

Impressed by You!

Portraits and stories of patients with lymphedema and/or lipedema

A book created to normalize lymphedema by getting to know patients as people, rather than leaving them to be defined by their illness.

By Joyce Bosman and Els Brouwer

Lymphedema is a condition whereby patients suffer from swollen limbs or other body parts, either due to cancer surgery or because of a congenital malfunctioning lymphatic system. The path these patients have to travel before they receive a correct diagnosis can be long and they often feel pushed from pillar to post!

Lipedema is often confused with lymphedema and literally means "swelling of fat". Lipedema appears almost exclusively in women and is expressed as a disproportional spread of fat in the lower body. Lipedema patients typically get little psychological support because they feel misunderstood and are often seen only as being overweight.

An important and inevitable part of the treatment protocol for lipedema and especially lymphedema is compression therapy. Wearing compression is unfamiliar to the general public. The resulting taboo (derived from lack of awareness) makes wearing compression difficult for lymphedema patients. They experience a double hit. Not only do they have a chronic condition but they are required to wear compression every day. This makes going to school, playing

sports, participating in social occasions or creating relationships more difficult. However, compression is to lymphedema, what medication is for many other diseases: indispensable!

Compression therapy with lipedema and/or lymphedema combines many different products. In the initial phase of lymphedema, bandaging is the main treatment and in the maintenance phase, medical compression stockings or sleeves are used, sometimes in combination with Velcro bandages. With lipedema, bandaging is an option when there is a lymphedema component, but in most cases compression will be in the form of therapeutic elastic stockings or Velcro devices.

Recently, the Dutch Lymphedema Network (NLNet) published a book titled "Impressed by You", that follows 28 patients with lymphedema and lipedema along with their clinicians, family members or friends. It shows that compression in everyday life doesn't need to be a struggle. Through the stories in the book, we show that the focus is not on the stocking or sleeve, but on the people, their personalities, and what they are up against in daily life; having to be concerned about their appearance and obligation to wear compression garments. We intend to break the taboo and show all the health care professionals the environment of the patient, that you can be



seen with lymphedema or lipedema. You are allowed to be beautiful. Awareness and understanding of these disorders facilitates early diagnosis so that long term problems are prevented.

The book was created on a volunteer basis with personal stories of patients. The impressive stories have one thing in common. Lymphedema and lipedema always come uninvited into your life. **LP**

Editor's Note:

One of the photo portraits in this book is featured on the cover of our *Pathways* magazine.



Impressed by you

A book with 28 portraits of people with lymphoedema or lipoedema



Joyce Bosman and **Els Brouwer** are board members of the Netherlands Lymphedema Network (NLNet) and creators of the book "Impressed by You". The book is currently available in both Dutch and English and can be ordered via www.impressedbyyou.com.