THE SCOTTISH WOMEN'S CONVENTION

A BLETHER ON...

Lipoedema

June 2026

Lipoedema

In recognition of World Lipoedema Day on 11th June 2026, the Scottish Women's Convention hosted an online blether session to give women a platform to share their experiences of lipoedema and to signpost the support options, if any, that are available to them.

Lipoedema affects an estimated 1 in 10 women yet remains one of the most underdiagnosed and misunderstood conditions in women's health, often dismissed as general weight gain, leading many sufferers to face years of medical dismissal before their symptoms are even listened to and seriously addressed.

The women we spoke to discussed experiencing painful and distressing symptoms; inexplicable changes to their body shape, loss of confidence and emotional wellbeing as well as difficulties in their relationship with food: all in addition to the wider impact of being fat shamed and ridiculed.

Our discussion covered several key areas of interest:

- Understanding and recognising the symptoms of lipoedema
- Barriers to diagnosis and dismissal of symptoms
- Fat shaming and emotional wellbeing
- Lack of medical knowledge and the need for proper research
- Lipoedema and broader conversations on women's health
- Shared lived experiences

We hope that the findings from our session will help build a clearer picture of this debilitating condition, leading more women to challenge for changes in women's health care.

4 Key Recommendations:

- Raise awareness of lipoedema and its associated conditions
- Challenge social norms around women's bodies
- Properly funded research to improve medical understanding of lipoedema
- Investment in support services for the condition, including to address the physical and emotional challenges relating to lipoedema

The Scottish Women's Convention (SWC)

The SWC is funded to engage with women across Scotland to ensure that their views are represented in policy and decision-making processes. The SWC uses the views of women to respond to a variety of parliamentary, governmental, and organisational consultation papers at Scottish, UK, and international levels. The SWC gathers information using different methods, including roadshows, thematic conferences, surveys, and both in-person and online roundtable events. This submission presents the views of a range of women, reflecting their opinions, ideas and lived experience. Working together with many other equalities

organisations and community groups, we use our broad network to ensure that women from a range of backgrounds are heard and acknowledged. We are continually reviewing innovative ways of engaging with women and developing our trauma-informed and culturally sensitive practice to support vital contributions from as many women as possible.

Women's Views

"It's nothing to do with lifestyle, nothing to do with not eating the right things, or not exercising correctly, absolutely nothing."

Understanding Lipoedema

During the first part of our session, we heard from Yolande Borthwick, a lymphoedema specialist, who over the years has worked with many women suffering from lipoedema. Yolande explained that although awareness of lipoedema has greatly improved, many women are still being left unsupported and misdiagnosed.

"Unfortunately, I still have stories from many women …they've either had a misdiagnosis, been told they need to lose weight, or [told] what they have is lymphoedema."

Yolande explained that in comparison to lymphoedema, which is mainly due to a fluid imbalance linked to the lymphatic system, lipoedema instead involves the presence of abnormal fat distribution, pain, tenderness and changes in the connective tissue: this typically affects body shape, the knees, ankles and gait. However, Yolande further explained the two conditions can co-exist which can make proper diagnosis even more complicated. She explained that while classic presentations often involve the legs and sometimes the arms, each person's experience can be different and encouraged women to seek assessment when they notice changes in their bodies.

"We know it's mainly women, and we know it seems to be triggered by hormonal changes, so puberty, pregnancy, menopause."

The lack of strong evidence also affects treatment options. Yolande noted that NHS services are evidence-based, but the evidence base for lipoedema is still extremely limited. This makes it harder for clinicians to know which approaches work best and leads to different levels of support across services.

Yolande explained that because of this, diagnosis often depends on clinical judgement and on ruling out other explanations. This becomes harder when women are not listened to when they first raise concerns with their GP.

"So, we're having to exclude what it's not to get to the diagnosis of what it is"

"Life would be so much easier if we could take a blood test or a scan and say, 'Yep, that's definitely it'."

Awareness and Recognising the Symptoms

> "I was really really struggling to lose weight, and I thought my diet was pretty good, I exercised a lot too."

