

Lipoedema survey

Respondents **1416**

Statistiks 1 : What is your age?

15 - 25 years	3.53%
26 - 30 years	5.99%
31 - 35 years	9.91%
36 - 40 years	12.52%
41 - 50 years	28.03%
51 - 60 years	23.50%
61 - 70 years	13.67%
Older than 70 years	2.84%

Statistiks 2 : In which country do you live?

Land	Persons	Percent
USA	420	29,66
Nederland	404	28,53
Great Britan	162	11,44
Germany	142	10,03
Australia	69	4,87
Canada	21	1,48
Others	85	6,00
Unknown	113	7,98
Total	1416	100,00

The others are: United Arab Emirates, Finland. Sweden, Denmark, South Africa, Belgium

Slovenia Switzerland, Israel, South Korea, Puerto Rico. Austria, New Zealand
Egypt, Ireland, Dominican Republic, Italy. Peru, Norway, Slovakia,

Africa India, Saudi Arabia, Greece, France, Switzerland and Ghana, west

Statistics 3 : Do you smoke?

Yes	6.37%
No	88.86%
Once in a while	4.76%

Statistics 4 : Do you drink alcohol?

Yes 13.36%
No 39.63%
Once in a while 47.00%

Statistics 5 : My Lip(o)edema started :

In puberty	39.76%
In pregnancy	5.53%
At the menopause	5.07%
At puberty and worsened during pregnancy	14.86%
At puberty and worsened with menopause	7.70%
At puberty and worsened during pregnancy and with menopause	8.97%
Beginning with pregnancy and worsened with menopause	4.62%
After starting with contraception	4.71%
Started at a stressful period	8.79%

Other answers:

Summary:

- after surgery or trauma
- born with it
- young child (4-8 years)
- after birth control pil

After ovarian cancer diagnosis and hysterectomy

I think late puberty, certainly by early 20's. I started contraception at age 17 and stopped at age 25.

Over 4 years

minder pijn na de zwangerschap

From the way my young body felt and my physical limitations, I suspect it began before puberty

4 weeks postpartum; possibly due to breastfeeding working well or maybe the bf supplement fenugreek

Age 42

Combination of menopause, stress, maybe surgery?, and intravaginal steroids

Na trombose daarbij gestopt met de pil.

perimenopause

mijn benen waren als kind al veel steviger/groter/dikker dan leeftijdsgenootjes

After a major operation

I had surgery for an ectopic pregnancy. It started soon after that.

ik ben in de overgang gebracht om zwanger te kunnen worden. Via het medicijn Lucrine. hierdoor ben ik 30 kilo aan gekomen en zijn de kilo;s op mijn benen gaan zitten

I do not remember symptoms worsening during any of these times.

Surgery

Not really sure when it started as legs always seem to have been larger in proportion.

Mother has it too

noticeable pre puberty in photos

Aangeboren en rond 24e verergerd

Na een operatie verergerd (vanaf kind)

In puberty and after starting with contraception.

In de puberteit begin het. Ben nu ruim 2 jaar in een kunstmatige menopauze en daardoor verergerd het ook.

In de pubertijd en werd erger met pilgebruik

eigenlijk weet ik het niet precies omdat ik het fenomeen niet kende

na hormoonkuur om zwanger te raken

After taking cortisone and worsened during pregnancy†

I have Hashimoto and Fibromyalgia and now I ghet Lip-Lymph^dem

After c-section to deliver my baby and blood clots in legs after

As a child (5 years)

Na hormoon gebruik om zwanger te raken

At puberty and worsened after pregnancy

After loosing a lot of weight

Na de eerste menstruatie

in childhood and worsened in puberty

befor

My father died and i hot diabetes. After that My pain starts

not sure when it started? i grew up bigi never knew any differences being big and active in sports.... later when i gotten older pain bothered me more

I am sure it must have been started before puberty, as I always had big legs and knies

have Lymphedema, was diagnosed with Lipodema last year.

Childhood,8 y.

In puberty after starting contraception

Weet ik niet precies starten al vanaf 11 jaar met de pil (tegen acne). Tezamen met de pubertijd

unknown

na dat de baarmoeder is verwijderd,toen is er dwars door de lymfbanen gesneden en 6x trombose en 1x longembolie na operatie,s.

Aangeboren,de trigger was wondroos in 1990

Na oparatie

1 year after major surgery (Abdominoplasty/ Panniculectomy)

After operation

Na pilgebruik tijdens puberteit en vergergerde tijdens zwangerschap

Nach einer op. Entfernung von endometriose und dann beim absetzen der Pille

na chemotherapie

After an emergency caesearean

I had it from birth, got worse after puberty

only diagnosed after botched surgery after having been misdiagnosed when I was 62 at puberty and got worse when PCOS got worse in 20's
had womb cancer last year they thought I had lymphodema, was sent to the clinic only to be told I had lipo-lymphodema
Al voor mijn puberteit, alleen wist ik niet dat het lipoedeem was.
Onduidelijk wat de oorzaak is
nog maar kort geleden
Geen specifieke aanuiding waardoor het is begonnen
Don't know
after aerioplane flight from Brisbane to Perth.
Always had tree-trunk legs from childhood
after cancer
After knee replacement surgery
could have started as a kid as my upper arms were always big but definitely spread to stomach a little later and more recently my legs
on
At eight years old in pre-puberty. Periods started at just ten years old.
May due to infections Lyme and TBE and stress ?!
operation
Was als jong meisje al opmerkelijk fors op bovenbenen en billen. Verergerde met puberteit en met zwangerschappen
not sure they think after I had my first child 22yrs ago. then switched to lymphedema
After knee replacement surgery
Not entirely sure
In de puberteit en verergert door gebruik hormonale medicatie.
Out of the blue, when I was playing softball, at age 34.
begon na spataderen strippen
Right after my hysterectomy
on
Na het lopen van de Vierdaagse op 40-jarige leeftijd
Childhood and worsened with hormone change, child birth and stress.
3years after puberty
3years after puberty
before puberty
Begonnen toen ik nog jong was....voor de puberteit
on
After surgery
Unclear, hadn't recognised myself then diagnosed last year
After a double knee replacemrnt
Before puberty
Childhood
Na puberteit, maar wanneer precies kan ik me niet meer herinneren.
At puberty, worsened with birth control and hashimoto's thyroiditis. Continued to decline after 2 c-sections.
in de pubertijd (ben ik ook) begonnen met 'de pil' gebruik
I think I had it since puberty but just looked pear shaped and still thin. I had no other symptoms. I did not look like a typical lipedema. So probably always ben in stage 1. I was injected with botox and had an adverse reaction - getting botulism. I am not sure if this triggered it or the stress that being ill caused my body. It has progressed rapidly over only 1 year.

Na de tweede operatie i.v.m. palato schisis, pierre robin sequentie, op driejarige leeftijd. Maar pas vastgesteld op twintigjarige leeftijd.

verergert door de pil

na wondroos

geen idee.heb sinds en 15tal jaar last van opgezwollen onderbenen/enkels

Puberty worsened after pregnancy when on no contraception.

In my 30's

There were no life events when it began.

weet ik niet

It really started at puberty, but worsened after pregnancies and a stressful period made it go full force.

After hysterectomy

I've had Lymphedema for 30 years and my Lipoedema was diagnosed last May

I remember pain from a young age about 8 or 9

After an Operation

since I was little but worsen during puberty

After cancer surgery.

Do not know. Always thin.but hippy Swimmer ???1957

Born with big legs

After surgery for a brain tumor in 1991.

ThinkI have had since birth, but worse after a splenectomy due to Idiopathic thrombocytopenic purpura at age 6. Multiple blood transfusions and cortisone.

Don't know for sure, but aware after hysterectomy at age 44.

After a knee replacement surgery

on

at puberty and worsened after double knee replacements

After breast cancer.

I'm not sure. I've never been pregnant, I have been on the pill and I have had stressful times. I don't know which caused it. I have lymphodema too

Noticed when I reached 40 yrs

After kidney transplant

breast cancer affecting lymph nodes

Forever

Na puberteit, ook stress ik veel

Geen idee

Begon voor pubertijd na start corticosteroÛden i.v.m. Astma.

not sure

Begon bij mononucleose

Na mijn baarmoederverwijdering op 29 jarige leeftijd

I don't really know. My legs have always been heavy. Two of my brothers and one of my sons also have the same type of heavy leg. As I've gotten older in the last several years they seem to be worse and more like you describe. My brothers' legs have stayed the same, just thicker and heavier without the symptoms of lipedema.

rond mijn 20-25ste levensjaar

before puberty

After my hystorectomy

my aunt and her mother my grandmother both irish have had this

Approximately age 20

don't know

I had a total hysterectomy at 23 and the lipomas started then. Wasn't diagnosed with

DD til 39yrs, Im now 40.

on

inherited, since birth. started to worse in puberty

I think in puberty (inner thighs), but definitely something happened to my lower legs after I had sinus surgery with anaesthesia as a 28 year old.

i was told i was probably born with it but didnt notice it before pregnancyl was diagnosed at age 55

weet ik niet maar is geconstateerd nadat ik na mijn geknapte blindedarm operatie het vocht niet meer kwijt raakte.

Don't know..had early hysterectomy, hormone treatments, traumas

When I gained weight in college.

when i turned 32. legs started to swell, progressively worsened. no children. i have pcos as well.

Diagnosed after cancer/stroke

I am not sure. Looking at my pictures probably in puberty but I had no diagnosis until 4 years ago

on

Na erythema nodosum begon.

I noticed the swelling started in my left ankle in my 30's after emergency ectopic pregnancy surgery.

Not exactly sure, i'm thinking puberty otherwise when birth control was started.

Pas sinds paar maanden, klachten bestaan echter al zeker 10 jaar. Oorzaak niet meer te achterhalen.

When I was 25, was taking contraception for years already

on

geen puber, geen zwanger en geen meno gewoon opeens was het er.

Started in my 40's no menopause

early childhood

Had since I was born. My Mother is also a sufferer.

After kidney transplant

Ik weet niet precies wanneer. Waarschijnlijk aan het einde van mijn pubertijd.

since puberty very minor, but had had surgery and had half of each ovary removed along with some other work and it triggered it to progress since (at age 50)

Skiing accident bi lateral MCL tears and sprains. Resulted with DVT in one leg.

Swelling is bilateral lower extremity. Diagnosed by vascular surgeon as lymphedema, yet my lymph therapist thinks it is also lipedema, as I have symptoms for both conditions

Begonnen bij de puberteit en in de loop der jaren steeds erger geworden. Nu 41 jaar

After 50 yrs, diagnosis Non-Hodgkins Lymphoma and Rutuxin txt and

immunoglobulin repacements

Rond het 7e levensjaar en verergering in de jonge puberteit 9jaar

Started in puberty, but I was just diagnosed with it!

Began when I was an infant, has worsened over the years.

In childhood my legs were big and ached

After a severe trauma, fell hard on concrete

Puberteit... verergerde met pil.. en wederom na periode met veel stress

Age 6

ik weet het pas een jaar. had wel altijd dikke benen t.o.v. lijf

unknown

I was 4 years old, and it worsened during puberty

I have apparently had it since about 18. Menses started at 11.
Car accident at aged 8 yrs seemed to trigger it
Car accident at aged 8 yrs seemed to trigger it
Car accident at aged 8 yrs seemed to trigger it
Car accident at aged 8 yrs seemed to trigger it
After hysterectomy and removal of pelvic lymph nodes
Prior to puberty
Was always a bit overweight, but got very big after divorce, a tummy tuck, and after meningitis.
Other: Genetic. I know from a before my puberty that I had the symptoms
At puberty gradually worsening until age 58 - a fall started it raging out of control.
Not sure
just found out but doctors feel after my hysterectomy in 1987
perimenopause and when I moved to China
Started after hysterctomy
always had it
Before Puberty, from about grade 3
Was not diagnosed until about 6 years after I started noticing symptoms
From 3 or 4 years old
Started when I had to stand up at work
I had the lippy shape on my legs since I was little. Worsen during puberty and after moving to Australia at the age of 25
I'm not sure when it started.
na de zwangerschap
van kinds af
on
unsure. started looking into it after the bruised lump that appeared on my leg was ruled out from what the doctor thought was a DVT. and has progressed since -
3years of test
Na trombose in onderbeen
on
Na vruchtbaarheidsbehandelingen.
Vliegreis of blessure knie, door zwangerschap verergert Precieze oorzaak niet helemaal duidelijk, knieblessure en lange vliegreis zelfde periode

Statistics 6 : The Lipedema started at the age of:

All ages are mentioned.

Most around puberty, around pregnancy and menopause age but also some very young until the age of 68

Some do believe they are born with it.

- 13

- 47

- Approximately 18

- 18
- 18 jaar
- rond mijn zeventiende
- Approx age 18.
- 16
- Zoals ik terug kijk op mijn 25 ste maar wist niet wat het was
- 12?
- 4 years
- Ik denk ongeveer 17, maar weet het niet precies. Waarschijnlijk ook sinds het gebruik van de pil
- 13 or 14.
- 16
- 16
- 12
- Not sure, but noticeably by 12.
- 20 jaar
- 47 years
- 17
- 14 jaar
- 30
- 14
- 8 years old
- 16
- 53
- 18
- 10
- 10
- 15
- 32
- 11
- 12
- 10
- 11
- 13
- 10 years old
- 33
- 8
- 35
- Childhood. Worsening after my first child, at 19.
- 13
- 36
- 42
- My guess is age 44.
- 42
- 9 a 10 jaar
- 14
- 13/14 years of age
- 20
- 17
- 31

- 15
- 30
- 11
- 38
- 56
- zie vorige vraag. Als kind dus al. Kon als kind ook al veel minder hebben aan de benen als bijvoorbeeld zitten op de knieën en heel snel blauwe plekken hebben. Ook was ik veel sneller moe van fietsen en rennen dan andere kinderen en was ik heel slecht in sport. Zelfs angstig. Vanaf een jaar of 15/16 kwam de lipoedeem uiterlijk en fysiek meer tot uiting.
- 18??? Waarschijnlijk ... toen toename benen
- 27
- 16
- Weet ik eigenlijk niet pas in mijn derde zwangerschap is de diagnose gesteld
- 30
- 13
- 12 years old
- 17
- Is altijd wel aanwezig geweest maar is na de zwangerschap erger geworden.
- 13
- 24
- probably around 16 / waarschijnlijk rond mijn 16e
- 14 jaar
- 26
- 11 jaar
- 11
- 52
- 45
- 11 (onset of period)
- born with it i think
- 27
- I think at 13 years
- 15
- 12
- 14
- 20
- 12/13
- 17
- 14
- 12
- 11
- 13
- Tijdens mijn jeugd, een jaar of 12
- 13
- 14
- 12 jaar
- 17 jaar
- 68 years old
- 15
- 11

- Waarschijnlijk rond mijn 15e jaar maar was toen nog niet bekend wat het was.
- perhaps 20
- From photos it was evident from age 2 but lip/lymph did not start in its present state until after menopause at age 50
- Geboorte/birth
- 17
- 24
- Weet ik niet precies.
- 16
- 13 I think. But I'm not sure, ist to long ago
- 15
- 18
- In mijn pubertijd had ik al dikkere benen en is erger geworden toen ik aan de pil ging en dat was op mijn 17e.
- Toen mijn lichaam begon te veranderen en mijn menstruatie begon. Rond 11 jaar.
- 12
- 13
- 45
- 25
- 15
- ca. im Alter von 12 Jahren
- 6
- 11
- 11 years
- 20
- 11
- 13
- 44 jaar
- 19
- 13
- 13
- 15
- 20
- 16
- Around age 10
- 19
- 24
- 13
- ???50-55
- 16
- 16 jaar
- 12
- I'm not really sure when it started. I have always bruised easily and even when I was very thin my nickname was ."thunder thighs" as they were the biggest part of me. I was diagnosed at the age of 54 along with a Dercum's Disease diagnosis
- 28
- 28
- 10 years old
- 11
- 14

- 14 jaar
- 11
- 16
- 13
- 13
- 14
- 20 jaar
- 12
- 8/10yrs
- 32
- 9 jaar
- 13
- Altijd al stevige benen gehad werd erger tijdens 1e zwangerschap(36)
- 13
- 17/18
- perhaps 14
- 33
- 40
- +- 15 jaar
- 14 years
- 16 jaar
- 14
- 15 jaar
- Officially diagnosed at 40 years old.
- 33
- 5
- 16
- 14/ 15 ears... but I got the dignose only 3 years ago
- 11 years old approximately
- 28
- When I was 35 after my hysterectomy
- I'm not sure
- 12
- 13
- 31
- 22
- 16 jr
- ongeveer 14 jaar
- 13/14
- 10 jaar
- 14
- 13-15
- 15
- 35 jaar
- family state my legs have always been disproportionately larger than the rest of my body but became more obvious and painful from age of 11/12
- 11
- 20
- Exacte leeftijd weet ik niet. Rond 24 is diagnose gesteld. Liplezen was er al eerder.
- 34

- 20
- 10
- 11
- 10-12
- 13
- 16
- 25
- 18
- 19
- 11
- Ongeveer 17?? Weet niet meer precies
- 25
- 12 jaar
- Unknown - think always had it
- 16
- 12
- 16
- 10
- 15
- 16
- 15
- w.s. toen ik 10 jaar, menstrueerde ook al. Wist alleen niet dat het lipoedeem was. Werd uitgescholden vanwege extreem dikke benen. Verder was ik mager.
- 16
- Toen ik ongeveer 11 jaar was
- 46
- 30
- 45 jaar
- 18
- 14
- 15
- 21 years
- 14
- 16
- 23
- 14/15
- 15
- 30
- 24
- ca. 10
- Can't say the right age, i suspect till 20-25
- 15
- 20
- 12
- near 15 years
- 14
- 18
- 15
- op jonge leeftijd voor 8 jaar
- 17

- i think i was 16 years old
- 12
- 10 years old
- 12
- 12
- 15
- 16
- 12
- 12
- unknown not sure.... i noticed third grade i was bigger than all my classmates so
-
- Pubertijd
- 19
- I don't know but I think around the age of 8
- 12
- 28
- 14
- 35
- 14
- 66
- 14/15
- 11
- 15-18 years
- 15
- 32
- 15
- Approximately 11/12, I always have been a "big" girl, from toddler on...
- 27
- 24
- 20
- 14
- 14 years
- 10
- 10
- 8-9 Years, worse with 20 years
- 16
- 19
- I guess when I was around 12 years old.
- 12
- 8 I think. Got worse in my late teens and escalated after an accident in my late 20's.
- 42
- At age 22
- Weet ik niet is pas op me 22 geconstateerd
- 14 jaar
- 27
- 15
- I do not exactly know, my legs always have been Fat, unly since my knee operation I suffered from pain. This started in 2008. Just in September 2013 Lipodemia was stated/diagnosed.
- 16

- 16-17
- 13
- 40 jaar
- 14
- ~10
- it started for me about the age of 12 or 13 but i only found i had it 3 years ago
- 36-38
- 37 maybe
- het begon in 1990 met lymfoedeem en ik was 45 jaar en daarna hadden ze het 10 jaar later over lipooedeem.
- 11
- 39 Jaar
- 31 jaar
- 22
- 26
- Rond de 53
- 45
- 10
- 13
- I would say around 14 years
- 13
- 23
- 12 or maybe younger
- 15
- 15 or so
- Approx. 30
- Mine started just before puberty, around 8 years old.
- Ten
- not certain, 30 perhaps
- Achteraf bekeken zal dat rond 17/18 jaar geweest zijn, verergerde tijdens zwangerschap op 26e.
- 14
- Around 30years
- 15
- 15
- 15/16
- 12 years
- 20
- 15
- 16 years
- 16
- 15
- 20
- 16
- 16
- 13
- 2008. Ik was 58 jaar. Zo ver ik weet begon het toen.
- 10
- 16
- 66 jaar

- 18
- Age 9-10
- 13
- 35
- 25
- 14
- 14 / 15 years
- 13 jaar
- 14
- 35
- 15
- 21
- 14
- 15
- From birth, I always had thick ankles and heavy legs
- 9
- 8-10 but that's in retrospect
- 18
- 15 jaar
- 22
- 12
- 15
- 35
- 10
- 39. waarschijnlijk was het er al sinds de pubertijd, echter last begon na de zwangerschap
- 12
- I was 39 but have always had fluid in my legs
- 22
- 16
- i would say 15 years ago age 34
- 30
- 13 jaar
- 23 jaar
- 14
- 14 · 15 jaar.
- 8
- I was about 14 when I noticed that there was something wrong,
- 20
- 14
- 60
- Na een aantal jaren therapie benoemde een huidtherapeute het lipoedeem toen ik 23 jaar was. Ik ben begonnen met manuele lymfedrainage toen ik 21 was.
- 17
- 17 years
- 50 jaar
- 16
- 12
- 63
- vanaf ongeveer 9 jaar. daarvoor was ik veel ziek en was een dunne spriet. toen

amandelen geknipt en nooit meer ziek geweest, en toen begonnen de benen te groeien

- 27

- 20

- Around 10 years. We moved to the other side of the state. my weight went up & my ankles started swelling a lot.

