St Margaret's
Hospice Care

General Information and Advice on Lipalgia Syndrome (Lipoedema)

Introduction

This leaflet provides information and advice about managing your Lipalgia Syndrome (Lipoedema) based on what we understand so far. However, we want to learn more about what people with Lipalgia Syndrome need to help them with this condition. We have started to assess and re-assess people with Lipalgia Syndrome using new detailed specifically designed documentation.

The term Lipalgia Syndrome better reflects the condition as it means ‘painful fat’, whereas Lipoedema suggests there is oedema (fluid) present, when often there is not. For the next few years, we will be using both terms Lipalgia Syndrome and Lipoedema but it is important to remember that it is the same condition.

What is Lipalgia Syndrome (Lipoedema)?

Lipalgia Syndrome is a build-up of fatty (adipose/ lipid) tissue that affects areas below the waist (i.e. buttocks, hips and thighs), extending down both legs equally to the ankles, but never in the feet. The shape of the legs can create a bracelet appearance at the ankle, and sometimes a fatty lump below the knee on the inner shin. The legs are often described as being painful, tender or achy, and the fatty tissue can give the impression that the legs are out of proportion with the rest of the body.

There is no evidence Lipalgia Syndrome affects the stomach. Fatty tissue around the abdomen is usually due to obesity. Lipalgia Syndrome can occasionally affect the arms, but again this is more often linked to obesity being present as well. There may be other symptoms that are related to Lipalgia Syndrome and more research is needed to confirm these.

What is the cause of Lipalgia Syndrome?

The cause of Lipalgia Syndrome is unknown; however, it predominantly affects women. It seems likely that there is a genetic link as it can occur across generations (i.e. grandmother, mother, daughter, aunts); but to date, no gene has been identified. Many women report that they notice symptoms starting at times of significant hormonal changes, for example puberty, pregnancy and menopause.

How is Lipalgia Syndrome diagnosed?

There is currently no test that can diagnose Lipalgia Syndrome. The clinical diagnosis is based on a thorough assessment performed by a trained clinician.

Is Lipalgia Syndrome related to Obesity?

Obesity is not known to cause Lipalgia Syndrome; however, all research evidence to date has shown that an increase in body weight will make Lipalgia Syndrome worse in that the size of the legs will increase and pain increases. We understand weight loss can be difficult and challenging, but it is really important to recognise that weight gain increases Lipalgia Syndrome problems.

Is Lipalgia Syndrome the same as Lymphoedema?

No, these are two separate conditions. Lipalgia Syndrome is a painful fat condition mainly affecting women and their legs, whereas Lymphoedema is a fluid based swelling that can affect anyone, any part of the body, and there is usually an identifiable cause for the swelling.

If lymphoedema is left unmanaged, the swelling will increase causing changes to the skin and shape of the affected body part(s).

Complications such as skin infections (cellulitis) and wounds (ulcers) may also occur. In most cases, the feet are also swollen if the lower limbs are affected.

You can have lymphoedema from obesity as well as Lipalgia Syndrome.

Image of Lymphoedema

How do I manage my Lipalgia Syndrome?

Firstly, a detailed assessment is needed to confirm that you have Lipalgia Syndrome. Early identification and advice can help you gain better control of your condition. It can take time to understand the diagnosis and adapt your life accordingly as there is currently no cure for Lipalgia Syndrome. Be kind to yourself and take your time to focus on what you can do to manage your symptoms.

1. Movement, Activity, Exercise

Any movement of your body will help improve and maintain your flexibility, keeping your bones and muscles strong. With Lipalgia Syndrome, inflammation and hypoxia (lack of oxygen to the tissues) is a cause of pain. By moving your body, the muscles will increase the blood flow that will remove toxins causing inflammation. It will also increase the amount of oxygen your tissues will get, thus improving the hypoxia. Therefore, you may find that moving your body more will help reduce some of the pain you may have. Activities can help you better manage your weight, or help you lose weight if needed. Research has also proven that there is a huge benefit to your emotional wellbeing if you are more active as it releases natural endorphins. Lastly, being more active can also be a good opportunity to meet others and socialise, which can help us to feel better and more connected.

Below is some general advice and guidance to consider. Current evidence supports that keeping active reduces the symptoms of Lipalgia Syndrome. As with any new activity, do your research or ask advice from your GP, a physiotherapist or your lymphoedema therapist.

What types of activities?

