic programme of compression, physiotherapy, dietary and exercise programmes once they have been diagnosed. The teams' careful monitoring of the effectiveness of the programme also showed how effective non-invasive, diet and exercise based techniques can be at vastly improving the quality of life for lipoedema patients.

UK Best Practice Document for lipoedema patients announced

LipoedemaUK were delighted to announce that a collaborative team, spear headed by Denise Hardy (Lipoedema UK's nurse consultant and Anne Williams – Trustee of Talk Lipoedema) would be working with Wounds UK to facilitate a Best Practice Document for Lipoedema. This work will be

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immensely helpful for Lipoedema UK, which will provide a working document including a Standard of Care Pathway. It will provide a blueprint on how to diagnose and care for lipoedema patients, including evidence based practice on which treatments should be included in best practice. It is hoped that the document will be completed by March 2017.

There was also a fascinating update by Dr Pia Ostergaard, on the next phase of the genetic research project about to commence at St George's Hospital searching for the gene responsible for lipoedema.

Practical solutions

Whilst the focus this year was surgical, the members' workshop on Sunday had a strong practical component. There was a rousing presentation on diet by chairwoman Sharie Fetzer, who advocated the benefits of eating anti-inflammatory and whole foods and listening to your body to work out which foods make you feel good – or bad.

There were individual pre-booked consultations with Lymphoedema specialists Denise Hardy, Rachel Warth, Mary Warrilow and Kris Jones for diagnosis and compression prescription. Many members welcomed the session on cognitive behaviour therapy (CBT) from Jane Durston and how it could help with the emotional impacts of lipoedema. Catherine Seo from the Lipedema Project in the USA offered a taster of her embodiment sessions, which are also available on line. Members were inspired to take up more exercise by aqua therapy sessions in the pool with Carole Anne and yoga workshops at Circle Hospital with Kay Hickman.

Learning exchange

It's exciting watching change happen, and to see the medical community galvanised into action. And this was palpable during the 2016 Lipoedema UK Annual Conference.

Throughout the conference, surgeons swapped tips and techniques to improve patients' outcomes and experience of liposuction for lipoedema, whilst the offers to collaborate and share research data and treatment guidelines came from the speakers as well as experts within the audience.

This sharing and exchange was a defining feature of the conference. The team from the Hanse-Klinik shared tips with surgeon Anne Dancey on bruise reduction. A dermatologist from the Netherlands offered the opportunity to share data from a seven-year longitudinal study, whilst member and mediation specialist Micci Gorrod volunteered to run a mediation workshop to give patients some simple techniques to manage the emotional fall out of the condition.

Changing landscape

Living with lipoedema can be a struggle, but the landscape is changing. Momentum is building and the message is getting out to the medical community. Professionals across the spectrum have noted the wider

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recognition from GPs, attributed in part to the Lipoedema UK-supported RCGPs e-learning course, whilst interest in the condition, and in improving patient outcomes, is growing. There's still a long way to go, but the Lipoedema UK 2016 conference was a heartening reminder of how far we've come, and how many reasons there are to look to the future with hope.

Lipoedema UK's Big Patient Survey 2014

The conference also launched the Big Survey results, which will be released in a report in early Fall 2016.