- 12..... large legs and went from there

- 15

- 22

- 13 dikke benen 27 pijn in benen na zwangerschap

- 20s

- 14

- 11

- 14

- 15

- 12

- 12

- Rond mijn 15e/16e jaar

- Started in my 20's diagnosed at age 85

- 16

- 14

- 21

- Approximately 12 years old.

- 60

- 25

- 23

- 40

- Early childhood

- 65

- 11

- volgens mij had ik het al in de kindertijd , heb nooit een jurk kunnen dragen in verband met de verschillende maten breder van onderen slank van boven

- 48yrs

- 10

- volgens mij had ik het al in de kindertijd , heb nooit een jurk kunnen dragen in verband met de verschillende maten breder van onderen slank van boven

- 10

- 30 jaar

- 11

- 16

- 19 jaar

- 14

- 13

- 27

- 45

- na mijn bevallingen in 2002

- 14-18

- rond 12 13 jaar en uiteindelijk rond 45 jaar werd het erger

- 13

- 52

- 16
- Merkbaar vanaf ongeveer mijn 17e
- 12 or ealier
- 12-13 (diagnosed at 37)
- 16
- 17-19
- 10
- maybe 8 yo arms, 14 years old stomach and 35 legs
- weet ik niet. Werd ontdekt toen ik al 57 was
- Omdat ik pas enkele jaren weet dat mijn klachten behoren bij lipodeem is dit een schatting. 30 jaar.
- Na mijn zwangerschappen denk ik, echter op latere leeftijd pas ontdekt dat het Lipoedeem was. Mijn leeftijd na mijn zwangerschappen was 34.
- 26
- 14
- 45
- ik weet niet wanneer het begon eigenlijk, ik ben alsmaar dikker en dikker geworden en het stopte niet meer, ook niet met dieten, dus op een gegeven moment kom je dan in de obesitas hoek uit, ergens rond mijn 30 merkte ik dat het niet goed zat.
- 14 Jahren
- Eight years old
- 44
- 13
- 10
- 23
- 12
- when i was 15 year.
- 16
- 12
- 15
- 49 jaar
- 40
- rond 14 jaar
- 31?
- 62
- 40
- 20?
- 16-17
- 17
- Looking back at pictures I would have to say 14-16 years old.
- 16
- 37
- 12
- About 31
- 15
- around 23 years old
- 59
- Around 15, got worse, but was stable until I got on prednisone and my legs grew three times their size, and I gained 200 lbs in a year...yet my upper body stays the same.

- 35
- 12
- 12
- 35
- don't know. I had other issues
- 13
- 13
- 14 - I could see my legs were a different shape
- Early 20's
- First it was oedeem, tahn later lipoedeem at the age of 24
- 11
- 32
- 14
- 16 jaar
- 50 jaar ongeveer
- 47
- 10-11
- Fourteen
- Vanaf mijn 16e (toen ik tevens aan de pil ging), maar dit ging zeer geleidelijk aan. Na vele onderzoeken weet ik pas sinds mijn 37e jaar dat ik lipoedeem heb.
- 16
- 25
- 27
- 20/22
- 35
- Became aware by about 13
- 15
- 14
- 14
- 9
- 13
- ?
- Het allereerste begin van wat ik me nu herinner moet geweest zijn rond mijn 13de denk ik.
- about 12 years old
- I'm unsure when it started. Perhaps early 20's. I was diagnosed at age 4 years ago.
- 23
- 7 or 8
- 55
- 34
- 38
- rond mijn 15e jaar
- 57
- +-18
- 12
- 52 jaar .
- 25
- 45
- 30 jaar
- van plus minus50 jaar

- 16
- 12
- 30
- 35
- 13
- 54
- Schat 14 jaar
- 49
- 30
- Weet ik niet. Bij spataderonderzoek attendeerde de dermatoloog mij erop. Heb wel altijd dikke benen gehad, ondanks normaal lichaamsgewicht.
- 14
- 25
- 14/15 jaar
- 22 years
- 18
- 16 jaar
- 40
- 12
- Kindertijd
- 14
- 14
- 10
- 10
- 13, maar altijd al dikke benen gehad.
- 14
- 50
- 22
- early thirties. Best guess.
- 17
- 6/7
- 68
- Precies weet ik dat niet meer maar ik denk zo rond mijn 18 jaar
- 14
- ?
- 15
- 43
- 12
- 37
- 30
- 27
- 11
- Unsure but diagnosed at age 38
- 15-16 jaar
- 12
- 47 years old
- 24
- 11
- as a child... pre-school .. maybe 3 o4 4?
- 35

- 7
- 60 years
- Als jong kind had ik al dikke benen... dus bij geboorte..
- Ik weet het niet precies. Ongeveer tussen de 20-25 jaar.
- I was aware of being different around age 8 years
- 13
- 16? Maybe younger. I know thhat at 17 I was twased for having no ankles. At 15 I could only buy wide legged jeans and the waist was always too big.
- 16
- 48
- legs tarted at the age of 6
- more mild at puberty but in late 20s under trauma, worsened greatly....[I gained 400lbs in 2 and half years]
- Vanaf 16 jaar ongeveer. From about 16 years of age.
- 17
- 14
- 11
- . recognized 2006 after a after venous Stripping . it started ... nobody knows ... everything presumptions
- 16 jaar
- 59/60 jaar
- 16 years
- BIJ ZWANGERSCHAP 24 JAAR BEGIN VAN LIPOEDEEM
- Kan ik me niet meer herinneren. Ik heb altijd gedacht dat het aan overgewicht lag.
- Rond 12 jaar
- 13 and got worse with birth control pills
- I think it started at the age of 13 or 14
- 14
- 13
- 13
- Ik heb geen idee, ik had al een grotere maat voor mijn onderlichaam in mijn tienertijd, eind tienertijd/begin 20er jaren hield ik vocht vast in mijn benen en pas op mijn 37ste kreeg ik de diagnose lipoedeem
- 13
- Possibly 14-15 years old - stage 1. But triggered growth, onset etc at 32 due to botox injections as listed before.
- Drie
- 26
- 13/14
- 16 jaar
- 11 Jears
- 14
- 23
- 44
- 16
- 16 Jaar
- 12
- 15
- 14
- 33

- 33
- 12
- 38
- 14
- 13
- ?
- 49 jaar
- not sure, was not aware. make it 16 years old.
- weet ik niet zo goed ,erger rond de menopauze
- 17
- 15, maar ik weet pas sinds 2jaar (toen wist mijn moeder die een vergevorderd stadium heeft) pas wat t was en dat ik het ook heb.
- 18
- 14
- 18
- 31
- 16
- ik denk ongeveer 14 jaar geleden
- 10
- 20
- 18
- ?12-13
- Had since teen years progressed from there.
- Not sure exact age. It seems like I have had large, tender legs my whole life. I remember it hurting to sit in "sling" swings on the playground in elementary school.
- 11
- 14
- 11
- 12
- 16
- 12
- 37
- 14
- apprx 32
- 15
- 24
- 15
- pubertijd met pijn in scheenbenen en rond 40e met vetophoping onder knieen, ben nu 60 en pijnklachten verergeren.
- 15
- onbekend
- visibly about 28-30
- 48
- My weight started to go on most after starting the pill for heavy periods, at 16.5 . By 18 I'd gained almost 28lbs.
- I believe my legs really started growing after puberty at age 14. Before that I was a twig of a person.....
- 16
- Ik denk rond 17
- 40, but I think I'd had it always. My legs were thicker, especially my calves and

ankles, all my life, even though the rest of me was "normal" size.

- It started at 15 years old

- 17

- 16

- 35 Years

- In my 30's

- 13

- 13 years approx

- 12

- 45

- 18

- Puberty around 12 years old

- 32

- 13

- 13

- 12

- 13

- 66

- 5 or 6. I remember being very normal and then starting first grade and not being able to wear boots. Having to wear plus size pants.

- 12

- 16

- 15

- 21 years

- 12

- Around 50

- 17

- Don't know for sure

- 20

- 10-11 years

- 10

- 35

- 8 or 9

- 11

- 18

- I don't know exactly. I only know that I have always been thin at the top of my body and fat from my thighs to my ankles. Others have commented on this unsightly discrepancy throughout my life.

- 25

- Around 12 years old

- 14 years

- I showed signs of heavy legs at 10 but this did not grow until 22 and pregnant, then I was involved in a road accident and my legs and arms then grew to an alarming size, but I also had a hysterectomy during this time and v/ veins removed from my legs

- 13

- 37

- I noticed it from a fairly young age, say 12

- I believe I had it since birth. I always had heavy legs and could never get boots on even since the age of about 5 or 6

- 55 years old
- 10 to 12years old
- 15
- ca. 18
- 15 or so
- 18
- Teens
- not sure exactly, had always had legs looking like this
- 15 years of age
- 14
- 57
- 11
- 43-44
- 12
- 13
- 14
- 18
- 15
- 13
- 8
- 13
- 13
- Not sure--18?
- 30
- @age 14
- 20
- 16
- 18
- 20 jaar
- I think possibly from 1957 but as I was always active and basically slim after the war of39/45.Weight dropped after second baby. Then over the years went on a little at a time. Holiday snap late 70's show stage 2 weight just increased but did not bother me. Diet and exercise was good.
- 13
- 5 - 8
- 19
- late 40's
- 7 years I noticed swelling in my ankles
- 15
- 12 or 13 years old.
- 7 years of age
- 23
- 9
- 46
- 14
- 10-12
- 12
- 24
- 15
- 33, possibly. This is when I got pregnant. But I didn't notice signs, or didn't pay

attention to them. I've only recently self-diagnosed based on symptoms and research.

- I think I was about 12 when I noticed my legs were larger.

- age 6

- childhood

- rond mijn 20 ste

- 44 or before

- 25

- 48yrs

- 11

- Was dx'd at 48, always had nice calves but heavier thighs. Really noticed an increase in lumpiness in my 40's

- 22

- 8 years old

- 12 years

- 12

- at least puberty, if not before, aggressively spread peri menopause

- 10-12

- 13-14

- Maybe about, the age of 14 or 15

- 10

- 15

- 11

- 45

- 13

- 18

- 20

- 30

- 59

- 15

- 65

- 30?

- 29

- Als kind

- 27

- 15

- 13 or 14

- At the age 12-13

- 12

- 11

- 59

- 13

- 14

- 11

- 12

- started at 54 years old

- 50

- Not too sure. I have always had big legs but they began getting even worse after a pregnancy at 41.

- 18

- not sure, but I was young. 9 or 10 maybe.
- 54
- approx 35 years old
- Legs hurt in my twenties but wasn't diagnosed until I was 40
- 16
- 9
- 10
- 19
- weet het niet \r\nhet was vroeger niet bekend
- In mijn tienerjaren ... Na mijn 40ste is het zeer verergerd
- ongeveer 11/12
- 47
- Childhood
- Junior High School
- 12?
- 16
- 12 jaar
- 18 jaar
- Junior high
- 12
- 13
- 14 ± 15 jarige leeftijd
- some time as a teen,
- 13
- 20
- 20
- 11
- 12
- 15
- Early 20s
- 54
- 42-43
- 15
- 13 years old
- about 16 I think
- 13
- ???
- 13
- 8 jaar
- 12
- 60
- 15 years
- 12
- 28
- rond mijn 16e denk ik?
- 29 jaar
- 19
- ong.14 jaar
- 9-10
- Approximately 8 yrs of age

- I really don't know. I have always had heavy legs and saddle bags since I can remember. Even before puberty my legs were straight and thick. Two of my brothers have the same type of leg, but look more "normal" more like just a thick heavy leg without the fatty part. So does one of my sons.

- 31

- 31

- 34

- 13

- tussen 16 en 20

- 20-25-jaar

- Childhood born with heavy legs

- I first noticed that my legs looked "different" around age 17.

- Approx 14 years

- 15

- 19

- 45

- 12years

- I remember always having puffy legs, even as a child they looked as if they were swollen.

- Don't really know. First conclusive signs were not until late 30's.

- 13

- 30

- 45

- 14

- unsure - in teens; in my early 20's I began to ski and noticed that I could barely buckle the boots (I have lipodem of the unterschenkel (calf) type)

- approx. 17 I think

- 16

- 35

- 19

- 23

- 16

- 18

- 20

- I realized there was something going on when I was about 28, but I realized that my legs bothered me around 35 (pain, fat that wouldn't decrease, having to put my legs up as soon as I got home from work)

- 29

- 31

- 60

- 14

- don't know

- 28

- 40 years

- 50

- 13

- 15

- 12

- 13

- 12

- About 16
- 13
- 13
- 20
- 11
- about 23, went into early menopause after a total hysterectomy due to endometriosis and ovarian cysts. yes both ovaries were removed.
- Not sure
- 47
- I think late 20s early 30 s
- 12
- about 3+, I was normal until then. I had mono when I was 3, had my tonsils out (in 1953), and also remember having some type of sores in my mouth and my parents swabbing my mouth. I started gaining weight then. Also legs started to look like columns.
- 14
- 12-15
- 16
- Ik weet het niet precies. Na mijn 25-ste. Er was geen specifieke aanleiding.
- 15-16
- 30-31
- 30
- since birth, started to worsen in puberty
- worse after age 60 with continued healthy diet and exercise
- 16
- 50
- 13 years old
- 12
- 14
- 10-12
- 16
- 13
- 35
- 20
- I always had strong legs, so I am not sure when exactly it started.
- 12
- 15
- from my recollection I always had "trunky" legs but it wasn't until about 12 that things started changing
- 12
- 28
- 13/28 (see previous)
- Geen idee
- the therapist said I was probably born with it but I knew my legs looked different after pregnancy
- 32
- I had some signs at age 9 but worsened around age of 30.
- I believe I controlled it through years of dieting, exercise, etc. And did not recognize it...and when I did have problems with my legs, every doctor missed the problem. I believe the active onset was in my late forties.

- Probably in my late teens/early 20s
- 17
- 45
- 32 years old is when swelling started. legs have always been large since puberty
- 17
- 14
- Diagnosed at 45
- 11
- Weet ik niet, weet het zelf nu 2,5 jaar. Maar het is eerder begonnen, terug denkend misschien wel 10 jaar.
- 25
- 13/14
- Late 30s
- 16
- around age 30
- 17
- 16
- 18
- Around age 11/12
- 17
- it began hurting and with strong inflammation at the age of 40 years, but it was visible from my 12 years old
- 48
- 40
- 14 years old
- 15
- 28
- 47
- 12
- 12 years old
- 12
- 60
- 31
- 16
- 13
- Before age 15
- 34
- Didn't know anything about this condition until today. I have always been heavy with large legs. So I guess about 16.
- 14 years
- 47-49
- In my 30's
- 13
- 12
- Legs have always been large and column like even when I was slim otherwise. More noticeable 14 onwards.
- I am not sure; I was bit overweight since age 6.
- 21
- Between 18-23
- Officieel weet ik het pas enkele jaren, maar de klachten die ik heb zijn al vanaf mijn

18e 19e levensjaar. Ze zijn alleen door de jaren heen verergerd en waarschijnlijk ook door behandelingen en onwetendheid van mij en arsten.

- 8?

- 29

- 11

- weet het niet zit nu pas in de onderzoeken van omdat het begin vorig jaar extreem begon te worden mijn eigen gedachten gaan terug naar de pubertijd

- 10

- 16

- 41 jaar diagnose. Klachten waarschijnlijk veel jaren eerder al.

- 25

- 17

- 18

- 50 yrs.

- 16

- When I was 5years old

- 13

- 15

- 16

- ca 35-36 jarige leeftijd

- 17

- 45

- 42

- 56

- 15

- 10

- 12

- 30

- Always had big legs since I can remember. Got worse through pregnancy & again in late 30's early 40's.