Any activity that gets your body moving, your heart to beat faster and your blood to pump more around your body will do. Think of something you enjoy doing and that you could repeat on a regular basis. Activities such as walking are ideal, as are swimming, cycling, bowling, gardening and even going to the shops. Some people enjoy dancing around the house when the radio is on, or when they do their housework. Why not start by walking or marching on the spot while waiting for the kettle to boil? Some watches and mobile phones can capture the numbers of steps you take every day to help you measure the progress you are making.

Some people purchase gadgets or machines at home to help them move more. Some people with Lipalgia Syndrome have recommended the following items:

- **Vibroplate** - it is thought that the shaking from this device can relieve pain and aching. It can be set up in any room convenient to you. No more than 10 minutes a day is needed. It can leave your skin tingly for the first few times you use the device, but this lessens if you use the machine regularly.
- **Mini-Trampoline** - rebound therapy or just walking, jogging or jumping on the trampoline gets the muscles stronger, improves balance and helps reduce pain and aching. There are many short films on the internet that can help you with an exercise programme that would suit you.
- **Walking pads** - these are easily stored under sofas and beds. Great for those who want to catch up on their favourite T.V programme while getting their steps in!

If your mobility is limited, try to find ways you can move your body in a way that is possible. If you tend to sit a lot then try getting up and moving around a little bit more every day, or lift your arms and legs while sitting in the chair, or get hold of some pedals and cycle while you watch / listen to your favourite programme; or even while you work.

Toning exercises are also beneficial. Using low resistance bands or hand weights (can be tins of food of various weights) with more repetitions of the movement, can achieve better muscle definition without bulking the muscles. The British Heart Foundation website offers ideas of movements using a resistance band:

https://www.bhf.org.uk/informationsupport/heart-matters-magazine/activity/resistance-bands

Chat to your health professional to work out what form of activity may suit you. They may be able to help you with a with local exercise programme.

Is swimming good for Lipalgia Syndrome?

Evidence suggests that water-based activities, like Aqua Aerobics and walking in the water, have the benefit of the tissues being supported by the water thus reducing pain in the tissues. When moving in water there is less impact on the joints, which is helpful for those with pain. There is growing evidence that cold-water swimming helps regulate body temperature, reduces pain and helps manage hormonal changes especially due to menopause. You will need to search up on the internet if there is a group near to you.

How much exercise should I do?

Public Health Guidance recommends 150 minutes of moderate intensity activity a week spread evenly over 4 to 5 days, or every day. That means half an hour for five days a week, or just a little over 20 minutes every day. Ideally two of these days should focus on strengthening exercises. However, just moving a little more today than you did yesterday is a great goal to aim for, gradually being more active every week. For some people, moving little and often during the day, building up to 20 minutes works best. It means you do not have to do the full time in one go - spread your activity a few minutes at a time so that you get a bit warm and breathless each time.

My pain gets worse doing activity; what should I do?

Try wearing support/compression on your legs to see if the support they give to your tissues and joints reduces any pain when being active. Support/compression may be sports leggings or tights. Water-based activity is often favoured as the water pressures support the tissues like compression garments. Walking in the water may be easier for those with joint aches and pain.

If you are on regular pain medication, consider taking them at least half an hour before doing your activity to see if it helps manage your pain better. Pacing yourself is important. Listen to your body; when it says it is tired, rest. Talk to your therapist, a physiotherapist or your GP for further advice.

What should I do if I become short of breath?

It is normal to become slightly short of breath when exercising. This is due to the heart pumping faster and the higher demand for oxygen needed in your muscles to continue doing the activity. Once you stop the activity, you will find your breathing will slowly go back to normal. The good news is that the more often you exercise, the longer it will take to become short of breath, and the faster you will recover afterwards.

If you are unsure or frightened by your shortness of breath, or you have a heart or lung condition, talk to your therapist who may be able to adjust what you are doing, or refer you to a programme where support is available to monitor you.

What intensity of exercise should I be aiming for?

Moderate intensity exercise is recommended. To achieve this, your activity needs you to be working hard enough to increase your heart rate and break a sweat. A way to tell if it is moderate intensity is that you will be able to talk, but not sing the words to a song playing in the background.

Is there somewhere I can be referred for help with exercising?

Every Health Board and Local Authority in the UK has a support programme to improve your health and wellbeing. Check online or ask your therapist or GP for more information for a referral.

