

# Lymphedema

Living with the disease



**Clive West**

# Contents

*Foreword*

*Introduction to lymphedema*

*What is lymphedema?*

*What are the dangers of lymphedema?*

*How do you get lymphedema?*

*What is the treatment?*

*What is the treatment like?*

*Where should you go?*

*Paying for the treatment*

*Do doctors recognise lymphedema if they see it?*

*About the author*

## Foreword

The front cover shows my right leg before and after the lymphedema had set in. It's hard to think it's the same leg but I can assure you that it is.

I've written this book to give fellow sufferers the information which I wish I'd had before my first clinic trip. I'm also hoping that my suggestions will both serve to make your stay more productive as well as saving you money. In return, I'm going to put the money from the sales of this book towards an expensive operation which, if successful, will remove the 'spare tyre' from around my waist. It is this which we believe is causing the extreme back pain which dogs me morning, noon and night.

Thank you

Clive West

March 2012

## Introduction to lymphedema

Lymphedema is a particularly insidious illness which affects an incredible estimated 250 million sufferers worldwide. Despite this, many GP's and other doctors are almost totally ignorant of both the malady's diagnosis and its treatment.

That ignorance can have calamitous consequences since, if lymphedema is not caught in the early stages then it is with the patient for life. Not only that, it is potentially a life-threatening disease and believe it, this is no understatement. During my 20 years of living with lymphedema, I have recorded a temperature of over 42C and blood pressure of 240 over 200. That's a lot closer to the edge than I would choose to be but it's not atypical for lymphedema sufferers.

Given all my experiences, I felt it was about time that someone produced a short book describing the illness, how it is caused, what life is like with it and what treatment is currently available. Hopefully that information may allow others to either avoid or come to terms with the full consequences of this debilitating illness.

I've also looked at the high cost of lymphedema treatment and have made some suggestions for saving a significant amount of cash as well as making your stay in a clinic go smoother.

I'd also like to clear up the misconception that it is a 'fat person's' disease and thus some anatomical form of retribution for the generally perceived self-inflicted abuse of overeating. In fact many lymphedema patients are anything but obese and there are a number of very diverse possible causes for the disease with obesity being just one of them.

My goal for this booklet is to:

- Describe in simple terms what the illness is
- Look at the ways in which lymphedema can be acquired
- Explain what the treatment is like
- Give sufferers the information necessary to educate their own doctors
- Talk about where treatment can be obtained
- Suggest ways in which sufferers can save money on their treatment

If, after you've read my book, you feel I've gone some way towards achieving these lofty goals, please be so kind as to leave a review for others.

## What is lymphedema?

Lymphedema occurs when the lymphatic system fails. Alongside the blood system, the lymphatic system is the other main system at work in the body.

The lymphatic system plays a major role in keeping the body's immune system functioning and it does this by purging excess fluid (known as 'lymph') from the spaces between the tissues. The lymph is held in lymph vessels and it contains a variety of waste material including bacteria. It is normally removed by muscles contracting and expanding (in normal usage) which pump the lymph around the body until it reaches a lymph node which then filters out the harmful elements. These, in turn, then exit the system in the usual way.

While blood and lymph are similar in that they are both pumped around our bodies, there is a distinct difference in the way in which they are propelled. Blood is moved by the heart which is a dedicated pump whose sole purpose is the pumping of oxygenated blood through the body. Lymph fluid, on the other hand, relies upon muscular contractions which are primarily intended for movement and other activities.

Once the lymphatic system is interrupted (and we'll look at the causes in a moment), the fluid builds up causing the body to swell dramatically. This swelling increases the overall weight of the body reducing mobility which, in turn, diminishes the effectiveness of the remaining part of the lymphatic system. On top of that, the extra folds (which many doctors erroneously perceive to be pure obesity) trap even more fluid.

In other words, once it gets to this stage, you've got a runaway train on your hands.

## What are the dangers of lymphedema?

If it wasn't bad enough having parts of your body swell up to twice their normal size or even bigger, there are further dangers awaiting sufferers. In increasing order of life-threatening danger, they are as follows:

### **Scarring**

If the limb swells sufficiently, the skin will break open and something akin to neat battery acid will leach out. When it first threatens, it will appear to be an ordinary blister – something which inflates, bursts, dries up and heals. A lymphedema blister may look similar but that's all – it swells up, bursts and then keeps on leaking day in, day out.

The fluid which leaks out continuously (and I mean around the clock) will burn any skin it comes into contact with. To give you an idea, my first blisters appeared on my lower legs nearly 15 years ago. Although (after considerable treatment) these blisters have virtually stopped leaking, there is a band of, perhaps, 10 cm or more which has turned a shade of purple and which no amount of skin treatment will change. The skin is also creased and distorted (something which the leaking blisters caused). The skin is so thin there that even a gentle tap on it is agony.

While these are not, in themselves, life endangering, they are open sores with all the dangers that this entails. In fact, mine got infected by flies and threatened to go gangrenous. Because of the obesity which lymphedema is frequently (and incorrectly) perceived to be, I was almost unable to get treatment in our local hospital.

<CONTINUED>