

## **Cross-Party Group on Women's Health: Lipoedema**

Tuesday, 22 January 2019, 6:10pm-8:00pm

The Scottish Parliament

Topic: Lipoedema

### **1. Welcome**

Monica Lennon MSP welcomed the group to the meeting and gave apologies for MSPs who were unable to attend.

Introduced the BBC who were filming the event for an upcoming feature on lipoedema and advised guests re data protection.

Monica welcomed the speakers:

- **Mr Alex Munnoch**, leading surgeon who performs liposuction as a treatment for lipoedema.
- **Anne Williams**, Nurse and Trustee with [Talk Lipoedema](#)
- **Anne Henry** will speak about her personal experience, which you can also read about [here](#)

### **2. Presentations**

#### **Alex Munnoch**

Mr Munnoch's presentation is available on the CPG webpage. Key recommendations from the presentation include:

- Greater awareness – a medical condition, not simply obesity
- Better education of all healthcare professionals & public
- Adequately resourced facilities for diagnosis, support & management
- Similar recognition to other long-term conditions

#### **Dr Anne Williams, Lymphology Nurse Consultant (Lecturer and Researcher on Lipoedema)**

Dr William's presentation is available on the CPG webpage. Key recommendations from the presentation include:

- Improving knowledge of lipoedema amongst health care professionals; most do not accurately distinguish obesity, lymphoedema and lipoedema; BMI is commonly used and is misleading
- Pathway to enhance diagnosis and treatment decisions
- Education in schools and for young people
- Early diagnosis to keep people well and in work: women with lipoedema are central to healthy family and work life in Scotland
- Obesity focus in Scotland does not consider lipoedema: NHS Health Scotland, SIGN guideline, Growing up in Scotland: overweight and obesity at age 10 (2017)
- More cost-effective if women can be supported to stay mobile, manage their weight, avoid unnecessary surgery such as joint replacements.

## Anne Henry

- Anne shared her personal experience of lipoedema.
- Anne said she received a diagnosis of lipoedema in August 2017, 30 years after she first noticed her symptoms.
- She said her symptoms were frequently dismissed or misdiagnosed as obesity by health professionals.
- Anne highlighted the issue of long waiting times. She said she had to wait 9 months to be referred to specialist Mr Alex Munnoch. She said that as of the day's meeting on 22<sup>nd</sup> January 2019, she was still waiting on surgery.
- Anne highlighted the difficulty in obtaining liposuction as a treatment for lipoedema. She said she had investigated treatment privately but the cost of £40,000 was prohibitive for most people.
- Anne raised the issue of fertility treatment for people with lipoedema. Fertility treatment requires women to be within a certain weight range. Due to lipoedema being underdiagnosed and misunderstood, there is a risk fertility treatment is withheld until people are within the specified weight range.

### **3. Discussion/ Q&A**

Wide ranging discussion about points raised in the presentations and about attendees' personal experience. Key points include:

- There were concerns that people with the condition experience stigma and negative comments about being 'fat'.
- There were concerns that it takes too long to get diagnosed with lipoedema. There was concern that health professionals do not have adequate training to recognise the symptoms of lipoedema so the condition is not recognised. Mr Munnoch said that lipoedema could be diagnosed in minutes if health professionals have the appropriate training.
- There were concerns that there is not enough public awareness about the condition, so people do not recognise their own symptoms. This can lead to frustration as people do not understand why they cannot lose weight despite diet and exercise.
- There were concerns about the negative impact that a slow diagnosis can have on people's mental health. Attendees spoke about not feeling believed, and that their symptoms are dismissed or misdiagnosed. Attendees with the condition reported finding the journey to diagnosis a 'lonely' experience.
- There was concern about the availability of lipoedema specialists and the sustainability of the service. There was concern about succession planning for Mr Munnoch, who is the only surgeon in Scotland who performs liposuction as a treatment for lipoedema.
- There was concern that the obesity strategy does not adequately address lipoedema.
- There was concern that there is not enough accurate data.
- The group was advised by a representative from Lipoedema UK that there is a 30-minute Lipoedema online course that is free to all GPs, but that currently there are only a couple of thousand who have taken this course.
- There was discussion about lipoedema not being the sole responsibility of GPs, and there are opportunities for other health professionals, for example community nurses, to recognise the symptoms.
- The group agreed to write to the Cabinet Secretary for Health & Sport to raise concerns identified during the meeting.

Attendance list

Name	Organisation	CPG member
Agnes McGowan	Lymphoedema therapist	
Aileen McGarry		
Andrena Coulstock		
Ann Gray		
Anne Henry	Speaker	
Anne Williams	Speaker	
Anne Yolung		
Carol-Anne Buchan		
Carole Doyle		
Cath Bussey		
Cynthia Prentice		
Daniella Crolla		
David Berry		
Dr Alison Scott	NHS Lothian FSRH Scotland	Yes
Eilidh Dickson	Engender	Yes
Elaine Purvis		
Elinor McDowell		
Fiona Rogan		
Isobel Harris	Lipoedema UK	
Isobel Macewan	Talk Lipoedema	
Jane Hannah	Lipoedema UK	
Jane O'Connor		
Jonathan Sher	Queen's Nursing Institute Scotland (QNIS)	
Julie Arnott		
Kate Forster	Lipoedema UK	
Kenneth Gibson MSP	MSP	Yes
Kevin Coulster	Lipoedema UK	
Kimberley Berry		
Laura Goodwin		
Lorraine McDougall		Yes
Liita Cairney	Kalitasha/Secretariat	Yes
Mairi Handy		
Monica Lennon MSP	Convener	Yes
Natasha Zivkovic	Red Alert	Yes
Robert Arnott		
Rodney Fetzor	Lipoedema UK	
Ronnaug Smith	Talk Lipoedema	
Rose Harkness	South Lanarkshire College	Yes
Sally Millar		
Sharie Fetzer	Lipoedema UK	
Sheena McDonald		

Verity Stuart	Red Alert	Yes
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