2. Weight Management

Normal fat cells increase and decrease in size as you put on or lose weight. Fat cells multiply if we allow our BMI to increase too much, leaving loose skin when we lose the fat from these cells. Fat cells in the Lipalgia areas are different in that they multiply more quickly and do not readily shrink when losing weight. When losing weight, people with Lipalgia Syndrome may find that their legs are the last part of their body to reduce in size. In addition, people with Lipalgia Syndrome may find that every time they gain weight it becomes more challenging to lose it again.

Positively, most people who lose weight find that their Lipalgia Syndrome symptoms greatly improve. Aiming for or maintaining a healthy weight is therefore an essential part of managing your Lipalgia Syndrome. Weight loss is very challenging but with the right support and information, it can be possible. Current evidence warns against yo-yo dieting as each time you stop a diet after losing weight, you are more likely to regain weight in excess to where you started. This will make the Lipalgia worse. Therefore, if you need to lose weight, do so steadily and work at keeping the weight off.

Lipalgia Syndrome does not affect the waist area. If the size of your waist is going up, this will be due to weight gain and can lead to obesity if the weight gain is not stopped. You also need to be aware that the higher your BMI gets, your risk of developing other health conditions including lymphoedema increases.

We can look at whether obesity is part of your problem in two different ways:

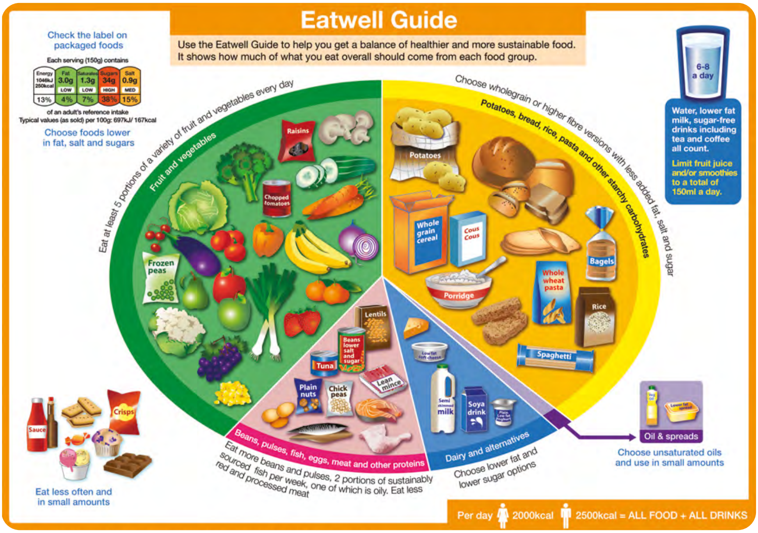
- Body mass Index (BMI) - your weight and height are used to make the calculation. If you want to calculate your BMI, try the NHS BMI Calculator: **www.nhs.uk/live-well/healthy-weight/bmi-calculator**

- Hip to waist ratio - measuring your waist and hip to work out a ratio between them. For more information on how to calculate hip to waist ratio, and what it means, have a look at: **www.omnicalculator.com/health/waist-hip-ratio**

What is healthy eating?

The NHS website has pages full of information and guidance about eating a healthy, balanced diet: **https://www.nhs.uk/live-well/eat-well**. The Eatwell Guide is one of many documents available on the government website that gives you guidance to help you eat a healthy, balanced diet. They advise that eating well and having a healthy lifestyle can help you feel your best and make a big difference to your long-term health.

Source: **https://www.gov.uk/government/publications/the-eatwell-guide**



There is a video film explaining 'healthy eating' tips. Follow this link and QR code: **https://youtu.be/XN_vQFWzE2E**

Is there a specific diet for Lipalgia Syndrome?

There have been a few studies looking at diets that may help with Lipalgia Syndrome. Consensus documents conclude that maintaining a healthy weight leads to reduced symptoms. They advise avoiding short-term diets and to try energy balance over calorie counting. Furthermore, it may be that anti-inflammatory dietary habits such as fasting periods within each 24 hours, like 12 hours over night and another 4-6 hours in a day, will be particularly useful to some people. Further information should be available from suitably qualified professionals.

We encourage a healthy eating plan to ensure you get the vitamins and minerals your body needs to function. For some people, keeping a food diary may help them see what they are eating. Research into the use of Ketogenic diet where the focus is on low carbohydrates, is ongoing. Some research suggests a Mediterranean diet to be of benefit. Overall, any healthy diet that leads to weight stabilisation and weight loss if needed will improve symptoms.