- 14

- 13

- 23

- 40

- 50

- 15 years old

- 50

- 15

- 16

- Don't know. Has been so gradual can't really remember.

- Can remember it since 14 year old.

- 16

- 13 yrs old

- 19

- 16

- 14

- 19

- 11

- 10-11

- started at 12 years of age

- 25
- 8
- noticeable at 11 or 12 but definitely predisposed even earlier probably around age 10
- 13
- 10 yrs. Started having periods
- 15-16
- 17 jaar
- 21
- 15
- 55
- 17
- 16
- Before teenage years
- 13
- 11
- 12
- 23
- 37
- most likely in my late teens early tweens
- 13
- very slight at puberty, but was truly triggered after lower abdomen surgery - age 50
- 45 years old
- 9 years with my first period
- 42 approximately.
- 25
- 51
- 17
- I have always been heavier in my hips and legs, however has become really bad from about 8 years ago after I had lap band surgery.
- 12 /13 jaar (met gelijktijdig heftige vermoeidheidsklachten)
- After 55 yrs old
- 7
- 17
- 33
- 46
- 11
- 13, everyone called me thunder thighs
- 13
- 13
- 10
- Nine
- 9
- 15
- It seems that it may have been present since birth. I always had columnar legs. But the weight gain became much worse at twelve years old, with my first menses. And my weight has been a terrible problem ever since.
- I can't be sure as i've been told since young my legs are fat.... as long as i remember even though i was a swimmer at National level
- 15? Not sure. I always remember having heavier legs.

- My mother said I always larger things, even when I was 7 - 8 years old.
- Discomfort (intense leg pain) has always been present. Noticeable swelling began at around 10 or 11 years of age.
- 38 yrs old
- 10
- 18
- 12
- 13
- 12
- I remember age 7 thinking my legs were very big. If I walked any distance they ached badly from earlier than 7.
- 15/16 years of age
- 40
- 15
- 14
- 13/14
- 68
- 30
- 13
- 12
- 14
- Not really sure, however it has become much worse in the last five or so years
- 15
- 12
- 6
- 14
- Geen idee wanneer precies. Heb mijn hele leven al stevige benen maar laatste 10 jaar steeds erger.. Weet sinds jaar of 7 pas wat het is en huisarts ziet het nog steeds als iets dikke benen bij een stevig lijf.
- 9 or 10
- Weet ik niet denk ongeveer op 33 jarige leeftijd
- 36
- 9 yrs
- 14
- I'm not really sure. I've always had heavy thighs. But the painful fat started in my 40s.
- 12
- 13-14
- I believe it started at around 11. Right when I hit puberty. By the end of fifth grade I weighed 200 lbs. Doctors just told me to diet and exercise more. My first diet was in fourth grade.
- 6 or 7
- 14
- Noticed my legs were bigger than everyone else's in middle school
- 33
- eigenlijk al met 45 jaar
- 15 or 16
- Pffff ik weet het niet meer zo precies maar begon al op de lagere school, jaar of 9/10 denk ik
- Best I remember I was about 13 yearsbold.

- 48
- full Lipedema on both legs exploded at the age of 15.
- 30
- 12
- 13
- In my thirties
- 16
- around 35 40
- 15
- 14
- 17
- 29
- My lipodema started sometime around the age of 14, however, upon my first pregnancy, I gained 100#.. almost entirely from the waist down
- 16
- unknown-it is something I have had a long time but have only just been diagnosed with
- 14
- 17
- 32
- I was 4 years old. I got very sick, and suddenly in less then one month I gained more than 10 kg, mainly in my legs and arms
- 14 - when I began menstruating
- 50
- 12
- I'm not really sure, I know I started getting heavy around 1976 and it just got worse, When I was in the hospital after giving birth to my son in 1989, the nurse me if my swollen area just below the knee had gone down. I just thought it was fat and it again has just become worse, I just thought it was because of my weight. Now I know and I feel there is hope.
- 13
- erfelijk
- 27
- 13
- 14
- 17
- Unsure. Started having unsightly ankles in the late teens, early twenties. Official diagnosis age 50
- 13years
- 28
- 36
- 27
- Approx 9 yrs old
- Approx 9 yrs old
- Approx 9 yrs old
- Approx 9 yrs old
- 15
- 54
- 48, after a removal of all my female parts
- 17

- dat is moeielijk te zeggen. helaas pas op mijn 30ste geconstateerd dat het lipoedeem was al die jaren
- 13
- 17
- 8
- When I was 9 years old, I had a much larger buttocks/hips upper thigh area than my upper body. So much so that my mother had to 'fix' all my waistbands on my pants so they wouldn't gap. This is my earliest memory of this difference in upper and lower body sizes.
- 13 years
- 12
- 18
- i don't really know. they say i was probably born with it but wasnt diagnosed until a year ago. i gained alot of weight during pregnancy
- 15-16
- 12
- 17
- 15
- 32 jaar
- 11
- approx. 16 years old
- 14
- Have had heavy legs since about 12 has got worse at age 47
- 12
- Twelve
- 14
- As I said previous I know it was there from a very young age. Before puberty.
- 15
- 13
- 11
- 12
- 48
- 14 years
- unsure 56?
- I believe it started in my teens, although i didn't know about Lipoedema until this year, when I broke my ankle and did some research on why I was having issues with swelling
- About 16/17 years old
- Very young. 8? I remember always having trouble with pants and shoes.
- 12
- not sure
- 12 jr, toen ik ging menstrueren werden mijn benen dikker. Maar of er toen al sprake was van lipoedeem is niet voor 100% te zeggen. Het blijkt wel een "familiekwaal"te zijn.
- 31
- 15-16
- 12
- It's my guess after my hysterectomy in 1987 so I was late 20s
- 35
- I have always had fatty pads from childhood on, but it got bad after hysterectomy

and a very stressful divorce. Then it really progressed when I learned I had breast cancer in 2013.

- 12
- 12years old
- 45
- 53 jaar
- 45
- 32
- 10
- 13
- a friend commented I had big legs at around 44 years of age
- 26
- 14
- 15-16
- 15
- 16
- 13
- 12
- 19
- 21
- 16
- 24
- 12 years
- 25
- 12
- 5
- 13
- about 10 years old
- 7 seven
- I had it from childhod, but got worse aged 13
- 16
- 12
- 27
- 13
- 30
- 34
- 11
- 13
- 12
- 16
- 16
- Ik denk 16/17 jaar. Toen begonnen benen en billen in verhouding dikker te worden
- 16 jaar
- 16
- 13
- 22 years
- teenager
- 3 Or 4
- 11years old
- 15

- 17
- Always had big legs but worse in late 40's
- See prev comment - puberty
- Not sure. A photo at age 13 or so shows my legs with no real shape to them, but it could have been earlier.
- I think approximately 14
- 36
- ? 12
- As a child: slim Teenager: slim-upperbody size S, lowerbody size: M-L Adult: slim-upperbody size S, lowerbody size: M-L After age 35 (when my twins where born): Upperbody: L, lowerbody: XXXXL
- 8
- 35
- not sure - about 14-15
- Er zij foto w aar ik al iets merk vanaf 3 jaar en erger rond mijn 10 de
- 18
- 18
- 12
- noticed the lump at 33 but have struggled with what i thought was just weight issues esp in the lower body since puberty
- I can see it in pictures as a child of 2
- i am not sure maby 13years
- 32 werd het erger
- 16 jaar
- 42
- I'm not exactly sure 12 or so.
- 12 13 jaar
- Ik denk rond mijn 15e alleen de diagnose is gesteld op mijn 30ste
- Rond de 18 jaar
- 28
- Niet bekend. uitte zich met 42 jaar
- weet ik niet ik denk rond de 16
- 16
- 7
- 12
- 22
- 34
- 12 years/ 12 jaar
- 17
- 21
- 16
- 46
- 17
- 17
- 35
- 13
- 30
- 18
- 12
- 18

- 27
- 12
- 22
- 16
- 16-18
- 14
- 16
- 12 or 13yrs
- 17 a 18 jaar
- 13
- APPROXIMATELY 15
- 17
- 32
- 16
- 21
- 9 years old
- 10

Statistics 7 : Who diagnosed you?

My GP (regular doctor)	12.93%
The Dermatologist	27.76%
The Phlebologist	21.71%
The Internist	2.14%
The Endocrinologist	5.10%
I am not officially diagnosed	30.37%

Others are diagnosed by:

- MLD therapist
- Lymphologist
- Lymphology Nurse/ breastcare nurse, diabetes nurse/ venous nurse
- Surgeon (plastic / vascular/ general/ vein)
- Several Doctors, hospitals and clinic names are mentioned (unknown their speciality)
- Dr. Karen Herbst
- Lipoedema and/or lymphedema specialist
- Lipoedema and/or lymphedema therapist
- Lipoedema and/or lymphedema nurse
- Skin/oedema therapist
- Cardiologist
- Lymphoedema clinics
- Health consultant
- Nurse practitioner
- Vascular/ vein specialist

- Woundcare specialist/ nurse
- Angiologist
- Bandagist
- Biatric physician
- Chyropractor
- Gynecogolist
- Infectious Disease Specialist
- Liposuction doctor
- Physical Therapist
- Rheumatologist
- Occupational Therapist
- Oncologist
- Podiatrist
- Self diagnosed
- Ayurvedic doctor
-

The actual answers were:

Not yet diagnosed but my mother and her siblings all had it.

Lymphoedema nurse

fysiotherapeut

Venous Nurse at Salisbury hospital UK.

lymphedema's doctor

I sent pics to Dr. Rappich, Dr. Smeller, and Dr. Stutz. All three confirmed I was stage 3.

hospital consultant

MLD therapist

lymphoedema specialist

Lymphedema therapist

Specialist (Dr. Herbst)

my rheumatologist

Therapist

Dr. Karen Herbst

Physio

I figured it out myself and then I went to Dr. Herbst

Rheumatologist

lymphodema nurse

ik heb de diagnose zelf gesteld en navraag gedaan bij de dermatoloog. Die gaf aan dat ik inderdaad lipoedeem had.

Lymphoedema nurse at clinic

Dr. Karen Herbst

US Endocrinologist said if Dr. Rappich said I had it, then he would agree.

podiatrist

Myself

Vascular Consultant

Specialist non Dr at a university

fysiotherapeute

Infectious Disease Specialist

Lymphoedema nurse

District Nurse Wound Management Specialist
Nij Smellinghe hospital
Oedeemtherapeut
vascular surgeon
een arts van de Nederlandse Obesitas Kliniek
Dr herbst
I read in a newspaper and I told the doctor
Physical Therapist
Vascular consultant
A lymphadema specialist at a rehab clinic recommended by my endocrinologist
Lady in the medical supply shop
Dr Herbst
Vascular surgeon
my podiatrist sent me to the lymphedema clinic
A vascular specialist, after they were taught by a PT!
Lymphodema specialist nurse
ikzelf omdat de medici er niet uitkwamen wat het was. Toevallig via de site van tilly
Lymphoedema specialist nurse
physiotherapeut
Osteopath
Huistherapeute
Door het horen van de ziekte ben ik er me in gaan verdiepen en via bijeenkomsten
en later via de huisarts
Vascular specialist
Lymphodema nurse
A plastic surgeon
Physical Therapist
Professor Mortimer
Rehabilitation doctor
Surgeant
lymphoedema nurse specialist
ik zelf en daarna een internist bevestigd
Fysio/oedeemtherapeut
Chirurg
Mld therapist - officially lymph clnic
schoonheidsspecialiste
fysiotherapeut
gynecogolist
Consultant
my family doctor keep telling me to lose weight i never gotten smaller...just odd
shaped..... that last three years gotten worst so my sister found another doctor to do
my knee area,,,,,
Lymphologist
De huidarts waar mijn moeder heen ging zei dat ik ook lipoedeem had.
A friend and myself, then doc
I read about Lymphedema in Google and found the Lipoedema and see that is me
physical therapist
Wounds service nurse
De oedeem/fysiotherapeut
My surgeon who was treating me for Lymphedema identified the Lipodema too.

DR sent me to lipedema clinic for final diagnosis

Na 10jaar ziekenhuis in en uit gaan ben ik er in 2011 zelf achtergekomen doordat ik een typfout op Google maakte.ik kwam op de site van Tilly terecht waarin ik mezelf herkende.ik heb 14paginas uitgeprint en ben daarmee naar de internist gegaan die me zei "Dit kan het wel eens zijn als ik het zo lees en vergelijk" Zei nam contact op met de dermatoloog waarna de diagnose met de woorden "gefeliciteerd je hebt zelf de juiste diagnose gesteld"

lipoedema nurse

Ik was 31 jaar oud maar ongeveer 4 jaar later door huidtherapie diagnose was gesteld

Huid specialist

Dr. Karen Herbst

Dr Karen Herbst

Lymphedema specialist

physical therapist

Fisiatra

a lipedema/ lymphedema specialist when I was in my forties

First PT, than verified by GP and re-verified by Mayo Clinic.

Physical therapist vodder trained

Dr. Herbat

Zelf ontdekt, huisarts kende lipoedeem niet, dermatoloog en internist hebben vastgesteld.

Physical therapist

Clinician at hospital lymphodema clinic

Huisarts heeft een vermoeden

Podoloog en vaatchirurg

Een vriendin , ze is fysiotherapeute

vascular surgery

Fysiotherapeut

Professor Christine Moffatt

Vascular surgeon

Lipodema nurse. At age of 53 was always told . To diet take ibruon tablets realise was something wrong . As weight loss to legs were non

My gp noticed something abnormal, after internet research i pushed for a diagnosis

The lymphodema specialist

Prof Neil Piller -research doctor

Physical therapist who does MLD

The GP diagnosed Lypheodema and referred me to the lypheodema clinic and it was the lypheodema nurse that diagnosed both lypheodema and lipoedema.

I diagnosed myself from Foeldi's textbook, then educated my doctor who then officially diagnosed me

At a lymphodema clinic (not specialised in lipoedema)

MLD therapist

Lymphklinik

Lymphedema specialist diagnosed in my late 20's

Physical therapist

lymphodema nurse and myself

I have been informed by a TV program (Act 2010), and had then visited a specialist.

Previously, no doctor has diagnosed lipoedema

Huidtherapeute

Ik samen met mijn huisarts. Het komt in de familie voor. En ik zit zelf in de medische wereld. Door een symposium werd het me duidelijk wat ik had.

A plastic surgeon whom I contacted for liposuction

bandagiste

Lymphodema nurse

huidtherapeut

fysio/oedeemtherapeute. later bevestigd door dermatoloog en fleboloog

Lymphology Nurse

The Reha clinic

Vascular nurse practitioner

Physiotherapist to hint about ... than officially by Phlebologist

Lymphatic Specialist Doctor

physical therapist

PHYSIOTHERAPIST

Lymphodema specialist nurse

liposuctiespecialist

liposuctiespecialist

Dr at a rehabilitation center

fysiotherapeut

fysiot

Dr. Herbst and Guenter Klose

Fysiotherapeut

Een masseuse

degene die de steunkousen aanmeet. Huidoedeemtherapeut.

Chirurg und Lip^dem-Operateur

on

Occupational therapist at lymphoedema clinic

doc in rehabilitation facility

plastic surgery Dr

Fysiotherapeut

Lymphoedema specialist Doctor and lymfterapeut

Huidtherapeut

Oedeemfysiotherapeut

Physiotherapist

Huidtherapeut

Huidterapeut

Dr. Karen Herbst. I had to go outside of my clinic for a diagnosis.

General surgeon

Lymphadema Therapist, need doctors diagnosis

Lymphtherapist

Vascular Vein Physician

internist, Regular dr. thought it was lymphedema

For liposuction

a friend who is an MLD therapist advised me to go to my Dr, who knew nothing about the disease, but referred me to a local lymph clinic where I was officially diagnosed Diagnosed with primary lymphoedema but believe cause of it is lipoedema. Awaiting second opinion to confirm

I was originally diagnosed by a stranger who approached me at a motorway service station - she turned out to be a lymphoedema consultant. I got confirmation from an MLD therapist and diagnosed by a lymphoedema nurse (after asking for a referral by

my GP).
lympodema sociaty
Dokter oedeemkliniek.
Venenchirurg
family member; mother-in-law (working in a medical supply store)
Oedeem fysiotherapeut
With a TV show, I have found it and then I went to my internist.
De fysiotherapeut, daarna door lymfoedeemwerkgroep in drachten.
Vascular Surgeon
Skin specialist
oedeemtherapeute
Dr. Karen Herbst
dame die steunkousen aan meet
Huidspecialist
oedeemtherapeute
Lymphodema clinic
Diagnosed myself and brought it to the attention of Physical Therapist and he agreed
after seeing the info I gave him..he was not aware of it's existence.
Dr karen herbst
huidtherapeut
Dr de Ridder, SFG, Rotterdam, puur als formaliteit voor de verzekering.
therapist then doctor
therapist
fysiotherapeut
Self
a lipodema/lymphedema therapist
de verkoopster in een winkel voor orthopedische middelen. zij verwees mij naar de
dokter, die er nog nooit van had gehoord
Self
Lymphedema Clinic
De huisarts en de dermatoloog.
Pro Peter Mortimer
Vascular surgeon
a nurse practitioner at a lymphedema diagnostic center at Spectrum Health in Grand
Rapids, Michigan
Physical Therapist
lymphatic specialist [backed up by other doctors]
huidtherapeut
Duke Vein Clinic
Myself and then professor mortimor in london as he is only person in UK that seems
to know of the disease.
Internet then Gp
Manuele Fysiotherapeut
I was in a klinik suppose to loose weight and the doctor there diagnosed me
Vaatspecialist
oedeemtherapeut
My Lymphedema therapist
Lymphologist
Lymphoedma clinic
circulatory center

physical therapist

Lymphedema Doctor

Lymphedema nurse and gp

bij de fysiotherapie

Angiologist

Venous Consultant.

A heart doctor

The oncologist, who referred me to a Lymphedema clinic, where the Lipedema dx was confirmed by the specialist (PT)

A consultant I had seen regarding another health problem. As soon as he saw me he said I had Lymphoedema, I was later diagnosed with Lipoedema by a specialist nurse.

Ny del and later ab specialist

Cardiovascular

Lymphodema nurse

The Physical Therapist and just had an Apt with Dr. Mark Smith in NYC and he confirmed it

Haematologist

I found it myself. I was in so much pain and thought it was because I am fat. I googled "big fat legs with pain". There it was.

Mmy

physiotherapist

Dr. Karen Herbst

Prof. Pillar

a lymphadema/Lipodema specialist

Lymphoedema specialist

Lymphoedema Therapist

Specialist after I told my GP what I thought was wrong with me.