We heard from women at various stages of their lipoedema journey. Some women had only recently began to notice symptoms, whilst others had suffered from the condition for many years, facing long battles to receive a proper diagnosis and support. Some of the women even had healthcare backgrounds but even they found it difficult to recognise the symptoms in themselves.

"I'm from a nursing background…I had a broad understanding that lipoedema was a disorder in which there's a kind of abnormal laying down of excessive amounts of fat or adipose tissue."

However, despite having some awareness, recognition was not always straightforward. Some of the women had linked their symptoms to menopause and described realising that their bodies were not responding as expected, even when they made strict efforts to manage their weight.

"I have to start thinking differently about this, this is not a me and my dietary habits thing, this is a me and my body not working thing."

One of the women we spoke to described recognising the physical changes to her body through photographs taken during open water swimming sessions. Seeing herself alongside other women helped her notice that her legs were totally different and not just larger like she thought.

"…there were women in the group who had bigger legs than me, there were women in the group who had smaller legs than me, but my legs were just lumpy…it didn't look like cellulite, it was just different."

She eventually sought a private diagnosis and then took information from this to her GP. Her experience demonstrated the importance of women knowing their own bodies and having access to reliable information. Many of the women spoke about how they felt about the changes to their bodies.

"it looks as though my fat's got fat on it."

"I would never want to fat shame anyone, but you can recognise it in other people. You know they've got the same as you and there are so many of us out there who its affecting."

Diagnosis and Healthcare Experiences

> "You feel like you're banging your head against a brick wall because no one's listening to you."

The most consistent theme in our discussion was the difficulties many women face in being believed by healthcare professionals.

Most of the women we spoke to described having their symptoms dismissed as just weight problems, often without any exploration of lipoedema or other issues.

"I'd already been about my weight and just been told to go on a calorie restricted diet."

"I'm now down to restricting myself to 500 calories a day, and it's still not shifting."

One woman described the severe pain she endured during routine health checks but felt she had to comply because she was told there were no alternatives.

"Getting my blood pressure taken is excruciating."

"I felt really blackmailed and coerced into just toeing the line and behaving myself about it."

Another shared her own experience of knowing something was wrong with her body from a very young age yet having to wait decades for a diagnosis and recognition. She was ultimately offered bariatric surgery even though her body shape suggested something far more complex than general weight gain.

"How can they offer me bariatric surgery when I'm standing there with a size l4 waist and a size 22 trousers and saying, 'I don't eat enough to need bariatric surgery'."

Our discussion recognised that women need to be more assertive about their health concerns because services do not yet have clear and consistent routes to diagnosis. This places an unfair burden on women themselves, especially when they are already dealing with pain, emotional distress or reduced confidence.

"it is about knowing your body…and learning to recognise some of the signs."

"…go armed with your pack and be sort of really strong and say, no, I would like to see someone, even if you don't think it is, I would still like to go and see someone, can you refer me please?"

Physical and Emotional Impacts

> "I don't want to be this size. I don't want my body to be this way."

During our discussion, the women made it clear that lipoedema affects much more than their appearance. They described pain, bruising, reduced mobility, difficulty in exercising and the challenge of managing lipoedema alongside other health conditions.

"I've got rheumatoid arthritis as well, had that for about 7 years…and currently, I've got long Covid as well."

"I've gone from l0,000 steps a day to l00 steps a day at max."

The women agreed that the emotional impact of lipoedema was also significant. One woman described the exhaustion she felt trying to manage the condition.

"Here I am, no matter what I do, this thing seems to be resistant to it."

"It has a really corrosive effect on your self-esteem, I think."

"You're very disempowered in your own life."

"I think for me, the frustration is not having any control over it."

Some of the women pushed back on the unrealistic expectations of what a women's body should look like and the implications this can have on the way women see themselves.

"Who decided what shape women should be anyway?"

Due to this, others reflected on how repeated messages about weight affected their relationship with food, leading to an eating disorder.