I am struggling with my weight management. What help is available?

We understand that losing weight is a complex issue which is more than just finding the right diet. All health boards in the UK offer weight management or bariatric services for people who have tried all the usual things. Talk to your GP if you would like a referral to one of these clinics where professional guidance and support is offered. Your GP or pharmacist may also be able to advise if an anti-obesity medicine that may help you. All weight loss medication needs a prescription to ensure you receive the treatment that is best for you and where you can be monitored against side-effects. The NHS website has a useful page (**https://www.nhs.uk/conditions/obesity/treatment**) of information explaining treatment options for Obesity. For those who have a higher BMI, Bariatric surgery (weight loss surgery) may be an option for you to consider. There are strict criteria to meet for this surgery on the NHS, but private options are also available.

Your GP may refer you to your local weight loss or bariatric service for further information and support to help you with your weight loss needs. There are also private weight loss clinics that offer medicated weight loss options such as the well-publicised weight loss pens/injections. Always ensure that a qualified medical doctor prescribes this treatment and you fully understand the risks as well as benefits.

3. Pain Management

It remains unclear why some people experience pain in the fatty tissue of Lipalgia and others do not. Research suggests that long-term low-grade inflammation exists together with tissue hypoxia (reduced oxygen) causing pain in Lipalgia Syndrome. The experience of pain can have many causes and may be in combination with other health conditions such as arthritis, diabetic neuropathy or peripheral arterial disease, etc. So, the cause of your pain needs to be understood to help guide your therapist in how best to support you.

What can I do to reduce the pain?

As with any painful condition, there is not one known thing that can be done to reduce pain. Women with Lipalgia have suggested different remedies they have used to help relieve their pain which include:

- Alternative therapies such as Reflexology, Acupuncture, Reiki and Aromatherapy
- Activities such as swimming and walking
- Hot or cool pads. Some people report that trickling tepid water over their legs helps their symptoms
- Massage using ginger oil
- Topical (on the skin) anti-inflammatory cream or gel
- Compression garments or supportive leggings.

You may benefit from talking to your GP about medication that may help control your pain.

Will compression garments help my pain?

Compression garments or supportive leggings will provide support for the tissues. In most cases, support wear helps with hypersensitivity and pain.

Where can I get compression garments?

There are many forms of compression garments available on the NHS, online or from department stores. Some people prefer to purchase their own compression leggings as they are more cosmetically acceptable than what is available on the NHS. Compression leggings or tights are available from:

- Department store body shaper tights/hold me in tights or leggings/spanx type support
- Sportswear compression leggings/vests for running, Gym classes etc.
- **https://snagtights.com**

NHS options available include below knee, thigh length stockings, tights and leggings. Colours are mainly black or beige. Light compression in most cases is enough to control some of the Lipalgia Syndrome symptoms, with stronger compression recommended for those people who also have lymphoedema. NHS compression garments last for 6 months of daily wear. You will receive two pairs of garments to allow you to wear one whilst the other is being washed. Therefore, your compression garments should last for 9-12 months. Compression garments can be hand or machine-washed but do not use fabric conditioner. All garments come with manufacturer's guidance and it is important you follow their instructions. Please do not keep one garment for best as this will not help to manage your Lipalgia Syndrome.

Remember compression garments will not reduce the size of your legs.

4. Skin Care

Why should I look after my skin?

Generally, people should look after their skin to reduce the risk of damage and infections. We recommend applying a moisturising cream to your skin after washing to alleviate dryness and cracking of the skin. When in the sun, use a high factor sunblock to reduce your risk of sunburn. General recommendation is to use Factor 50.

5. Is there an operation that can help Lipalgia Syndrome?

There is no specific surgery that can 'cure' Lipalgia Syndrome. There are surgeries that may help reduce some of the symptoms you experience and these include Bariatric Surgery and Liposuction. Bariatric Surgery is aimed to help with weight loss and can have a positive impact on improving symptoms of Lipalgia Syndrome. Liposuction aims to remove the fat from the affected areas; however, this surgery is not currently available in the UK.

Liposuction

Liposuction is considered a cosmetic procedure used to remove unwanted body fat. It involves sticking a catheter into small cuts in your skin and sucking the fat out. For Lipalgia Syndrome it is recommended to use tumescent liposuction where fluid is injected into the tissues to loosen it before sucking out the fat. It is considered the least painful method of liposuction with faster recovery times.