Vein specialist

Dr Mackie at Mt Wilga Rehabilitation Hosp Hornsby Sydney NSW

Lipoedema specialist Mr Alex Munnoch

Lymph specialist nurse

cardiologist

Prof Peter Mortimer, just 3 years ago

I was diagnosed when i went to a lipoedema clinic in country south australia by the Flinders Medical Centre

lymphedema therapist

lymphoedema clinic

lymphoedema clinic

Diabetes nurse

my dermatologist in CR diagnosed me with lymphoedema. Year and a half later I was re-diagnosed to lipoedema here in Australia by a physio

Lymphoedema Clinic

skintherapist

Oncologist.

Physical Therapist

Oncologist

Like so many of us, my own online research found the diagnosis and it was confirmed by a lymphedema specialist.

Dr. Karen Herbst

rheumatologist

Myself, then went to GP who agreed with me

Ann Stone wound care and Lymphedema care

oedeemtherapeut, en zij heeft mij doorgestuurd naar de dermatoloog.

physiotherapist

Occupational Therapist

Vascular surgeon dx lymphedema. Plastic surgeon dx my lipodema.

bariatric physician

After treatment for breast cancer on the second side, I asked which arm to use for blood draws & pressure. Oncologist sent me to a Dr of Physical Medicine. He recognized the Lipedema. First I had heard of it.

Vascular Surgeon Advanced Practice Nurse at a Cancer Centre

LYMPHODEMA DOCTOR

Vascular specialist

physical therapist, then internist

dr herbst

Physical Therapist

Vascular doctor

Lymphodema consultant

vascular

dr iker- santa monica, californai

Lymphedema Physician Services

After 30 doctors, myself and when I told the doctor he said Yes

Dr P Mortimer

on

Brigit at the Lymphodema Clinic, London

Lymphoedema Nurse

self diagnosed, confirmed by PT

Lymphedema nurse fatter xrays yrs of ibruon for swelling dieting

I did myself and it was confirmed by breast care nurse.

Lymphodema nurse

Lyphodema clinic

Vascular doctor, Florida

Physical therapist

Physioterapist

plastic surgeon

Lympedema clinic

on

Occupational therapist who did lymphedema treatment

In India, an Ayurvedic doctor who specializes in Lymphatic Filariasis

Lymphodema nurse

Vascular MD

specialist in fibromyalgia and Addison's Disease

My renal doctor was first told had lypodystrophy/lipomatosis

hospital

Mld therapist

Occupational therapist

Vascular Surgeon

Dr. Dayan Plastic Surgeon

Lymphoedema nurse

lymphedema physical therapist

My sister-in-law treats patients with Lipedema and noticed my legs day, about 10 years ago. She sent me to her doctor who made the diagnosis. I live in Montgomery tx.

Physical therapist

DR HERBST

Karen herbst lipedema specialist

Katharine house clinic

Certified Lymphedema Therapist

eerst dermatoloog en daarna Internist

Oedeemfysiotherapeut

Lymphodema/Lipedema doctor

Physical therapist specialized in lymphedema. Finally I knew what I had.

Dr. Karen Herbst

Physical Therapist

Was dx with lyphedma but its not with research and being bilateral ..

fysiotherapeut

Huid therapeute

Vascular surgeon when I was 51

Chyropractor

Physiotherapist

hospital consultant

I found info on lipedema last night and consulted dr. Who previously was at a loss for what was wrong with my legs and said all he could come up with was lymphedema.

Vascular Specialist

Vascular surgeons

Physical therapist

primary/rheumatologist seem to acknowledge after my talking to them about it initially. I don't think they knew of it prior.

No one has diagnosed it. Inept physicians do not recognize it.

on

Vascular specialist

Therapist

Physical Medicine Dr. who treats many patient with Lymphedema

Lymphedeoma nurse at the hospice

GP is pretty sure and now just waiting on a confirmation appt with Sue Eaton

vascular doctor

Lymphedema specialist

Lymphedema clinic. My cardiologist referred me as having Lymphedema.

I self-diagnosed at age 38.

dietist en fysiotherapeut

i did major research. presented to my doctor who had NO knowledge until that point.

Een fysiotherapeut kwam erachter en die heeft me via de huisarts doorgestuurd naar een dermatholoog

MLD therapist and then...Dr. Herbst

vein doctor said I had mild elephantitis

Initially self-diagnosis

I was diagnosed in the Foldi clinic in Germany after visiting endocrine and vascular physicians for 3 years in Spain (more than 10 doctors). They even have surgery for varicose veins in both legs which worsened the Lipedemas and the worst phase of all

began.

Was referred to lymph clinic

Self diagnosed

lymphedema dr.

Cardiologist and rehab doctors after a stroke and a lymphedema therapist at a rehabilitation clinic

Surgeon Stefan Rapprich

My bariatric doctor.

Cleveland Clinic

I was seeing a specialist for fibromyalgia and she asked me what I was doing for my lymphedema.....after 8+years of treatment for lymphedema, another specialist said it was lipodema/lymphedema

Vascular surgeon

A Lymphedema specialist

Wounds/Lymphoedema nurse.

Officieel door dermatoloog, echter de kousenleverancier herkende het en stuurde terug naar dermatoloog

Dr at the mayo clinic

D.O.

I had to do the research. Doctors told me I had a calcium deficiency, I showed my doctor who confirmed

lymphedema therapist

vascular surgeon

Physical medicine physician

Physical Thephapy

By myself after reading an article in a magazine then by my doctor after I explained what it was

I have had it called many things but it was a renal doctor

Huidtherapeut

Traveled to Germany 2009. Was diagnosed by Foldi Clinic, Ehrlich-Lexer Klinik (in conjunction with visit at Foldi) and also was diagnosed by Hanse Klinik

physical therapist that I was referred to for lymphedema

Was told for years I had lymphedema, found a therapist who performed manual drainage and she stated it was lipedema not lymphedema

Lymphadema therapist

Myself after being told I had milroy's disease and it wasn't.

fysiotherapeut

I have an appointment with Dr. Rockson - but absolutely sure that it is what I have.

Consultant based at North Manchester Hospital diagnosed lipedema. The physio had referred me as he recognised something else was going on. Then sent to Helen Reader who is based at Royal Oldham Hospital. Lymphoedema Specialist Nurse and also deals with Lipedema.

Initially myself.

Vascular surgeon diagnosed lymphedema. I have symptoms for both lymphedema and lipodema

Dr. Emily Iker MD in Santa Monica, CA, USA

Nog geen officiële medische diagnose via een arts, maar weet zelf dat ik het heb.

Zelf ontdekt, gediagnosticeerd door dermatoloog

Cardiologist

a nurse practitioner

Dr. Karen L. Herbst, PhD., M.D.

vascular specialist

MLD therapist

Lymphedema was diagnosed by my internist. Lipedema was diagnosed by my lymphatic drainage massage therapist.

My cardiologist in connection with an oncologist.

I self diagnosed then got an official diagnosis from Dr. Karen L. Herbst.

Joseph Feldman, MD, CLT-LANA

Professor Mortimer

vascular surgeon

Lymph Certified Physical Therapist, then a doc who knows nothing about disease

Physiotherapist

Had zelf bij huisarts gevraagd of steunkousen hulp konden zijn . Zij gaf me verwijzing en bij firma die steunkousen aanmeet werd mij verteld dat het volgens hun eerder lipoedeem was dan gewoon oedeem . Verder gezocht via internet.

Myself on the internet when doctors knew nothing to help me.

Specialist doctore and nurse consultant at lymphoedema clinic

A doctor running a Lymphedema clinic. I went in because I matched the symptoms or so I thought.

Vein Specialist

huidtherapeute , huisarts vindt het "benen aaien"

Huidtherapeut

physical therapist, but not officially diagnosed

I had an infection that turned into cellulitis then my leg continued to swell. A friend asked me if I had lymphedema and gave me a lymphedema doctors name to go and see.

Arts van Polikliniek

my surgeon sent me to a lympadema clinic where I was diagnosed with Lipedema

A surgeon, with ultrasound on the legs

Physical Therapist

physical therapist with lymphedema specialty

Plastic surgeon

Plastic surgeon

Plastic surgeon

Plastic surgeon

Physical therapist

P.T. Experienced in Lipodema

CDPT therapist

i had lap band surgery and showed my surgeon my legs and he thought i had lymphadema and sent me to a vascular DR. He sent me to a lymhadema clinic where the therapist there told me it was lipedema.

Not officially diagnosed. I've mentioned it to many Dr.s and no one seems to have knowledge or care when I mention what I assume I have.

lymphedema nurse practioner

Lipodema nurse

Lymphoedema nurse

First my husband, then the official diagnose with an internist

I referred myself to a private consultant and then a German doctor who diagnosed me

A wound are specialist

My physical therapist, really
Alex Munnoch Plastic Surgeon
dx with Dercums & Fibro
Go diagnosed me with lymphodemia & I see a specialist and was diagnosed with
lipodemia
Liposuction doctor
Huisarts & oedeemtherapeut
Lymphodema nurse
my ortho doctor
on
I have researched everything I can. My Doctor keeps telling me it's hormones.
Physical Therapist specializing in Lymphedema
Lymph therapist
Physiotherapist
Consultant Doctor who specialises in this area
In the main, general practitioners are grossly ignorant and put it down to overeating.
Inherited condition I think, maternal grandmother and some aunts, but NOT my
mother and not my daughters, thank goodness.
Lymphedema nurse
A vascular specialists
A retired orthopedic dr who does disability check ups
Lymphoedema nurse
Lymphedema Therapist
Physical therapist
physical therapist
A plastic surgeon that was doing a procedure for my Mother
Vascular Surgeon and an Advance Practice Nurse at a Cancer Centre
Lymphoedema Clinic
Fysiotherapist
Nurse
Cosmetic surgeon
Plastic surgeon
My mother has been diagnosed and I have exactly the same shaped pzinfil legs
It at Gosford hospital
Australian physio after being diagnosed with lymphoesema in CR by a dermatologist
I had a vascular surgeon tell me it looks like lipedema
poli spataderen weet de benaming niet
after all the other test came up normal my regular doctor sent me to a PT who
specialized in edema whom then diagnosed me
Physical therapist
huidtherapeute later een dermatoloog
Na een gesprek met fysiotherapeut over lipoedeem. Afspraak bij huisarts gemaakt en
toen heeft zij het gediagnosticeerd
Huidtherapeute
oedeem therapeute samen met huisarts
I found out myself and got confirmation at a dermatologist
fysio
Fysiotherapeut/oedeemtherapeut
Fysiotherapeut
Fysio

physiotherapist
Huidspecialist
Physical Therapist during therapy for lymphedema
Originally the lymphatic therapist but officially a Neurologist

Statistics 8 : Did the doctor who diagnosed you give you enough information about Lipedema

Yes 17.92%
No 55.28%
A little bit 26.80%

Statistics 9 : What kind of tests (research) did the doctor/specialist perform after diagnosis

9.1	No tests were done / geen enkel nader onderzoek werd gedaan	41.37%
9.2	Blood tests / bloed onderzoek	9.08%
9.3	Bloodvessel research / bloedvaten onderzoek	14.81%
9.4	Muscle strength measurement / spierkracht onderzoek	6.34%
9.5	Measuring of the Lipedema arms and legs / meten van de Lipoedeem armen en benen	28.40%
9.6	Inapplicable / niet van toepassing	12.82%

Most other answers:

- [Lymphoscintigraphy](#) (radioactive Lymphatic scan)
- Biopsy
- Stemmer sign

Andere antwoorden:

- weet niet meer hoe het onderzoek heet. was bij afdeling nucleaire geneeskunde in het ziekenhuis. Ik kreeg een prikje met vloeistof tussen mijn tenen en moest daarna in een soort 'wafelijzer" stil liggen. Daarna moest ik een half uur bewegen en toen werd er weer opnieuw gekeken hoe de vloeistof was verdeeld.
- only physical examination and history
- ct scan with radioactive dye
- mijn dermatoloog heeft lipoedeem als specialisme, hij keek er naar en wist het meteen
- Surgery to remove angiolipomas
- Biopsy
- de 1e dermatoloog deed geen verder onderzoek. Bij second opinion kreeg ik lymfescan, spierkractmeting, opmeting oedeem
- cintigram of hoe heet dat, nuclear spul tussen de tenen

- Biopsies
- Manual research of symptoms and my complaints
- Biopsy
- Biopsy
- not a lot of Doctors in Minnesota know about it, so it was basically me asking for stuff, and them agreeing or not. They did not do any Lipedema-specific tests, only standard testing.
- Machine that measured legs
- Kwam er op neer je bent ongeneeslijk ziek en succes er mee.
- lymphe onderzoek, zenuw onderzoek
- Physical exam and biopsy
- Venous sufficiency scan by technician
- Venus insufficiency ultrasound
- clinical investigation, pressure tests, excluding lymphoedema
- Just looking at the skin and feeling
- MLD and wraps for legs
- Visual, stemmer sign.
- Ultraschall
- sent to lymphoedema clinic
- Ultrasound
- I don't know in english (in german: Venentest)
- allen bij kijken
- Gekeken naar vorm
- nuclueaire scan
- Look and feel
- scintygrafisch onderzoek naar de lymfevaten
- Vragen stellen, benen bekijken en aanraken
- no tests but he send me to other doctors (phlebolgist and internist)
- radiologisch onderzoek
- had healthy bloodwork reverse mirror for thyroid all counts normal range.
- Dont know the exact expression. Venes were checked if they work. Visual check.
- Lymphszinthigraphic
- blood tests, heart and complet Internist tests, bevor I had bloodvessel Researchs by another specialist.
- Visual
- Ultrasound of Legs
- listening to my complaints en looking at my legs
- MRI and sonogram
- Ik werd gelijk gemeten en kreeg steunkousen....achteraf super fout waardoor ik nog meer pijn kreeg dd het vocht nergens heen kon omdat m'n lymfe niet getriggerd werden
- Checking sore lipomas.
- Biopsy
- he transferred me to skincare to get stockings and lymfdrainage
- she assessed with questions and physical exam.
- scans
- Lymphadema
- lymftoscan
- Optisch. Drucktest dann Venen Untersuchung
- Lymfcintigrafie

- onderzoek door team artsen in ziekenhuis .
- Vascular ultrasound to rule out circulatory issues
- A procedure was done where dye was inserted into my ankles and watched how long it took to get through my lymph nodes
- some machine on my legs
- Studied and measured legs but did nothing invasive
- Visual recognition of ankle cuff & swelling.
- Venen tests
- ultraschall
- Afvoer van lymfe werd gemeten d.m.v. inspuiten vloeistof.
- only tests included with lymphedema mgmt
- Ultrasound
- ultrasonic
- doppler
- Stemmer
- Visueel onderzoek
- Lipedema massage
- Lymph-scintgrafi
- And a lymfschint that showed nothing wrong
- No tests
- Sent to physical therapist who measured
- Genetic tests
- Sent to a vascular surgeon for full diagnosis
- but he has send me to aphysiotherapist for massage and advised special stockings!
- van te voren gezegd dat de kans er in zat dat ik oedeem zou krijgen i.v.m. te weinig lymfvaatjes
- Lymphdrainage/ zwachtelen/steunkousen aanmeten.
- Machine for testing blood curculation
- Scan on legs lymph flow and veins
- Doppler
- Referred me to a doctor closer to home who checked my strength and may have measured. The diagnosing nurse did a laser measurement of my legs, not arms with lipedema, too.
- measuring legs, lymphscreening, compression tights
- De dermatoloog heeft niets gedaan. Met behulp van de oedeemtherapeut is er via de huisarts een skintigrafie gedaan die de diagnose van de dermatoloog bevestigde
- Onderzoek van het lymfestelsel
- Lymfecytogram
- bekeken en gevoeld
- Lymfevaten met radioactief materiaal
- Radioactief onderzoek lymfevaten
- doorverwijzing naar huidarts
- 2 jaar geleden is de diagnose gesteld. de huisarts zei dat er niks aan te doen was. Loop nu bij een dermatoloog en heb maandag een vatentest.
- I had been diagnosed by Dr. Herbst. I had all of the tests prior to coming to see her. This also included an MRI on my legs.
- Lymphscint
- Scanner on the veins
- I am seeing Dr. Herbst in a week. There will be many tests done by her. My doctor here knew nothing and doesn't care

- Linfocintilografia ...but just to make sure it was Lipoedema...
 - The look of legs and bracelet ankle
 - I was diagnosed with Lymphoedema which was a wrong diagnosis 20 years ago, but to get me to this diagnosis i was also given a veinogram & Doplar scan, and had all the above tests.
 - Differential Diagnosis of lymphedema (blood test and US abdomen)
 - All tests were done prior to diagnosis except a lymphoscintigraphy test was done.
- Excuse spelling.
- photographs
 - Ultrasound. Lymphoscintigraphy. Stemmer' sign.
 - No test, but prescribed MLD and compression.
 - Physical Examination
 - Self researched.
 - had prior test results, visual appearance
 - MRI of legs
 - MLD
 - All kinds of questions regarding body, history, pain, swelling
 - Pictures on the 'net
 - None of the doctors around me even know what it is
 - Vascular ultrasound, veins and arteries
 - referred to clinic
 - kijken en voelen
 - Ultrasound
 - Many tests, MRI, nuclear dye tests, lympscintigraphy
 - EXAMINE
 - lymfetest
 - onderzoek naar lymfoedeem
 - It was obvious I had something. I'm skinny on the top
 - Lymphscintigraphy
 - Lymphatic flow
 - ultra sound scan of legs
 - Ive been to many dr.s but none of them hsd knowledge of lipedema. No answers for 12 years.
 - history of previous surgeries and diseases also given
 - Ultra sound
 - No tests were done relative to lipodema; only normal tests for rheumatoid and diabetes.
 - EMG
 - Not sure what it was called but, pinched the skin on my toes & foot.
 - I sent photos to Dr. Manuel Cornely and Dr. David Amron to have them confirm.
 - lymfscintigrafie
 - My doctor didn't know what it was
 - Photos
 - Stemmer's sign
 - The lymphedema therapist diagnosed after one look at me. I have typical stage 3 fat distribution.
 - Ultrasound
 - They were done before diagnosis
 - Multiple test ruling out other issues such as arthritis, vascular disease
 - The drs did no testing and I am suffering in pain.

