



Women's Health Strategy: Call for Evidence, Spring 2021 Official Response from Lipoedema UK

Lipoedema UK, in collaboration with the Chronic Illness Inclusion Project, has compiled the responses of 180 women, all identifying as having Lipoedema, for inclusion in the Women's Health Strategy consultation, being undertaken by Government, Spring 2021. Also attached as a separate document is Appendix A – the source material for this response.

Demographic summary

81% of these women live in England, with 10% living in Scotland, 4% in Wales and 3% in Northern Ireland.

98% of respondents identify as white British.

There is a decent mix of responses from across the UK regions and nations.

Over two-thirds of respondents are in mid-life, aged between 35 and 65, at the time when Lipoedema often starts to have significant detrimental effects on overall health and mobility.

Key findings

Over 99% reported they had endured their conditions for over 12 months and expected them to last 12 months or more, in keeping with the knowledge that Lipoedema is a lifelong condition.

Almost a third of respondents identify as having stress, anxiety or depression.

Around a fifth identify as having Fibromyalgia, Hyperthyroidism, Irritable Bowel Syndrome, Musculoskeletal conditions including Arthritis.

Over 73% identified difficulty with mobility, for example walking short distances or climbing stairs.

Over half reported energy impairment (problems with fatigue or stamina).

A fifth reported dexterity problems, for example lifting or carrying things or using a keyboard.

Around a sixth reported problems with memory.

93% reported that their conditions affect their ability to carry out day to day activities, with almost half of these saying their conditions affected their ability 'a lot'.

Two thirds of respondents took over a decade to receive a diagnosis. Two thirds had been misdiagnosed before receiving a diagnosis. Only 13% of GPs identified Lipoedema in those who had had a diagnosis.

Almost three quarters had not been given talking therapies to come to terms with having the condition, or behavioural therapy (eg exercise) to help manage pain or fatigue.

Over two-thirds reported talking therapy as being unhelpful for managing physical aspects of their conditions.

94% has been made to feel disbelieved by a health or social care practitioner with 70% experiencing this 'often' or 'very often'.

90% of this disbelief was encountered in experiences with GPs. Almost 90% found being disbelieved affected self esteem.

Over 60% found being disbelieved affected close relationships including family and friends.

Two fifths found being disbelieved affected their relationship with their employer.

Two fifths found being disbelieved affected their ability to obtain benefits. Over two fifths identify as being Disabled.

Three quarters do not feel supported by the services on offer to them.

A quarter need Social Care support with basic daily tasks but almost half of these women cannot access it.

Almost two fifths do not believe they are receiving adequate mental health support.

Over half do not receive adequate pain relief.

Only just over a quarter have received a referral to a specialist.

A quarter are housebound or bedridden because of their conditions. Only 3% are able to access domiciliary care.

Over two thirds report negative impacts on their health due to the Covid pandemic with almost three quarters reporting that services have become harder to access.

Before receiving a diagnosis, nearly all respondents had been diagnosed as: fat, lazy, liar, obese, in need of exercise, hormonal, or suffering from a lymphatic condition. The vast majority were accused of having obesity, a completely different condition to Lipoedema.

Nearly all were told to focus on diet and exercise, despite these having no clinical impact on lipoedemic fat (they only work on 'normal' fat). Many had sought interventions for decades and were dismissed and disbelieved.

Of those who received a diagnosis and were referred to a specialist, most could only get as far as seeing a specialist nurse. None reported being able to see a surgeon about removal of lipoedemic fat.

Conclusions

The current interventions available for Lipoedema are woeful.

This is a progressive disease, especially at times of hormonal change (puberty, pregnancy and menopause).

It is imperative that GPs are educated on the condition to prevent disbelief, the tarring of patients with the deeply misogynist brush that they are 'making it up' or are 'fat and need to lose weight', and

misdiagnoses.

Better record keeping is needed on the condition – some estimates put the number of women who endure the condition as being above 10%. Proper statistical research is needed to identify the number of women with the condition, and to measure success metrics in treating the condition.

A dedicated clinical network is needed for the condition. At the moment, services piggyback Dermatology and Lymphatic Clinics. However, the knowledge about Lipoedema across these sectors is a postcode lottery with many areas of the UK suffering a serious dearth of those with even rudimentary knowledge of the condition, let alone experts.

Earlier diagnosis will lead to better early preventative measures, such as the prescription of compression, manual lymphatic drainage, and specialist diets which can help avoid comorbidity with obesity, but will not 'cure' or 'remove' Lipoedemic fat.

Proper research is needed into the benefits of surgery to get it on the radar of NICE and the NHS as a viable option for the millions of women with Lipoedema.

Surgery should be as routine as it is for hip and knee replacements as it is a management intervention for mobility and pain. At the moment, a single NHS clinic exists for the condition in Dundee, for the whole of the UK.

Funding applications need to go through NHS England rather than CCGs (who tell patients from the off that they cannot afford to fund it). Patients who apply for funding are knocked back as the default. Only single figures of patients, out of millions, obtain surgery every year.

There is evidence from the private sector that surgery drastically improves mobility, comorbidities caused by carrying excess weight, and significantly relieves chronic pain (Lipoedema leaves limbs painful to touch, and those in the later stages suffer from joint pain associated with excess weight which cannot be lost through diet or exercise).

This is a highly visible condition which when understood, is very easy to diagnose. The types and stages of the condition are clear. The progressions are clear. And they are catastrophic for those who move between them into ever increasing immobility.

This is a condition which at a certain point, influences mobility, the ability to carry out day to day tasks, which affects mental health, and self esteem. It is crowbarred into the same negative life outcomes as obesity: dismissal, a deep loathing by society at large which perceives sufferers as those who cannot or do not self care, a lack of ability to gain employment, a lack of basic amenities which physically fit – from seats in public spaces to clothing, a lack of high quality personal relationships.

Lipoedema is in essence a deformity, in essence a form of tumescence or growth, both things the NHS offers tangible treatment for in the form of surgery.

Surgery for the condition is currently seen as cosmetic. Cosmetic surgery for women can greatly improve mental health and self esteem – it is why the NHS offers breast reconstruction, or removes singular, globular tumescence.

Women with Lipoedema experience whole limb tumescence, most often in lower limbs, but also in upper limbs, buttocks and the stomach area.

Women with later stage Lipoedema carry around weight equivalent to constantly carrying around a child aged between two years of age and puberty – weight which cannot be removed without surgical intervention. There are few conditions where the NHS would conceivably allow people to endure such physical suffering without such non-surgical intervention as standard.

For sufferers, add in critical chronic pain relief and mobility as necessary outcomes and it is clear why we are adamant that a surgical network is also needed across the UK to start delivering positive outcomes for those who endure this condition.

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Visit Lipoedema UK to find out about diagnosis, treatment options and our pioneering work to help change the future for people living with lipoedema

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