Why is Liposuction not available in the UK?

The National Institute for Health and Care Excellence (NICE) produced a document in March 2022 in which they recommended stopping liposuction for Lipalgia Syndrome in the UK due to safety concerns and a lack of evidence on the effectiveness of the procedure. They advise that liposuction for Lipalgia Syndrome should only be used in the context of research.

Some people choose to have liposuction privately in Europe. We advise you to carefully consider where you choose to go and ensure that the compression garments for the surgery are provided by them. We are not able to support compression garments you may need for surgery done on a private basis. We will be able to support ongoing compression garments following re-assessment of your clinical needs and based on what is clinically appropriate at the time. *Please note: Symptoms can take up to six months to stabilise following surgery and therefore our garment provision may not be reviewed/altered until this time.*

(Reference: National Institute for Health and Care Excellence (2022). Liposuction for chronic lipoedema, NICE; downloadable from: **https://www.nice.org.uk/guidance/ipg721**)

Bariatric Surgery

Weight loss can make a big difference to the size of your legs and can help improve other symptoms such as pain and immobility. Weight loss surgery, or bariatric surgery, may be an option for you to consider if you are also struggling with Obesity. There are strict criteria to meet for this surgery on the NHS, but private options are also available. There are different types of bariatric operations; they are usually done under general anaesthetic (you are asleep) using keyhole surgery.

For more information on the main types of weight loss surgery, please look at the NHS website link: **www.nhs.uk/conditions/weight-loss-surgery/types**

6. Psychological wellbeing

A diagnosis of Lipalgia Syndrome (Lipoedema) can bring a huge range of emotions. Perhaps it is a relief to get some clarity after what can be a long time looking for answers, perhaps it leaves you with questions and concerns. Whatever the feelings, remember its absolutely normal to have such feelings and worries. Please give yourself time to take it all in, and be kind to yourself.

People with Lipalgia Syndrome have told us that their main concerns are often around pain and sensitivity, how they feel about their body (known as body image) and the impact both these things can have on their social and work activity.

What can I do?

Firstly, think about what matters most to you. What small improvements would make life easier for you, or enable you to try something you have wanted to do, or keep doing something you love? Many things are still possible, but you may have to find slightly different ways to do them.

Where do I start?

Focus on things within your control. When we spend our time focused on things we cannot change, this can leave us feeling low and frustrated, and it means we have little energy left for other things. If we can move this focus and energy onto things that we can control, it lifts our mood and gives us more hope and confidence.

What kinds of things might help me emotionally?

We are all individual, and we like and value different things. Focus on the areas that give you joy - whether it be family; a hobby; friendships; nature; animals, it can be anything.

There are recognised key areas of wellbeing that are proven to help lift our mood and support our emotional health. These are to:

1. Keep your lifestyle as healthy as possible

Eating healthy foods and getting a good sleep are integral to our mood, and our ability to cope with life's ups and downs. Moving our bodies and getting out into nature are also shown to release endorphins and make us feel good, as well as being good for our physical health. These kinds of small changes in our everyday lives can also help with symptoms of pain, partly through improvements in our physical health, but also mentally, as they take our mental focus away from the pain, improving our experience of it.

More tips can be found here: **www.nhs.uk/live-well**

2. Connect with others

This could take any form - friendships, work colleagues, people with similar interests, and other people with Lipalgia Syndrome. Wherever it feels like you can create a sense of belonging. Connecting with other people, although it can be hard at times, can really lift our spirits and reduce our feelings of isolation. It often feels like we are the only ones struggling, until we talk with others, and we realise that life does often feel that way to many of us. Sharing our experiences can help us to make sense of our worries, seek support, and provide us with ideas that others have found helpful. Most of all, it helps us to feel part of something, and can be a great distraction from worries. It may even lead us to new adventures!

Sometimes this step is difficult, as we worry whether others are judging us, what they think of us, or if they will ask us about our condition. It can also be helpful to plan for these situations, and make decisions about what you want to share, and what you don't. It is okay to want privacy and set boundaries with others about this. Having some stock phrases planned that you can say can help, e.g. 'I have a condition that causes pain and problems with my legs'; or 'I appreciate the concern, but I would prefer not to talk about it thank you' - whatever feels right for you.