- Dr. Herbst
- Other tests as at first thought I had cancer of lymph glands
- Ultrasound of Thyroid-result, very small but just within "normal"
- Hij heeft naar de vormen van mijn lichaam gekeken. En hij heeft mij een aantal vragen gesteld mbt de ziekte.
- nothing
- Scintigraphy I think it was called
- my appt is in October with Dr. Rockson
- Not diagnosed by doctor, Lymph drainage therapist told me to research the condition as she thought it might be my problem
- I went to a vein specialist and they had me measured with compression stockings, they closed up some of the veins that were causing pain.
- ultrasound of legs
- I haven't been officially diagnosed.
- For the past 3 years, I have had MAJOR leg pain, I was diagnosed with Fibromyalgia. I recently came across information on Lipedema and took that information to my doctor; hence, the diagnosis.
- Physical exam.
- NA
- I was never officially diagnosed
- from Physical Therapist Certified in Lymph Therapy
- Liden5?
- was diagnosed with lymphedema therapist and new Dr, believe it is Lipidema
- diagnosed during varicose vein treatment
- Had operation by plastic surgeon when 19 yrs old back of legs from knee to ankle opened fat tissue removed to shape back of leg unfortunately on walking 2 days after op ankles burst skin grafts followed after 10 months recovery. Shape of legs much better further op for front was scheduled but refused. Had liposuction in my 40's to remove fat tissue from front. Successful. Although bruising occurred legs much better shape.
- Had operation by plastic surgeon when 19 yrs old back of legs from knee to ankle opened fat tissue removed to shape back of leg unfortunately on walking 2 days after op ankles burst skin grafts followed after 10 months recovery. Shape of legs much better further op for front was scheduled but refused. Had liposuction in my 40's to remove fat tissue from front. Successful. Although bruising occurred legs much better shape.
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- Had operation by plastic surgeon when 19 yrs old back of legs from knee to ankle opened fat tissue removed to shape back of leg unfortunately on walking 2 days after op ankles burst skin grafts followed after 10 months recovery. Shape of legs much better further op for front was scheduled but refused. Had liposuction in my 40's to remove fat tissue from front. Successful. Although bruising occurred legs much better shape.
- not formally diagnosed yet
- Onderzoek spataderen en verder niets

- ultrasound of blood vessels
- Observeren
- am being referred to lymphoedema clinic but physio thinks I have lipoedema
- Visual
- Ultrasound of legs
- It was a physio
- Mld
- not officially diagnosed
- echo
- I was just diagnosed this week. All i know is she is going to call when my compression stockings come in
- En de site van tilly
- lymfvaten onderzoek en spierkracht
- Test lymphesysteem en meten
- She looked at my whole body and directly saw the bizar proportions wich was a direct confirmation for her that I have Lipedema
- geen onderzoek direct doorverwezen naar het ziekenhuis

Statistics 10 : My Lipedema is in stage:

I	7.41%
II	16.73%
III	9.78%
IV (lipolymphedema)	11.92%
I do not know	31.09%
Between I and II	8.48%
Between II and III	14.59%

Statistics 11 : Did you change your lifestyle after diagnosis

Yes	32.40%
No	12.70%
I already had a good lifestyle	24.33%
A little bit	30.57%

Statistics 12 : What do you do trying to keep your Lipedema under controle

12.1	Sports	39.41%
12.2	Diet	34.39%
12.3	Healthy eating	63.70%
12.4	Reduce stress	22.39%
12.5	Psychological help	9.11%
12.6	Getting therapy	27.26%

Most other given answers:

- MLD
- Liposuction
- Compression stockings /clothing
- Hydroexcercise / Swimming
- Lymphapress

Andere antwoorden:

- following HFLC diet
- ortopedical compression clothes
- ander werk gaan doen en drie keer liposuctie ondergaan
- Still trying to get treatment
- MLD
- I got liposuction w/ Dr. Stutz
- Manual lymphatic drainage
- Compression thigh highs, had DVTs in both legs, lots of pain
- nothing
- aqua therapy
- Lymfe drainage en steunkousen
- Swim
- acupunctuur, kousen
- Swimming
- Keep feet/legs raised
- working on trying to find a therapist who specializes in chronic illness
- Compression
- unable to do anything until my legs stop weeping
- Steunkousen dragen
- Compression hosiery
- Steunkousen
- Ik vind het moeilijk om alles goed in balans te krijgen en te houden.
- Lymphapress en manuele lymphedrainage
- Kompressionsbestrumpfung, manuelle Lymphdrainage, apperative Entstauung
- therapeutic elastic stockings
- Yoga, weight lifting, compression hose
- manuele drainage
- Lymphapress Optimal
- elevate legs majority of the day
- wearing compression garments
- LPG en mld
- Compression tights
- Exercise when able
- Healthy eating, diet, exercise, lymphdrainage, compression garments everyday
- Liposuction
- compression legs and MLD
- Vibration plate

- Zo weinig mogelijk gluten, zuivel, suiker en bewerkte producten eten.
- Heel veel bewegen, lopen
- Nothing
- N.a
- Liposuctie
- kousen, liposuctie
- MLD daily
- Oerkrachtvoedings idee. 80/20.
- rebounder/trampoline, massage
- Everything. I was very ill immediately
- My husband trained in manual lymphatic drainage for times that I am in a flare up
- compression
- compression stockings
- exercise
- Pump and compression
- MLD
- Steunkousen
- lymphatic drainage
- Flowtron
- Compression stockings
- compressie
- hydrotherapy
- As I have both lymphedema and lipoedema I get regular leg bandaging and compression hosiery.
- Reduce what I drink (alcohol) wear compression garments
- lymphedrainage
- Flexitouch, compression.
- niets
- Lymphatic drainage once a month, occasionally wearing compression socks
- compressie en dagelijks half uur lopen
- niets
- Low Carb
- aqua aerobics and lymph drainage massage
- compression stockings
- nothing
- Compression stockings
- huidtherapie
- huidtherapie
- volodende rusthouden en plannen, dragen van steunkousen
- MLD and compression garments
- Ik slik pijnstiller: diclofenac
- I started taking Yoli. This has helped so much.
- Nothing really. I'm over having treatment.
- Dont Know what to do
- Fysiotherapie
- Watergymnastiks and kompression trousers
- Meer bewegen en wekelijks naar de huidtherapeut
- trying to get help but no money, no insurance. had to quit my job.
- Can't afford
- Lymph massage 1/month

- support stockings
- mld, Dorn therapie in combinatie met sportmassage
- compression, MLD
- Compression stockings
- Ik draag steunkousen als ik veel last heb en heb thuis een lymfdrainagesysteem (circa om de dag 1x 2 uur)
- Steunkousen
- Nothing
- Steunkousen
- steunkousen dragen
- IMT
- Manual Lymph Drainage therapy
- MLD and Lymph pump
- Mld
- Compression stockings and looking into mld therapy
- niks
- Lymphdrainage massages
- MLD massage
- Niets
- Compression. Hoping to have liposuction in Germany at a cost to myself.
- therapeutische elastische kousen dragen
- Manuele lymf drainage
- Manuele lymdrainage
- Nog niets. Heb de diagnose net gekregen
- Weinig want alleen steunkousen werd mij als middel aangeraden maar dat is met mijn werk als schooltuintjuf niet haalbaar. Ik leef vrij gezond en ben buiten mijn bovenbenen slank
- compression garments
- Compression
- MLD
- I use compression, a Flexitouch, and my daily exercise and routine to help me keep it at bay. I hope that I am doing the right things. I have lost a total of 50 pounds after my diagnosis. My goal is to maintain Stage 2 and not to grow.
- Pressuresocks
- Lymphatic Massage
- None
- Compression
- cirurgy (liposuction)
- Swimming
- Compression
- Compression stockings
- MLD
- Unable to do any thing as legs have not stopped weeping for the last 13 months
- wraps and self massage
- Exercises and compression stockings from an occupational nurse
- LDM, organic eating as much as possible, compression garments
- Nothing--I didn't know you could change it.
- elevation of legs
- odeem
- Use pump daily

- MLD swimming exercises
- MLD and Aquatic Lymphatic Therapy
- MLD, compression, diet, exercise
- Naturopathic
- MLD weekly, compression garments
- Unknown as what to do No Dr.
- None
- compression and flexitouch
- Wear compression daily, purchased vibrating plate & pillow for legs.
- Manual Lymph Drainage
- Compression garments
- Don't really know what to do!
- Staying active And watching foods i eat
- Use Ketogenic practices
- exercise
- I walk & do yoga
- compression, P.T, had varicose veins closed and saphenous ablation L leg.
- Ik ben bezig om zoveel mogelijk info te verzamelen
- I try to lead a normal life
- I drink more water
- No diagnosis yet and other health complications. Plan to maintain healthy eating, and to resume exercise once other health issues are resolved. Would like some therapy to deal with anger about this!
- Ik moet nog beginnen
- Compression when I can tolerate it..difficult when hot!
- My sister-in-law will occasionally perform MLD on my legs and arms
- Compression tights
- Walk a bit more
- Voedingssupplementen (orthomoleculair)
- steunkousen en lymfedrainage (via apparaat)
- Met de hond lopen
- Nothing
- I just learned about it, so nothing yet.
- See below
- NONE
- I do kinesio taping have done alot of other therapies but geared toward lymfedema.
- I was prescribed Lasix and advised to diet.
- Compression stockings
- Compression hose lasix pills daily
- Nothing
- Looking for a doctor.
- daily walks when the pain isn't bad, and working in the garden helps mentally too
- Exercise, Massage
- Water pills and keeping legs up
- Eating better. Light exercise
- weight lifting (barbell)
- Sometimes MLD, sometimes compression, research & therapy from Lipedema groups on Facebook.
- Developing my own program after inadequate treatment at clinic
- compression wraps. was already living healthy

- Elliptical work out
- moderate exercise 3x per week
- Nothing yet - gathering information
- Exercise
- Using compression stockings all year.
- Recently diagnosed prior to hip replacement. Will resume swimming when I can.
- I am researching a doctor in my area to treat it and bariatric surgery.
- Compression stockings and leg wraps
- TEK
- Exercise
- chiropractor
- compression wraps daily massage
- Exercise classes and increased physical activity
- rebounding; walking; bicycle riding
- Doctor said there was no cure and liposuction wasn't ususally successful.
- Keep active. I go to Curves.
- compression & MLD
- compression keep moving
- Ik ga voor een Liposuctie behandeling aan mijn benen.
- compression
- Too early to say
- nothing since I just now found out about it
- I was an athlete at time of onset, but still workout, although it is difficult, I work out 5
- 6 times a week.
- see box below
- Lymphatic massage
- do not know what to do
- Suikervrij eten
- walking
- gluten free diet (i also have Hashimoto's) long walks, avoid sweets and anything with sweet taste (honey, stevia ec), avoid salt, cook my own food
- I have a lymphatic drainage machine, which I don't use enough
- Bariatric surgery
- Compression, MLD and swimming
- Herbal therapy
- Manual Lymphatic Drainage & bandaging
- I was only informed of the condition of lipedema about a month ago. I had never heard of it before that.
- None
- MLD massage
- Buddhist Meditation
- Psychological support through online groups and forums so I know I am not alone.
- give up. Doctors don't believe me
- Nothing yet
- Wear compression garments
- still learning what to do
- Niks
- Manual lymphatic drainage by self
- I have never been diagnosed, I was talking to one of my colleagues and she gave me a website to look at.

- 120 mg Lasix
- mld and compression stockings
- Nog niks, ik krijg nog verdere begeleiding
- aquatic
- Elevating my legs a lot; compression via Ace bandages; drinking lots of water and no things that create bloating (soda, for example); massaging and stretching my legs thoroughly at night before bed
- swimming, water aerobics
- I am just now learning about this disorder and what I can do to help it
- Oedeem therapie
- Compression
- exercise
- physio exercises
- massage
- Oedeemtherapie
- Trying to reduce stress but this is adding to it!
- keep active
- Use of strong leggings
- Compression wraps
- compression wraps
- herbal supplements
- Compressions
- Wear compression
- Nothing
- Mld
- Walking
- Compression garments suggested by physiotherapist
- Wear compression
- Occasionally swimming, everyday compression stockings
- I'm not diagnosed and I dont know what to do
- may need to adjust what I am doing at the gym as the weight training I currently do may be more harmful.. need to reduce weight and intensity
- Lipo benen en armen gedaan
- Mld
- Operatie
- Elastische steunpanty
- Nothing
- Compression wraps, manual lymphatic pump

Added comments to this question:

- Use support socks and tights
- Physical
- Lymfdrainage
- compression
- MDL
- Pressotherapy
- Manipulatory Massage and compression hosiery.
- I have had MLD, wear compression, do water aerobics, and have had 2 WAL procedures.

- wear compression stockings
- compressant hose
- Manual Lymphatic Drainage Compression Stockings Swimming Lots of walking Elevate legs at end of day
- baths, acupuncture, Chinese herbs, modified Gua Sha and manually breaking apart lipomas
- cognitieve therapie
- Swimming
- Manual lymphatic drainage
- I had MLD for several weeks, but then insurance would no longer cover.
- Lymfe drÉnage
- Tried MLD also. Doctors look at me and have no clue. Think I have fat legs, or swollen legs but vascular doctor says it is not vascular but I do have reflux and V Veins. Been put on nerve meds by neurologist to stop pain
- MLD, lymfepress
- Counselling
- Near infrared sauna
- Lymfe drainage, lymfepress en kousen
- steunkousen dragen elke dag (lange kousen)
- weekly manual lymphatic drainage / wekelijks manuele lymfedrainage + support stockings class 3 / steunkousen vlakbrei klasse 3
- MLD
- compressiekousen.
- Physical therapy, flexitouch (after waiting for 2 years), tried compression garments (not able to wear), juicing works (but on limited income)
- MLD
- physiotherapy
- MLD, compression garments, supplements
- Huidtherapie
- liposuctie 2x de derde operatie zal dit jaar of volgend jaar plaatsvinden
- Kompression
- limited walking, in one week i have opted for 3 weeks intensive therapy in Austria as it is unaffordable in Australia
- MLD
- Sinds vandaag Project XL in Dordrecht met sporten op maat en psychische begeleiding.
- Fysiotherapie/ oedeem therapie
- steunkousen enkele maanden lymfe press, maar hielp niet afdoende, kreeg ook geen toestemming meer vd dermatoloog
- lymfe behandeling
- in germany it is called "manuelle lymphdrainage"
- lymfdrynage
- Mld
- fysio
- Compression and Drainage
- Lymphatic drainage
- MLD, supplements Butcher's Broom, selenium and Milk thistle
- Manual lymphatic drainage for some lymphoedema
- Lymphdrainage
- MLD and compression.

- Oedeem therapie
- MLD, Kompressionsstrumpfhose
- lymfapress
- ik gebruik per dag huidpres apparaat type hydrofen 12 dit 2 uur per dag voor de benen en 2 x per week voor de armen en om de 6 weken naar een heudtheraoeut
- Kompressions-Therapie, Manuelle und appative Lymphdrainage
- eating vegan and no white sugar, no white flour
- Manual Lymphatic Drainage, walking & gentle aquarobics
- Compression on arms and legs worn daily. Lymphassist at hospice at least once a week
- compression
- I use compression garments and I do lymph massages
- Physio
- endermologie therapie
- Support bandaging when I can get them on.
- lymphedrainage volgens Vodder
- compression stockings
- Manual lymph therapy, compression
- S L D and foot, ankle and leg wraps
- Lymfe drainage
- Mld
- Mld, bowen
- lymfmassage
- lymfdrainage
- voldoende bewegen elke dag. Heel moeilijk vanwege reuma en dyspnoe door spierzwakte, waarbij ook atrofie van de monnikskapspier. gewicht onder controle houden;
- Compression
- lymfedrainage (fysiotherapie) en lymfapress (thuis)
- Mld
- Lymphdrainage once a week for an hour
- lymphdrainage and Compression
- liposuction
- MLD
- Oedeemtherapie
- LPG Therapy
- manuelle lymphdrainage 2x week, compression clothing
- kine drainage
- MLD Kompression Liposuktion
- swimming whenever i can....
- Manual Lymph Therapie, Compression Tights
- I stopped all
- Lymphatic drainage and compression stockings
- Lymphdrainage, compression
- compression, and MLD
- manual lymphatic drainage, flat knitting compression
- lymphatic drainage; compressionsstocking
- N.a
- Fysiotherapie MLD
- Lymphdrainage & wearing the Stockings

- Mld
- Drainage therapie
- Lymphdrainage
- Compression & Lymphdrainage
- Eerst MLD, Daarna MLD met lymfepress, nu LPG
- not gaining weight anymore
- wraps and massage
- Mld
- Lymfe drainage
- i ware compression tights
- manuelelimfdrainage.
- pool therapy
- stockings /lymfdrainage
- manual lymphatic therapy
- Lymph drainage, supplements, compression, wbv, alcat test for inflammatory foods, organic acid test for supplements needed, three liposuction surgeries with dr stutz to remove lippy fat in legs and arms.
- Manual lymph drainage massage. Reid sleeve
- steunkousen massage
- Water Aerobics, Compression
- Oedeemtherapie
- lymphatic drainage
- heb ook nog multipel myeloom
- elastische kousen
- Compression tights
- Wearing compression tights and getting massages on my legs
- hydro 2x week
- Walking, lymphatic drainage
- trauma healing , the botched surgery was very traumatic since the surgeon was very hostile and aggressive towards me in the aftermath
- Compression garments
- Lymphdrainage / Kompression
- MLD and wrapping
- oedeem therapie en veel fietsen
- Rehabilitation, Compression, lymph drainage
- lymphatic drainage compression
- Massage (drainage) Steunkousen dragen
- Oedeem therapie
- Lymfepress en lymfemassage
- fysiotherapie
- Everything. I've been on extreme discipline diet and exercise since I was 12. I discovered the diagnosis online a month ago and went to a doctor who confirmed. It blew my mind that it wasn't my fault.
- Massage & wrapping. I had to quit therapies because of lack of money, only was allowed a few visits by insurance & missing time at work.
- MLD
- oedeem therapie, lymfedrainage en lymfe taping
- Massage and Pharmacological therapy
- Bandaging and compression also manual message now use compression machine and custom made stockings