"I had rather an unhealthy relationship with food because I was told that it was fat and it was all my fault so there was no other option."

> "If I was okay with the way I was, I wouldn't be so upset by it all."

Body Image and Wider Society

Our discussion also explored how lipoedema connects with wider stigma around body size. The women were clear that society often treats weight as a moral or behavioural issue and this makes it even harder for lipoedema to be recognised as a medical condition.

"I don't think there's particularly any stigma about lipoedema, I think there's stigma about fat and people just don't differentiate between fat and lipoedema."

The women also described how they had internalised some of the stigma themselves.

"I suppose what I'm saying is that I can't really fault other people for the stigma, because I'm as guilty of it myself, with myself. I give myself a really hard time about this."

Participants reflected on the wider culture of commenting on women's bodies, even when comments are intended to be positive, for example when someone loses weight.

"I lost quite a bit of weight…I was pleased, a bit fitter, I still had the heavy arms, and I still had the lumpy legs. But what I found was, I was really getting upset, because people were saying to me…you must be really proud of yourself … I found myself saying, I'm still me. This is still me inside this body."

Yolanda shared a reflection from one of her patients about the diversity of women's bodies.

"…when you walk through a forest, trees are all different shapes. They're all different sizes. No one goes, oh, look at that big fat tree, and look at that skinny mini tree. We just accept them as beautiful trees."

At the same time, the women at our session were clear that accepting body diversity should not mean ignoring the need for diagnosis, treatment and support for lipoedema.

Research, Awareness and Support

> "Nobody [in the medical community] really wants to own it."

The final part of our blether focused on what needs to change in terms of diagnosis and support, with the women calling for greater awareness, more research and better education for healthcare professionals.

"Research, research, research."

There was some recognition that medical conversations about lipoedema are increasing but there is still a lot of misinformation across social media which can often be quite challenging.

"A lot of it's not necessarily particularly accurate."

"There is quite a discrepancy across the UK as to how much support people with lipoedema can get."

"We want to raise awareness, but we also want to keep it sort of real, within an evidence base, as much as we can."

The women discussed the importance of networking, more open links between charities and professionals, and involving women with lived experience in future research. They agreed that research funding cannot simply be expected to appear from routine clinical budgets,

however there was definitely a need for specialist awareness going forward.

"I think money is the key here and if nobody's raising the money, the research won't get done."

It was agreed that there would be some difficulty in securing funding when the condition itself is not properly recognised.

"A lot of healthcare professionals don't even believe that it's an illness so what chance do we have."

The Importance of Shared Experiences

The women at our session described the value of speaking with other women who understood them and thanked the SWC for providing them with a platform in which to do this,judgement free. They shared that some of their previous experiences led to a lack of empathy from family and friends due to the misunderstanding of what lipoedema is.

"It's sad to hear that other people are going through the same thing as you, but it's also lovely to hear it, because it's like, well, it's not just me and hopefully get some confidence… not that it can be beaten, but it can be managed."

"To have a space that you can actually connect with other people, that you can share these things with 'cause most of my friends, have been saying to me, in the last year or so, do you not want to go on the jags? I just feel I can't talk to them about it, because… they don't get it."

Conclusion

Our lipoedema blether showed the importance of creating spaces where women are believed, heard and can speak openly about experiences that have until now been dismissed or misunderstood.

The women valued hearing from a specialist clinician and from others with similar experiences to their own. They described years of self-blame, difficult experiences with the healthcare system and the emotional burden of living in bodies that changed in ways they could not control.

Our discussion made clear that awareness about this condition alone is not enough. Recognition must lead to proper diagnosis, research, specialist services and training for medical professionals on all women's health issues.

An important message from our session was one of validation in that women living with lipoedema are not alone. We strongly believe that the findings from our session should be treated as essential evidence and go some way in improving healthcare and support for this debilitating condition in Scotland.

Thank You!

Thank you to the women who shared their experiences with us. We will continue to advocate for women across Scotland so that their views are included in the policy-making process.

Scottish Women's Convention

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