3. Focus on the present

As children, we are often great at living in the moment, but how many of us are able to do this now? We are programmed to worry about the future and think about what might happen. A bit of this can be helpful, to make plans and avoid situations. However, if it gets to the point where this is where our main energy goes, it can really impact us negatively. None of us can predict the future, and often we can't control it, so bringing that energy back to the here and now can be really helpful. This could just be about taking it day by day, or by trying out specific things that help with this, such as mindfulness or meditation. There are free apps you can try like Headspace and Calm. Some people find writing a diary useful for this, or writing down what they are grateful for each day before they go to sleep. Focusing on the positives of your body, and what it does do for you can also help with body image.

4. Challenge unhelpful thoughts

We can be our own worst critic. We will judge ourselves often harshly, and assume that others will do the same. Remember your thoughts are just that - thoughts - they are NOT facts! Challenge them - what evidence is there that this is true? What else are they not considering? Often thoughts can be about judgement of ourselves. It's so important to be kind to ourselves, if we aren't, then we won't expect that of others either... we need to be our own best advocate instead.
Tips and videos on the above and more can be found on many websites including the following: **https://www.nhs.uk/every-mind-matters**

What if things aren't feeling better?

If you are feeling overwhelmed, low, anxious, and tips like the above aren't making you feel better, please don't suffer in silence. Whilst we all feel up and down at times, and life can be tough, it's important that you don't continue to struggle. We all need some help from each other in our lives, and there are supports out there. In the first instance, as well as some of the support lines listed below, we would recommend you talk about how you are feeling with your GP. They will be aware of the range of services available in your local area and can refer you for the most appropriate support. For urgent or more anonymous support call The Samaritans (call **116 123**; **www.samaritans.org**)

7. Massage

Does massage help?

Massage is known to alleviate pain, inflammation, stress and anxiety, and can help improve your sleep. Self-massage can be done by hand, using a soft bristled brush (skin brushing) or any hand-held massager. Massage helps stimulate circulation in the skin and tissues, thus improving oxygen to the area and reducing inflammation which helps reduce pain in Lipalgia Syndrome.

Is there a massage that is best for Lipalgia Syndrome?

The best massage is the one you like to receive. It can be a sports massage, Reiki, Aromatherapy or Reflexology. It was previously thought that Manual Lymphatic Drainage (MLD) was the recommended treatment, however, in the absence of fluid in Lipalgia Syndrome, and the fact that MLD seems currently proven to be no better than general massage, MLD is not offered on the NHS and is not recommended above any other form of massage therapy. Thus, find what kind of massage your body prefers and enjoy the benefits it can offer.

Further Information

There are useful websites and support forums available to you where you can find out more about Lipalgia Syndrome (Lipoedema):

- **https://www.nhs.uk/conditions/lipoedema** provides information about the signs, symptoms and treatment for Lipalgia Syndrome (Lipoedema)
- **https://www.lipoedema.co.uk** - founded in 2012, Lipoedema UK is a charity whose aim is to educate doctors, health professionals and the public about Lipalgia Syndrome and its symptoms, so it may be diagnosed and treated earlier.
- **https://www.lipoedemaladies.com** - founded in 2012, Lipoedema Ladies is a support forum for ‘real time connections and news with Lipoedema Ladies’
- **https://www.talklipoedema.org**

If you want to read more about Lipalgia Syndrome, the following consensus documents are available:

- Lipoedema: a paradigm shift and consensus by Bertsch T, & Erbacher G. 2020. Available to download from: **https://www.magonlinelibrary.com/doi/full/10.12968/jowc.2020.29.Sup11b.1**

- Best Practice Guidelines: The Management of Lipoedema by Wounds UK, 2017. Available to download from: **https://wounds-uk.com/best-practice-statements/management-lipoedema**

- There is a short video that may help you know why the term Lipoedema has changed to Lipalgia Syndrome - the film is by Dr Tobias Bertsch: Big Legs - Always Lipoedema? **https://www.lympho.org/industry-lives**

Your notes

Your notes

St Margaret's Hospice Care Taunton Hospice,
Heron Drive, Bishops Hull, Taunton, TA1 5HA
☎ 01823 346950

St Margaret's Hospice Care Yeovil Hospice,
Little Tarrat Lane, Yeovil, BA20 2HU
☎ 01935 709150

✉ somicb.lym-smh@nhs.net

Publication date: Sep 2025 L|039|01 Registered Charity No: 279473

With thanks and acknowledgement to the
Lymphoedema Support Network Wales.

St Margaret's
Hospice Care