- wearing compression stockings
- Mld
- I used bandages and garments for 10 years while teaching. Then the muscles in my legs deteriorated. So now most of my exercise is in the pool.
- lymphatic massage
- COMPRESSION WRAPS
- lymfen
- Massage
- elastische kousen
- lymfen
- elastische kousen
- Compression machine and vibe pro
- Mld
- massage en penzel therapie
- Lymphdrainage Liposuction
- Volg het Oerslank-dieet van Yvonne van Stigt
- lymfedrainage therapie
- 30/40 compression, manual lymph massage, avoid being in heat
- Oerslank --> Yvonne van stigt
- MLD
- MLD
- psychotherapie en fysiotherapie.
- MLD, Kompression, Reha
- Compression
- I like to walk in the water.
- Kompressions stockings (flatsticked klass 2), I bandage with polstring when needed.
- Steunkouser
- massagetherapie voor zowel armen als benen
- Lymfterapi, watergym, "pulsator",
- Endermologie en lymphedrainage
- Oedeemfysiotherapie
- Lymphatic massage, compression tights
- Endermologie middels LPG
- Manual lymph drainage
- I can't afford therapy.
- manual massage
- Flexi touch compression treatment, manual massage, compression stockings, diet changes, detoxed, went from sitting job to moving around type job.
- massage.
- wearing compression, having regular MLD sessions
- Kine of Vodder system
- Lymphatic drainage
- wearing my compression trousers (every day; up to 17 hours); going to lymphatic drainage (3 times a week)
- Lymfedrainage en steunkousen dragen
- lymf drainage
- Oedeemtherapie
- Lymfedrainage
- lipodema massage and supportstockings

- MLD
- lymphdrainage
- Huid therapie
- Fysiotherapie
- iedere dag lymfcompressie en word in gezwachteld met gipsverband arm en been ,dat moet iedere dag .
- lymfdrainage
- bewegings en manuele therapie
- lymfvaten therapie
- krachttraining en manuele lymfedrainage
- Physical Therapy..MLD, Wrapping..Excercise
- fysiotherapie, inmiddels belindigd. Oefeningen voor thuis meegekregen.
- Manuele limfdrijnage
- Integrale manuele therapie en mesologie
- MLD
- MLD
- MLD, flexitouch, vibration, compression
- water exercises
- Salt water pool
- Manuele therapie doormiddel van het LPG apparaat (endermologie)
- lymfodeem therapie
- MLD
- bioresonantie /homeopathie
- Oedeem
- bindweefselmassage
- HivaMat (D.O) Self Pay
- Compression
- Mld
- Compression
- physical therapy to strengthen muscles around joints so that I may do more exercise. I also have Ehlers Danlos Syndrome, Hypermobility type (officially diagnosed). My physiatrist is treating my lipidema, told me to wrap one leg per night, alternating, build core muscle strength, build leg strength in order to burn more fat and reduce size. Pool exercises and walking are his goals for me. I progressed well at first, but have setbacks. I get discouraged. We are testing for adrenal insufficiency. I stopped working just before I met this doctor. I sped my days in a recliner with feet higher than hips and my legs are considerably smaller than when I was working. I cannot don my support stockings by myself due to Ehler Danlos's effects on my hands and wrists. I cannot do bandage care with lymphedema wrapping for same reason. He won't prescribe something like FarrowWrap, but recent cardiac issues with orthostasis and tachycardia have led cardiologist to write to him to ask him to prescribe them so that my blood pressure is supported when I exercise and bend. Gardening season is here and I need to bend! Since my knees do not bend while I am standing on them from 40 years of dislocating kneecaps, I bend from the waist. When I come up, I nearly faint. Lymphedema caused by lipedema does not play well with Ehlers Danlos!
- MLD
- Massage and compression therapy. I am going to get a Flexitouch system too as well.
- manuele lymfe drainage, bandages en daarna steunkousen

- lymphatic drainage
- LIPOEDEEM THERAPIE
- lipoedeem therapie
- massage
- MLD
- Ik sport wel maar dat deed ik sinds twee jaar voor de diagnose ook al (en ondanks dat ik door lipoedeem bijkomend lymfoedeem heb, heb ik het in een lichte mate)
- therapeutic elastic stockings
- oedeemtherapie
- LPG huidtherapie
- ik heb van alles geprobeerd maar niets helpen.
- stockings
- Oedeemtherapie
- Lip en Lymfoedeemtherapie 2 x per week
- Lipodeem therapie is speciale krachttraining voorgeschreven door ziekenhuis in Drachten.
- Fysiotherapie, steunkousen en broek.
- Hydrotherapy, compression, very occasional MLD
- Massage therapy and wrapping. I also wear compression garments too during the day.
- Pool
- Walking
- hydrotherapy
- gebruik DIM en Mangosteen
- fietsen veel tuinieren
- manual lymphatic drainage, shock waves, cavitation and mesotherapy
- I had a course of CDT, and followed with MLD and Compressions made to measure. I do my own SLD. My Therapist says I keep it well under control, but it's hard.
- I have MLD and Bowen, I also have treatment with the Hivamat.
- Walk 20 minutes every day
- MLD + special exercises & massage I do myself every day, I wear Knee high support stockings.
- MDL and compression bandages
- Compression and the occasional MLD
- Pressotherapy, RAD DIET, etc
- Phsio
- wearing wraps
- Laser treatment. Compression and lymphatic massage
- Herbal remedies for what I thought was vascular insufficiency and creams flu red and swollen legs.
- Bandaging
- I have had Liposuction on legs, thighs and bottom, I now wear compression 24/7. I have had both arms reduced by surgery. I also wear sleeves. I get measured every 12 weeks to keep on top of my care and see my Lip consultant and his team on all visits. I have full contact with the team at all times when ever i require any form of help.
- ML D
- CDT therapy
- Physical therapy approximately nice a year...Occasional MLD.

- wraps/bandage wrap
- oedeemtherapie en rugfit.
- hydrotherapy MLD
-
- Physical
- Purchased pneumatic pump for my legs
- Compression pantyhose,, compression wraps, MLD, pool exercises, walking, pneumatic pump therapy, elevating legs often
- compression wraps and will get custom compression garment as well as flexitouch machine for home massage
- MLD and compression wrapping for a while. Stopped because a new doctor (after moving to California) said the therapy would reduce leg size by less than 10%. We decided that little improvement was not worth the 2 hours daily of wrapping/unwrapping and MLD.
- oedeemtherapie
- MLD
- MLD
- mld, lipo with dr stutz
- Compression, MLD
- Still coming to terms with it all and the fact that I went so long with out diagnosis ... So heavy now don't know where to start need help but don't know who to go to ..not much faith with the medical profession at the moment .. Very depressed ...
- Mld
- MLD therapy
- Pneumatic Compression Compression garments occasionally
- Wrap therapy
- fysio/sport onder begeleiding
- Exercising in the pool daily.
- CLD
- seeing specialist at clinic for advice, manual lymphatic drainage and aquatherapy
- MLD
- Ben nu onder behandeling bij mesologe.. Niet direct voor lipoedeem maar wel om alle processen in het lijf weer op de rit te krijgen
- lymfe drainage
- I wear compression
- Manuele lymfedrainage, elke week, benen met wraps inzwachtelen (elke dag) Lymfepress, bijna dagelijks (vaak niet in het weekend). ik loop bij een gewichtsconsulente
- Trying to lower inflammation through diet and supplementation along with walking daily and wearing compression.
- Deep water aerobics & fitness
- MLD Compression Swimming
- Dryneedling
- Only just beginning to understand what the problem is
- Gastric Bypass
- Compression stockings, MLD
- Manual Lymph Drainage Technique
- Roller therapy
- Manual lymph drainage; Compression Hose
- I do not have the option of any therapy at the moment I would like to know what to

do

- NONE
- proberen af te vallen
- I will have a liposuction by the end of the month
- Massage
- compression stockings
- MLD, Compression
- Looking for a doctor.
- Compression tights
- Try to eat healthy (most of the time) and when I can afford it, water aerobics. Try to walk but swelling increases dramatically when I walk even short distances.
- Willing to start pharmacotherapy mention by Dr. Herbst
- swimming, MLD, self-water massage, swimming, herbal supplements and HIVAMAT treatments
- walking, bike riding
- exercise, MLD, compression stockings
- Compression garment, manual lymphatic massage, Supplements including selenium, butchers broom, citrus flavonoids. I will be having a first round of liposuction in 7 weeks (August 21, 2014).
- MLD; compression
- Water therapy, compression garments, treadmill, castor oil packs, supplements suggested by Dr. Karen Horbst.
- I am a fitness instructor. I am a certified holistic health counselor. I eat "cleanly." I have had a harder time though, as I contracted Lyme disease which made the lipedema worse. I was also diagnosed with an estrogen dominance problem which also exacerbates the condition.
- pilatus
- I'm still trying to learn about the therapy. I'm self diagnosed and still learning and scared
- compression stocking for arms and leags
- mld 1x per week en gebruik de lymfe pomp 2x per week
- Tumescen Liposuction
- Manual lymphatic drainage
- Massage
- Lymphatic drainage
- Manuele lymfdrainage en lymfapress
- Just started therapy this week (intake meeting).
- Tebound excersise
- Compression pump, wrapping and compression garments
- regular cardiovascular exercise and weight training
- Compression tights and massage.
- Wrapping
- manuele lymfdrainage en ik heb een lymfapress thuis
- huidtherapie
- deep tissue
- Physicaltherapy 3 times a week, with pneumatic compression pump, massage and exercise
- manual lymph drainage
- Oedeem therapie
- Doctor said there was no cure and liposuction was not usually successful.

- lymfmassage steunkousen voor de hele benen
- lymfe
- compression bandages
- lymphadema therapy with compression wraps
- Hypnotherapy to learn to accept my body
- I follow a no carbohydrate diet and have Chiropractic, Lymph drainage, Acupuncture, Massage, Yoga, Pilates. .Strenuous sporting activities beyond 15 minutes produces increase fluid retention in legs and arms and is very painful.
- Manual lymphatic drainage.
- I see a CLT for MLD therapy. I also have a Flexi touch compression pump and I wear compression stockings 30-40 everyday.
- As above and wearing compression stockings- increasing compression strengths over the years
- Physical therapy, compression wraps, lymphatic muscular drainage
- am just starting lymph drainage therapy plus I'll be getting compression socks
- Regular massages
- I am being set up for Manual Lymphatic Drainage Massage, with possible compression garments.
- I had WAL in 2013 and expect to have another de-bulking WAL in the future.
- Quercetin, vit. C, Bromelain Citrus Bioflavonoids, Rutin, selenium
- MLD and wrapping with compression bandages; now beginning this next week using exerciser called a NU STEP and swimming
- Compression Drainage
- Manual lymphatic drainage
- MLD
- Whole body vibration
- bij huidtherapeute
- Booked in for complete decongestive therapy
- Tried the compression wraps, and I try to eat low fat
- Manuel Lymph drainage
- Can't afford therapy at moment
- compression and mld
- compression wrapping manual massage compression garmets
- I wear zensa brand calf sleeves when I stand for long periods and when I exercise
- I am still learning and accepting the diagnosis, I have my second appointment in 2 weeks time -at this stage I do not have much info on what I am suppose to do
- Massage
- supplements, compression, MLD
- lymph drainage
- Compression Garments. Lymphatic pumping
- self massage
- Manual lymphatic drainage
- swim 30 minutes then use swim jets to push fluids upward from legs
- CDPT therapy with wrapping, skin care and self massage training
- Compression stockings
- exercise of legs
- N/A
- I walk 3 Miles a day, use rower and elliptical.
- Oedeem therapie
- CDT, bandaging, flexitouch pump twice daily

- Lymph Drainage Therapy
- MLD and compression tights plus currently having a course of MLD and bandaging for 2 weeks
- Mesologie en IMT
- MLD and psychotherapy
- I don't do anything at the moment as i have only just been diagnosed and waiting for follow up
- Compression tights
- Compression and manual massage.
- Physiotherapy
- Oedeemtherapie
- lipoedema and lymphedema therapy
- Compression
- Until I see physio and listen to what she has to say, I can't comment here, I have done the 'gym' thing and walking: dieted until I was borderline anorexic - but things still go back to the same shape. I do not overeat and eat well, fruit, vegetables, chicken, fish, some red meat
- Compression and lymph assist at lymphodema clinic
- Physical therapy
- compression
- compression
- MLD, Compression garmets, Vitamin Supplements
- Aquatic Lymph Therapy (swimming pool) Trauma Therapy for the Compulsive eating
- No diagnoses - Haven't really done anything - always thought I just had to live with HUGE legs!
- Lymphatic drainage
- Mld
- Just learnt about MLD
- support hose
- oedeemtherapie en loop bij een psycholoog
- starting compression therapy soon. Considering seeing a massage therapist for MDT but it is not covered by insurance
- Compression garments, wrapping
- I was doing massage a couple times a week and wrapping my legs.
- volg de hormoonfactor, heeft mijn lipoeem sterk verminderd
- Fysiotherapie
- Ik begin eind januari 2015 met oedeemtherapie en lymfedrainage.
- Lymphedrainage
- Verbeteren spierkracht onder begeleiding
- thuis home trainer en buiten lopen
- Oedeemtherapie
- Quadrivas
- manueel lymfedrainage
- Oedeem therapie 1x in de week
- lymfe drainage
- Mindfullnes
- Oedeem
- Graded Activity
- mld

- I am not being taken seriously and the dermatologist says there's nothing they can do about it.
- MLD
- compression -- I use the Flexitouch System
- Lymphedema therapy

Statistics 13: My Lipedema is located in the following locations of my body:

13.1	Upper arms	62.05%
13.2	Lower arms	19.24%
13.3	Buttocks	55.44%
13.4	Thighs	65.25%
13.5	Legs to mid-calf	36.81%
13.6	Legs to ankles	77.87%

Most other answers:

Belly, abdomen and stomach and sometimes also feet are mentioned. Interesting to find out because officialy this is nog due to Lipoedema.

All the given answers are:

- Around knees
- possibly upper arms and stomach
- buik
- belly
- Abdomen
- everywhere
- Stomach
- Belly
- back
- lower abdomen
- buik
- abdomen
- Het meest in de bovenarmen, je ziet wel dat ik het in de benen heb maar deze zijn ook weer gespierd door het vele sporten
- I am not sure if it is in upper arms????
- abdomen
- Enkels
- Heupen en (buik als het daar ook kan zitten!)
- starting in the arms now
- ook aan de buik uit gewezen is dat het overall zit type 3
- Stomach
- Hips and back and stomach

- Knees rib cage low back
- Abdomen
- Upper arms, legs, butt
- Neck, back and stomach
- buik
- Buik
- abdomen
- not sure.....
- Legs and Arms
- Hips & lower back
- Belly, Hipps, Breast sides
- Back, stomach, breasts
- Rechterhand tot aan de pols
- Everywhere
- Scalp to ankles
- Hips
- Po
- Feet
- hips
- Vulva
- Trunk
- Knieen
- Back
- Is begonnen met de onderbenen/ onderarmen en billen. Bovenbenen in eerste instantie alleen dijbenen. Later ook knie en bovenbenen en armen.
- Expected bottom part of stomach
- stomach
- Have had a large lipoma removed from midriff twice. It has grown back again.
- Onderbenen tot aan de enkels
- from waist down and feet starting to swell
- Back and chest
- stomach
- buik
- Rondom knie en vet rondom enkels
- Abdomen
- buik
- Upper body
- trunk abdomen
- Armen benen heupen billen
- torso
- abdominal and chest
- all over now, but was from waist down
- Tummy
- Maagstreek
- No one has ever identified the lipedema fat versus the "normal" fat. I am guessing.
- lower abdomen under the waist
- since 2013 the arms, too
- Arms, legs, feet, stomach, hips.
- hips
- Abdomen. Also I think I have had some in my face. My lips were swollen, and have

become fuller than when I was in my 30's.

- stomach also
- Abdomen
- Abdomen
- all of which i have chosen but i have now had surgery to help reduce the bulk of it all.
- Right side. Waist down to my foot.
- I have rare foot involvement
- to just below the knees
- Abdomen
- Arms legs bottom and lower stomach
- Let arm, wrist to shoulder. Left side of abdomen
- Belly
- Belly
- Buik
- Stomach/abdomen
- rondom knieën het ergst
- Its all on my lower body I look abnormal.
- knieën
- Abdomen
- Waist to ankles
- left cheek, bottom of right foot
- labia, vulva area
- Hips
- hips
- Legs, ankles to thighs
- thighs to above calf, including knees
- Present all over my body. Worst affected area is from my hips to just below my knees.
- Waist to ankles
- Buttocks to Ankles
- lower abdomen
- abdomen and trunk
- feet
- onderbuik/buik
- Hips to ankles
- Feet
- Flanks, Abdomen, Back
- Flanks & Abdomen.
- PAIN
- feet all the up to thigh in right leg minimal affect in left leg still needing to wrap though
- Hele benen en inmiddels ook oedeem in voet. En armen
- Nodules everywhere
- Specialy the knees
- severe at knees
- stomache and lower back
- Stomach
- mid stomach
- Belly, upper chest

- Hips
- Lower abdomen
- Stomach
- knees (but not calves to ankles)
- thighs down to ankles
- the main area is a large bump, nod, pouch, knot what ever you want to call it just under the back of my knee with another patch of swelling wrapping around to the front. after evaluation the pt said I had areas from hip to lower leg
- Legs and arms
- Van enkels tot knieen
- Linkeronderbeen begint ook
- knees
- Neck and chin

Statistics 14 : How long did you have to wait before you got diagnosed Lipoedeem?

0-2 Years	14.68%
3-4 Years	4.56%
5-7 Years	6.24%
8-10 Years	7.76%
11-14 Years	7.07%
15-19 Years	8.97%
20-25 Years	11.63%
26-30 Years	10.65%
31-40 Years	11.33%
More than 40 years	17.11%

Statistieken voor vraag 15 : About your Lipedema Did you ever:

	1) Yes	2) No	3) Inapplicable	4) No, but I want to
15.1 Visit a psychologist / een psycholoog bezocht	22.05%	66.67%	4.77%	6.52%
15.2 Did it help / heeft het geholpen	9.24%	28.94%	60.45%	1.36%
15.3 Visit a homeopath / een homeopaat bezocht	13.94%	73.86%	5.08%	7.12%
15.4 Did it help / heeft het geholpen	3.48%	29.70%	64.77%	2.05%
15.5 Visit a acupuncturist / een acupuncturist bezocht	14.39%	74.47%	5.61%	5.53%
15.6 Did it help / heeft het geholpen	3.71%	30.91%	63.18%	2.20%
15.7 Visit a naturopathic / een natuurgeneeskundige bezocht	12.95%	75.68%	5.53%	5.83%

15.8 Dit it help / heeft het geholpen	4.62%	28.79%	64.55%	2.05%
15.9 Visit an infrared sauna / een infrarode sauna bezocht	12.35%	76.29%	5.76%	5.61%
15.10 Dit it help (release pain)	3.94%	28.86%	64.92%	2.27%
15.11 Did or do you use a lymphatic pump (lymphapress)	25.30%	61.97%	4.24%	8.48%
15.12 Did or does it help / helpt het of heeft het geholpen	18.26%	23.48%	55.68%	2.58%

Statistics16 : How many calories do you eat on an average day

I do not count them 41.36%
Less than 1000 cal. 5.08%
1001-1500 19.24%
1501-1700 12.88%
1701-1900 6.97%
1901-2000 7.20%
2001-2100 3.33%
2101-2200 1.97%
More than 2200 1.97%

Statistics : Do you sport

Yes / ja 36.35%
No / nee 34.56%
Sometimes / soms 29.09%

There is a lot to change here! Not enough many women are active

Statistics 18 : The 36,35% that sports does it:

1 time a week 19.05%
2 times a week 31.36%
3 times a week 24.85%
4 times a week 10.22%
5 times a week 6.50%
6 or more times a week 4.65%

Statistics 19: The 36,35% that sports do:

19.1	Swimming	28.10%
19.2	Water aerobics	14.68%
19.3	Yoga	11.60%
19.4	Stretching	18.43%
19.5	Tai Chi	2.05%
19.6	Tennis	1.02%
19.7	Football	0.11%
19.8	Basketball	0.34%
19.9	Weight lifting	15.81%
19.10	Pilates	7.96%
19.11	Biking	26.39%
19.12	Running	8.65%
19.13	Nordic Walking	17.29%

Most other answers:

- Fitness
- Walking

All the answers:

- walking
- fitness en spinning
- walking
- hiking, kayak in recumbent position
- walking
- Resistance Training
- wandelen
- walking
- Walking
- Hiking
- NuStep - passive cardio
- Chasing 2 small kids
- Walking
- fitness
- dog walking
- loopband
- Walking Zumba
- no car have to walk most every were I go
- distance walking, elliptical trainer
- wandelen, fietsen
- Krachttraining met personal coach
- Walk
- Fitness
- Fitness & cardio
- walking

- power walking, walking, cardio training
- krachttraining
- fitness
- Spinnen, skaten, krachtcircuits voor bovenbenen, buikspiercircuits.
- Walking and hockey
- Longer walks
- cardio
- Stationery Cycle
- cardio training en krachttraining bij de fysio
- fitness en cardio training
- fitness en wandelen
- Fitness
- Zumba
- Walking, golf
- Zumba
- fitness
- Wandelen
- Fitness
- Loopband, hometrainer
- Walking
- Fitness
- zwaar beroep met veel lopen
- fitness
- wandelen
- Fitness Riding Dancin
- bij de fysiotherapeut
- medisch fitness
- Fitness
- Gym
- gewoon lopen kan door deze ziekte niet hardrennen
- Medisch fitness
- Power move
- Fitness en cardio training
- aerobics
- vacustep
- Sportschool olv personal trainer
- Biodanza
- paardrijden
- fitness (crosstrainer)
- body pump arabic dance
- Cardio fitness
- Zumba
- Horse Riding
- Gymnastik
- aerobics
- Circuit training voor vrouwen (curves)
- Dancing (Karneval)
- Fitness
- Fitness en zumba
- Paardrijden

- fitness
- Zumba
- specifieke oefeningen in de fysiozaal, lopen, fietsen, legpress, roeien etc
- EMS-Training
- Cross Trainer und Zumba
- Fat Burner
- Crosstraining
- stevig wandelen
- Fitness
- walking with dog yoga
- Elke dag minstens 1 uur. Wandelen
- Walking
- zumba
- Crosstrainer and gymnastics
- i do my ten minute walking daily when pool is not open here i wait for summer to swimming twice a week. i do little it of long walk twenty minute just casual as long i can walk i walk.... most of the time i keep legs up.....
- Walking
- Balance
- Aerobic
- Fysiofitness
- Milon circle op sportschool
- dumbbell exercise
- Zumba, Salsa Aerobic, Juming Fitness, ...
- Revalidatie
- Cardio fitness
- just walk. I playd tennis but had to stop and i playd hockey but had to stop, now I am in the phase that I am fedup with it and am Not practicing any active form of sport
- Sporten onder begeleiding van fysiotherapeut, ivm hernia klachten
- High intensiti trainingen.
- Walking
- walking
- met de bejaarden mee doen met gymnastiek samen met fysiotherapeut als vrijwilliger.
- fitness, cardio
- walking
- cross trainer exercise bike gym
- isometric and physical therapy exercises
- Taking care of my horses. Will get back to riding soon. Used to do above sports often.
- elliptical trainer
- slowly going
- Walking
- Dans
- Fitness en korfbal
- Walk
- Hawaiian hula (dancing)
- Hometrainer
- fitness en spinning
- paardrijden

- General cardio at the gym
- Vibration plates and Zumba class
- In a Studio or at courses
- walking for exercise
- Crossfit
- Body-Styling Course, Kendo
- Power Plate EMS
- cardio fitness
- Body pump, voor de spierkracht
- oefenen in oefenzaal fysiotherapie loopband etc
- Fitness, zowel cardio en spierversterking
- fitness
- I noticed that aerobic exercise does nothing for me. The only thing that makes me feel better is muscle work. I also sing opera, so I get a good lung workout all the time.
- wandelen en medische fitness bij de oedeemtherapeute
- Schaatsen en skeeleren
- via de sportschool xco
- Zumba
- Wandelen en Volleybal
- normal walking
- sportschool
- van alles wat
- van alles wat
- trampolin (bellicon)
- softbal en stevig wandelen
- Coach netball
- fitness
- fitness
- fitnessen
- Fitness Studio, Crosstrainer, dancing (Oriental)
- Walking
- met mijn shetlander wandelen, mee bezig zijn daar beweeg ik ook veel mee 3+ per week. En op school 2x per week.
- Fysio gym. Kracht en conditietraining
- sportschool
- Zumba Fitness, Show Dance
- Riding
- Zumba
- lopen
- Cardiofitness en wandelen
- Body combat
- Fitness
- Paardrijden
- Krachttrainen
- Walking
- Fitness - Cardio and Strength training
- Dancing
- Zwemmen onder begeleiding van therapeut. Oefeningen om spierkracht te behouden en versterken
- Using gym equipment: rowing machine, cross trainer, exercise bike, some weights

- kracht training fysio
- fitness
- just walk
- Gentle walking
- cardiofitness
- Aerobic
- Mijn hond uitlaten. 4x per dag.
- Fysio Fitness
- fitnis
- Walking
- wandelen flink tempo
- fitness
- Fitness
- Krachttraining
- Aerobic class
- krachttraining
- fysiofit
- soms wandelen en fietsen en heel soms zwemmen
- Walking
- Vibration machine
- Zumba
- Fysiosporten onder begeleiding
- Aquapilatus, golf 2-3x /week
- wandelen
- Walking
- walking
- Fietsen en lopen (5/10 km)
- Volley/skeeleren
- slenderen
- Krachttraining
- fitness
- Fitness, flink wandelen.
- Elliptical
- Walking
- Mom in Balance
- Zumba
- physical therapy exercises
- fitness
- horse riding/ paardrijden
- fitness
- BBP
- sportschool fitness plus diverse apparaten
- Fitness/Zumba/wandelen
- fitness
- Bodyvive
- wandelen
- Cardio- en krachttraining, fitness.
- Cardio en Fitness
- walking
- Bergop wandelen in fitness

- Fitness
- Fitness
- personal trainer en wandelen en vacustep
- normal walking
- paardrijden
- Zwaar werk altijd in beweging als schooltuintuf
- Wandelen
- Wandelen
- Walking
- 3-4 k walk
- walking
- Aerobic/plyometric videos at home
- personal training op sportschool
- Lots of walking and no walking when diagnosed. It hurt too much and was carrying too much fluid around.
- Resistance and cardio
- walking daily
- Elliptical
- treadmill
- Kick boxing, netball,
- Jazzercise
- Excercises every day but swimming four times a week for two hours
- Gym activities including cardio & weights. Try not to run
- gym/treadmill
- fitness
- Walking on treadmill
- gewoon rustig wandelen
- Treadmill walking.
- Aerobics
- Dancing
- Walking
- NuStep cardio machine
- Walking
- rugfit, oefeningen om de rug sterker te maken, maar ook de rest van het lichaam.
- cardio training kracht training
- walking
- elliptical machine
- Fencing
- TRX, INSANITY
- walking
- wandelen/fietsen
- Cardio
- walking
- walking
- Full body workout class at gym, with weights and cardio. I also walk
- Horseback riding
- fitness
- On vibrant machine . And arm cycle and walk . At gym once wk
- Jazzercise aerobics
- Zumba en xco

- Elliptical machine
- elliptical
- Kayaking
- Crosstrainer and long walks
- Ik ben sportinstructeur en geef 3 tot 4 uur aerobics en xco training per week
- Walking and cycling
- Dancing
- Farm Chores
- gym
- Zumba
- Walking 45 minutes on treadmill
- Cardio op mini-trampoline, kettlebel, crosstrainer, wandelen.
- Walking
- walking
- Dagelijks 2x per dag de home trainer ongeveer 15 minuten en 1x per week bij de fysiotherapeut op de loopband een half uur
- met personal trainer
- zumba
- walking and horse riding
- Walking
- Bootcamp
- fitness
- Walking, softball, basketball
- Walking, zumba
- mini trampoline
- walking, hiking in the mountains,
- Callanetics, Walking
- Treadmill
- fitness
- Weight training
- just cardio so far
- wandelen
- walking
- Horseback riding, rebounder
- walking
- elliptical, vibration plate
- Walk, dance
- walking
- crosstrainer
- walking, and swimming in the summer
- wandelen
- zumba and jazzercise or bicycling
- Fysiotherapie
- Walking
- daily walking 15 minute mile for 2 miles
- fitness
- Hiking
- Netball
- rebound exercise/trampoline, horse riding and gym (fysiotherapist)
- Walking 1.40 mins a day

- Walking
- Just plain walking
- Ik heb al van alles gedaan alles lijkt te zwaar te zijn en dan haak ik af
- Eliptical
- Fysiofitness
- eliptical
- volleybal en sportschool met begeleiding
- Interval training, elliptical, kick boxing, strength training
- Waliking -treadmill
- Netball
- Aerobics, strength training
- Sportschool
- Walking
- aerobic classes
- walk
- Fitness training
- 5 dagen in de week rij ik op mijn paard.
- zumba
- just walking
- run/walk, elliptical
- Wandelen op het moment veel
- Walking
- Fysiotherapie fitness
- walking
- Zumba, HIIT training
- treadmill
- Walking
- walking
- Walk 20 minutes on treadmill
- Cardio training en soms spinning..
- Crosstrainer
- gym
- fitness 3 x per week + 1 x zwemmen, boodschappen altijd op de fiets.
- Wandelen
- walking
- horseback riding
- Golf and personal trainwr
- Rugby, Kayaking
- I find it difficult to exercise, I swell up, and it is very painfull
- fysiofit
- stationary bicycle
- Walking
- elliptical, exercise bike, treadmill
- Floor and step aerobics; plyometric jumps
- walking
- Cardio such as spinning, stair climber, and eliptical
- Walking
- Walking, rowing, and elliptical
- Belly Dance
- Walking

- and aquapilatus and I play golf twice a week minium
- with a personal trainer once a week and walking dog other days
- Cardio
- Zumba & walking 3times week 4/5 miles a time
- Fitness
- ik heb een tijdje gefitnesst, op het moment even niets
- Meta fit / high intensity interval training (HIIT)
- walking at 4 km/hour
- Walking
- Walking
- Walking
- Crossfit
- Paardrijden
- Handbal
- Vibration machine r
- Netball, weights, aerobic
- Fitness, speciale spierkrachtoefeningen bij fysiotherapeut
- rebound excersise, horseback ridning, Resistance exercise
- les mills body pump group fitness
- Cross-trainer (3 ÷ 4 x p/w) en spieroefeningen (dagelijks)
- fitness 1uur 1/3 interval cardio en 2/3 kracht
- Fitness
- Buikdansen Fitness
- Spierkracht
- Krachttraining
- Fitnis cardiO apparaten
- fitness and walking
- Milon cirkel
- Fitness met fysio
- Fitness, cardio en kracht
- Cardio
- Lopen
- Graded Activity
- Cardio fitness
- Wandelen
- Walking
- sportschool van alles wat krachttraining fietsen loopband e.d.
- pulmonary therapy

Statistics vraag 20 : Do you read books about healthy food, eating

Yes	51.17%
No	15.12%
Sometimes	33.71%

Statistics 21 : Do you read books about a healthy lifestyle

Yes 44.97%
 No 19.15%
 Sometimes 35.88%

Statistics 22 : Please tick off the list below which physical symptoms or conditions you have (more choices possible)

22.1	(Pressure) pain	85.00%
22.2	Fatigue	81.91%
22.3	Fluid retention	78.45%
22.4	Problem falling asleep	47.02%
22.5	Awake for hours during the night	40.92%
22.6	Frequently up at night to urinate	47.55%
22.7	Leg cramps	55.39%
22.8	Arm cramps	12.96%
22.9	High blood pressure	24.94%
22.10	Heart problems	10.63%
22.11	Thrombosis (now or had)	7.69%
22.12	Erysipelas	3.77%
22.13	Diabetes mellitus type 1	0.68%
22.14	Diabetes mellitus type 2	5.80%
22.15	Vitamin B12 deficiency	15.22%
22.16	Vitamin D3 deficiency	20.95%
22.17	Vitamin B11 (folate) deficiency	2.71%
22.18	Fibromyalgia	17.48%
22.19	Gallstones	13.41%
22.20	Sleep apnea	13.11%
22.21	Can not stand up for long	59.08%
22.22	Not able to walk properly	39.86%
22.23	Osteoarthritis in the knees	27.58%
22.24	Osteoarthritis in other joints	21.78%
22.25	Other knee problems	37.15%
22.26	Concentration disorder	30.52%
22.27	Problem with making(finding) words	34.29%
22.28	Varicose veins or spider veins	53.13%
22.29	Quickly being cold (hands, feet)	66.77%
22.30	Problems getting your body warm	45.89%
22.31	Carpal tunnel syndrome (or had)	17.63%

22.32	Hyperuricemia	0.83%
22.33	Gout	3.39%
22.34	Metabolic problems	23.81%
22.35	Bowel problems	34.44%
22.36	Hairloss	22.00%
22.37	Dry skin	49.13%
22.38	Depression	39.71%
22.39	Emotional lability	27.58%
22.40	Eating disorder	16.50%
22.41	Loss of mobility	33.01%
22.42	Shortness of breath	32.03%
22.43	Skin ulceration	7.31%
22.44	Recurrent yeast infection	12.96%
22.45	Obesity	53.20%
22.46	Hypermobility joint syndrome (diagnosed)	14.09%
22.47	Bleeding gums	20.20%
22.48	Having a high cholesterol	11.83%

Other answers / Andere antwoorden:

- Bariatric surgery but did not help fat deposits on knees.
- week leg muscles, easy sweating
- Painful, heavy feeling on ankles
- Neuropathy
- Insuline Resistance, PCOS (Oligomenorrhoe, imbalanced hormone levels)
- most have resolved after lipo
- Seizures/shaking spells. Neuropathy.
- Sjögren's syndrome, pulmonary emolism
- endometriose, longembolieën, lekkende hartklep
- endometriosis
- tendonosis
- Ontstekingen overal
- Veel van de klachten zijn verholpen met supplementen, voeding en sporten. Van veel andere klachten ben ik mij niet van bewust dat ik ze eventueel zou kunnen hebben.
- Back pain requiring surgery. Unable to get pregnant.
- opstartproblemen met lopen (pijn) na tijdje zitten / liggen
- peesplaatontsteking/hielspoor, tennisarm
- migraine
- Knee replacement
- Rheumatoid Arthritis
- hashimoto
- van hyperthyreoidie naar een hypothyreoidie. moeite met lopen had ik absoluut voor de operaties in drachten
- Migraines

- Allergies to all penicillins and cephalosporins because cellulitis was treated aggressively prior to any knowledge of lipoeedema and nutritional changes
- Hashimoto Tyreoiditis
- Autism
- redelijk flexibel in mijn boven lichaam.
- Endometriose
- Psoriasis
- Abnormal gait
- Lyme disease, lipodermatosclerosis, chronic venous insufficiency, neuropathy, herpes simplex eye
- break bones very often
- hot, sweat easily and often, tingling, stinging, burning , twitches
- Reuma, astmatische bronchitis
- Migraine, Asthma, Acid Reflux. Had Gynaecological problems before hysterectomy. I had gout at 23. I hadn't eaten meat or drunk any alcohol for 6 years.
- Hypofunction of the thyroid
- heel moeilijk gewicht verliezen
- zomaar blauwe plekken; druk op de knien is groot; wond geneest langzaam en snel ontstekingen
- onderhuidse vetbultjes armen en benen, 's ochtends stijve en pijnlijke handen/vingers en enkels, inmiddels chronische tennisarm, zo nu en dan slijmbeursontstekingen schouders
- Hooikoorts; schimmelnagels aan tenen; scoliose; doorgezakte voeten; rechts extra rib; lichte overbehaving
- High Lipoprotein (a)
- get bruises for no reason sometimes.....polka dots or patches....
- Have had cellulitis. Don't like the heat.
- Traag werkende schildklier
- allergies
- Hashimoto Thyreoiditis, PCO
- Thyroid problem and endometriosis
- I dont know if I have a vitamine deficiencie
- lymphdema for 30 years - started first
- Ik ben ruim 25kilo kwijt en dd heb ik minder pijn en kan wat langer staan. Er is geen fibromyalgie vastgesteld maar het lijkt er wel op...de handen zijn ook strak(kootjes/spieren) vooral id ochtend en avond.
- in 2002,traumatische bus ongeval gehad.
- Seizures; Oxy-gen dependent; Anemia; CHF; Dercums Disease; Coumadin Therapy; Allergies
- Spinal Stenosis, degenerative spondylolisthesis
- high Lipoprotein A
- Twisted pelvis
- Painful hip joints
- cancer
- Excessive bruising on arms and legs
- zinc deficiency, intestinal problems, psoriasis on the parts where the lipedema is....,
- Blauwe plekken, voedselallergie, eczeem
- Ziekte van ledderhose
- Dercums, allergies, anemia
- Chronic Fatigue Syndrome/ME

- Vaak last van algeheel malaise gevoel. Pijn in spieren/ verkramping van nek en schouders armen. Hoofdpijn/Migraine
- poor body temperature regulation. Over heated, or very chilled - hard to be just a comfortable temperature.
- severe back pains
- Pituitary Gland malfunction
- Low blood pressure
- Breast cancer, costochondritis
- Rums
- Pain in My spine. Whiplash . Bad skin. Chronical sinusitis. Double eyelash lines. Astigmatism and nearsighted. Muscle cramps. Restlesslegs . Many cysts (normal tumors) om My ovaries. Endometriosis. Myofasciell pain syndrome. (Excuse My bad english). And tremors/shaking hands
- - Rosacea - Mijn galblaas is ondertussen verwijderd.
- Easily overheated
- anxiety,myoclonus,hashimotos,graves,raynaud's,systemic sclerosis,rapid heart thyroid,brain,lymph nodes,uterus,prolapsed rectum,bladder,
- Severe scalp dryness
- Inability to breast feed Never perspired underarm
- Microscopic Polyangiitis Vasculitis
- Dercums disease
- I am not sure about the lack of concentration or difficulty forming words. I sometimes have this but put it down to my age!
- Pijn in onderrug
- Bandscheibenvorf%olle ,Arthrose,
- Landkaartong Veel jeuk
- Te trage schildklier werking
- Pain when touching areas
- Droge mond
- lichen planus
- Rosacea, Dermatitis, Nerve pain started recently down left leg
- IgG deficiency, multiple stress fractures
- Some symptomsI had prior to getting treated
- schildklierpatient/hypo
- Ehlers Danlos Hypermobility Type, started with easily dislocated elbows as a toddler, then easily dislocated kneecaps from teens onward. Left kneecap is now embedded on a condoyle of the femur. Has been there at least 8 years. This is why I cannot bend that knee when standing on it, and why I often need to physically move my knee to bend it from a straight position. Hashimotos Thyroiditis for 17 years, Low White Blood Cell Count for past 17 years, One heart attack, but only that artery had any build-up, all the rest were completely clear. I had my gallbladder removed in my 40s, it was full of symmetrical, identical, pyramidal stones. My mother took DES - diethylstilbestrol - during all of her pregnancy with me, from as soon as she suspected she was pregnant. I have a T-shaperd uterus and a hooded cervix. I have never been pregnant. I have had asthma since age 25. My triggers are mostly pollutants, especially smoke and hydrocarbon fumes, and cold air. Muscle contraction of my chest wall is one of the symptoms I have with asthma. I have had irritable bowel syndrome for perhaps 30 years. Last 2 years my doctor has diagnosed me with episodes of diverticulitis, but colonoscopy revealed I have no diverticuli, so now she is calling it colitis. I get diarrhea for weeks and only antibiotics seem to stop

it. I use probiotic capsules daily to improve gut flora and fauna. Diabetes is well-controlled with HgA1c of 5.3. It has never gotten to 6. I have been slowly losing weight from 368 to 312 since 2-2011 (heart attack). I have successfully lost weight using liquid protein diets in the past. Went from 215 lbs to 165 lbs at age 30, maintained it for about 2 years. Once I started eating significant carbs, weight came back. At 165#, I still did not have ankles, though my top was size small and my skirt size was size 8 American. Then I regained 50 lbs and lost it with liquid diet again. It came right back. I gained until 300 lbs, then used liquid protein plus plain lean meat and green vegetables 1 cup for dinner. Lost 70 lbs. Went up again immediately to 368 lbs. I am losing weight now by eating less. I have exercised at times during these years, mostly doing physical therapy strengthening and isometrics and pool work outs. I have also lost considerable swelling in my legs by stopping work and sitting with my legs elevated most of every day. I had Shingles (herpes zoster) in my eye, on my eyelid, on my brow and forehead, and in my scalp in September and October 2011.

- herniated disc
- hypothyroid, high cortisol-pseudo Cushings, polycystic ovarian syndrome and high androgens, Aspergers
- pijn in rust
- Snelle verzuring in de spieren.
- Multiple Sclerosis; cerebral aneurysm; haemochromatosis; endometriosis.
- Nachtzweeten
- pain in beans
- e.d.
- Neuropathy, congestive heart failure
- granuloma annulara (goedaardige huidaandoening)
- cancer
- Pain, tingling legs in heat, aching, swelling
- rynauds
- Bruising
- Hearing loss
- astma en bronchiectasieën
- Last test, only the good cholesterol.
- Lupus, Raynaud's Phenomenon, Factor IV Leiden, MTHFR Mutation, chronic anemia
- Headaches
- had a benign parotid tumour
- Random Skin sensitivity. Just a single patch of skin hurts. It can last for days or hours. The areas of skin that hurts are very random. Sometimes the head, arm, hand, back?
- Allergy to adhesives
- vertigo
- Painful legs
- night sweating
- Kidney cystic disease Thyroid disease
- I had a bcg infection aged 14 after vaccination
- I have chronic progressive multiple sclerosis
- Note: blood pressure and cholesterol are controlled with drugs.
- Painful ankles
- "tingling" or "creepy feeling" in my legs in evening/before bed. Lessens with

movement

- celiac, chemical sensitivity
- Sjogrens
- Anxiety, IBS
- heel snel/veel blauwe plekken
- Thyroid under active
- Wegeners Granulomatosis with kidney and lung involvement
- one episode of thyroiditis
- Must of above have resolved
- peripheral neuropathy
- total cholesterol high after atkins diet. Lost 10 lbs
- Addison's Disease
- Blood clots
- Bo-Polar Disorder
- Inflammatory arthritis Hypothyroidism Low glomerular filtration rate
- bilateral lower extremity lymphedema
- Off and on pain when walking
- Swelling in legs thighs
- arthrose in beide knieen , nu 2 knieprotheses
- HPU, bekkeninstabiliteit
- overmatige transpiratie zeer heftig romp en gezicht.
- Low blood pressure Lyme disease
- hypothyroid plantar fasciitis
- Hypothyroid; Degenerative disk disease, advanced (L3-4; C7?) ; Nearsighted (corrected via laser surgery)
- stiffness when getting up. extreme tenderness, pain when massaging and/or pressing outer thighs, knees and arms.
- Vitiligo
- high functioning autism
- Tingling sensation after sitting short time..can feel pants get tighter on legs during day. Migraines ect
- Morphea
- rheumatoid arthritis, low thyroid
- Scoliosis Th-L - hyperlordosis, varixes, latent tetany, inner strabism, anxious insomnia
- legs get tingly and achey when I haven't changed my daily activity
- celiac disease (diagnosed at 40 years), large uterine fibroids, ovarian cysts, breast hamatomas which get larger and smaller cyclically
- bruising
- autoimmune disorders-psoriatic arthritis, hashimotos thyroiditis
- I have lost almost all hair on my legs after the surgery and worsening of lipedema - I don't have to shave any more.
- When the Lyme is active, I have bouts of Raynaud's in my hands. My legs don't hurt, unless they are touched roughly/grabbed. I do have odd sleeping habits/vivid dreams/sleepwalk/talk sometimes.
- i have pcos, my research has shown that every woman i talked to that had pcos also,had lipoedema. EVERYONE OF THEM.
- body image disturbance
- autoimmune mixed connective tissue disease (dermatomyositis)
- Nerve pain in hip/sciatic

- Hashimoto's hypothyroiditis and take levithyroxin
- Extreme weight gain and loss within days...8 to 10 lbs. In fluid
- muscle weakness; hallux valgus in both feet; pain in the instep of the feet and feet in general
- gluten intolerant
- Athletes foot
- M.E and an under active thyroid
- Had Gastric bypass surgery in 2003 thinking this would help.
- Low white blood count
- niet goed na te gaan of dit lipodeem is of chronische bronchitis
- Lower back pain
- SLE
- I get dizzy spells. Swelling is getting worse all the time.
- Thyroid problems
- Born premature; Factor V Leiden and Prothrombin G2101A
- Tennisarm en slijmbeursontsteking heup
- ascites, systemic lupus, short term memory problems, partial retinal detachment (bilateral), cataracts, Multiple sclerosis type neurological problems
- COPD
- swelling in legs
- Mosaic verrucas
- blue marks on legs headache impure skin in face
- pre-hypertensive, knee issues, overweight - working towards obesity per national standards
- Suspected rheumatoid arthritis in feet & ankles lock. Very painful. Calcification in shoulders weakness in arms and painful. Ibs bad flare ups. Left Kidney pain but not caused from water infection. Waiting for blood results. Reoccurring pus on left tonsil. Not forgetting tumour in back of right eye. Floppy heart valve. Dizziness left from acute labyrinthitis. Spondylosis neck partially fused. Other than that besides the lipedema, honkey dorey!
- Collagenous colitis, Inherited Insulin Resistance. Cholesterol and sugar levels rose with menopause other wise perfectly normal to this point, Massive fluid retention which is under control using Schuessler Tissue Salts.
- Multiple sclerosis, relapsing-remitting, the lipedema causes greater disability though
- Altijd ijskoude benen en billen, of het nu zomer of winter is .zijn nooit warm. Zelfs niet met masseren onder de douche met sisal handschoen 2 x per dag
- GERD, Structure of Esophagus, Hypothyroid, Diverticulosis, Asthma, Allergies, Food Sensitivities
- eosinophilic esophagitis, GERD
- Anxiety, fatigue
- Hypothyroid, Diverticulitis, Degenerative Joint, EDS, GERD, Stricture of Esophagus, Asthma, Allergies.
- Petechiae on inner ankles warm to touch.
- Burning pain like pins and needles
- reoccurring cellulitis in shin of right leg
- Hipofosfatemische rachitus
- memory loss
- Chronic fatigue syndrome
- Hypothyroid, interstitial cystitis, gallbladder removed, anxiety
- neuropathy, spinal stenosis

- Severe daily headaches and migraines
- constant pain
- ANEMIA, Headache, knee pain,
- Mpn et and sjuegrens syndrome
- psoriatic arthritis
- None, just lipedema
- Where should I start?
- primary and secondary lymphedema, Dercum's Disease
- Super overgewicht
- Hypothyroidism
- Rheumatoid Arthritis
- since my treatment I have less or no problems
- MS, RA, Lupus
- Dercums Disease & Fibro
- lichaam en geest uit balans, heb mogelijk stofwisselings- en darmproblemen
- Graves disease past/Hashimoto disease/breast cancer in remission/gallstones removed
- 2 hernias and high blood pressure
- I nearly 'ticked' obesity, but, honestly, if the 'weight' was removed from my legs I would be normal!
- low body temp (average 97.2 F), sensitivity to artificial ingredients, muscle weakness
- Hashimotos
- PCOS
- buise very easy weakness in upperarms and thighs
- I can't run anymore and have issues with bruising and heavy limbs also have had ovarian cyst
- had last van schimmelinfecties, traagwerkende schildklier, kon moeilijk lopen/staan, smetplekken, schuren van de huid. Dit alles is bijna weg of weg door de hormoonfactor/Jesse van der Velde!
- Syndroom Sjogren
- Hypothereoidie
- Lyme disease, chronic venous insufficiency, lipodermatosclerosis, herpes simplex in the eye, skin cancer regularly, Raynaud
- hyperparathyoidism
- Migraines

Statistieken voor vraag 23 : Did or do you use the Barnes test (morning temperature measurement)

Yes / ja	2.49%
No / nee	96.38%
Sometimes / soms	1.13%

Statistieken voor vraag 24 : If yes, what is your average temperature

Deze antwoorden werden gegeven:
 - 35.9

- 35.8 /36
- 35.5-36
- 96-97
- 97.4
- 97 degrees Fahrenheit
- 35,9
- 36.4
- 37
- 96.7
- 36
- 37,8
- 36,6
- 35,6 °C
- 96.3
- 97.4 F
- 35,6 Celsius
- 36.5
- 97
- 96.5
- 36.3
- 36,3 / 36,4
- 35
- 96.8
- 36,8
- 96
- 96.8
- 36
- 36,3
- 96
- 96.7 to 97.1
- 36.5
- 96.2
- 95.4
- 97.6 to 98.2
- 36
- 36.2
- 34 c
- 36,3 C
- was 35.9 is nu tussen de 36,9 en 37,3
- 36.2
- 35.9
- 35,7
- 96.7

Statistics 25 : Do you have a thyroid disease

Yes	22.34%
No	54.49%
I do not know	23.17%

Statistics 26 : If yes, which one

26.1	Hyperthyrodism	7.43%
26.2	Hypothyrodism	65.88%
26.3	Hashimoto	20.61%
26.4	I do not know de the name	7.09%

Most other mentioned:

1. Graves

All answers:

- Chronic autoimmune thyroiditis
- Morbus Graves, begon hyper nu hypo
- Hyperparathyroidism cured by surgery
- Multi - nodule goiter. Symptoms of hypothyroidism.
- Sub klinische hypothereodie
- Partial thyroidectomy when I was 24 due to cysts. I don't take any medication for it.
- Versnelde schildklierfunctie, radioactieve kuur gehad, nu te langzame schildklierfunctie
- Wisselende waardes
- Under active
- hyperparathyroid
- graves
- panhypopituitary disease
- Parathyroid
- history of some parathyroid problems. I have to take .475 of synthroid a day
- Graves disease. Post thyroidectomy
- Goiter
- Had thyroidectomy 1954 and did not need medication. Since heart problems and its medication thyroid problems have arisen
- Had a hot nodule, now removed. Still problem with reverse T3
- One episode of thyroiditis which then went away
- LUMPS ON BOTH SIDES BIOSPY OK
- Graves
- low to no thyroid function. Have been on meds many years; if I stop med there is no hormone registered in test at all.
- brought on in my mid 20s by untreated Lyme disease
- nodules in the thyroid, and subclinical hypothyroidism
- had surgery
- Ziekte van graves sinds 20 jaar. Diverse behandelingen gehad. Nu trage schildklier.
- I do not have a thyroid non surgical
- Had stage III papillary Thyroid cancer- had total thyroidectomy in Nov. 2012
- Under active
- Nodules
- cancer

- I've also for a period of two years had Graves disease
- thyroid now removed
- Unterfunktion
- Huge goitre with calcification
- benign tumors
- Graves basedown
- Under active thyroid linked to severe adrenal fatigue

Statistics : If yes, did your mother also had this disease

Yes 30.34%
 No 51.69%
 I do not know 17.98%

Other answers / Andere antwoorden:

Mother w hyperthyroidism & took synthroid during pg w me morbus basedow

type 2 diabetes mellitus

Possibly but not as severe as mine

No, but my grandmother did and she had the same surgery when she was 54.

My mother has hyperthyroidism

My aunt's did

Also my fathers mother.

Die had een versnelde schildklierfunctie.

Grave's Disease

Great grandmother and great great great grandmothers

Yes, mother had thyroid disease, she had a goiter in her early 20s and had her thyroid removed. I do not know if this is related to my Hashimotos, which was diagnosed with lab testing.

I am questioning my origins--could be late discovery adoptee. My mother did not have this.

Not able to answer I am adopted

She had hyperthyroid

My father had the thyroid goitre, my mother thyroid cancer

Not till age 84

I think so, but she wasn't diagnosed

I think she did, very thin young ...became obese(5 children)

My fathers mother has it as well as my aunts on that side.

Mother had goiter and over-active thyroid.

My mom has lipedema and hypothyroid. Her lipedema is relatively under control when her weight is lower.

no but her aunts did, and her mother

Sister and aunt do

Moeder schildklierkanker en diagnose na mij van graves. Grootmoeder ook ziekte van graves

Many female relatives on maternal side

My father

Hypothyroid

Aunts

Statistics : What was your birthweight

I do not know	17.11%
Less than 3.3 pound / minder dan 1500 gram	2.41%
3.3 - 4.4 pound / 1551 - 2000 gram	4.22%
4.4 - 5.5 pound / 2001 - 2500 gram	6.86%
5.5 - 6.6 pound / 2501 - 3000 gram	15.15%
6.6 - 7.7 pound / 3001 - 3500 gram	29.39%
7.7 - 8.8 pound / 3501 - 4000 gram	16.20%
More than 8.8 pound / meer dan 4000 gram	8.67%

Statistics 29 : Are you good at setting your boundaries

Yes	42.23%
No	17.57%
Sometimes	40.20%

Statistics : Do you think of yourself as an independent person

Yes	79.79%
No	4.22%
Sometimes	15.99%

Statistics 31 : Are you satisfied with your life

Yes	35.17%
No	28.01%
Sometimes	36.82%

Statistics 32 : Did Lipedema play a role for you in the choice of a partner

Yes	14.98%
No	74.02%
A little bit	10.99%

Statistics 33 : Did the Lipedema play a role for your partner in his (or her) choice

Yes	2.71%
No	40.66%
A little bit	3.92%
We did not now it then	35.02%
Inapplicable	17.70%

Statistics 34 : Did the Lipedema effect your choice in having children

Yes	9.95%
No	57.20%
A little bit	6.56%
Inapplicable	26.30%

Statistics 35 : If yes in what way

I (we) decided not to have children. 80.52%

I (we) decided to have children. 19.48%

- Most other answers:
 - Stopt after one child
 - Dit not know I had Lipoedema while I was pregnant
 - I was not able to have children (some tihink its is due to the Lipoedema)
 - Afraid to pass along the Lipoedema to a daughter

All the answers:

After the second child I decided not to have more

I did not know lipedemia when I had my child

wel eerst met de dermatoloog gebeld om te vragen of het verstandig was.

I could not have children

I was not able to have children - I suspect it is related

we decided not to have more children than 2

Unable to have children but never really knew the reason for it other than it was likely to be poly cystic ovaries

Afraid I would pass it along

Could not get pregnant

I am afraid of getting pregnant.

After having a Son , we were afraad of getting a girl, so we only have 1 child

I had two children before I was diagnosed. After diagnosis, I had IVF to avoid passing the lipoedema gene onto another girl. I miscarried twin boys in 2005.

Kinderen nemen beetje ongelukkige woordkeus, maar los van dat: ondanks dat mijn lipoedeem door zwangerschap erger is geworden hebben we besloten toch een tweede zwangerschap te proberen (icsi)

Had al twee kinderen voor de diagnose

besloten geen kinderen te nemen vanwege mijn klachten. Ik wist alleen niet dat het lipoedeem was. Zal niet de enige factor zijn. Traumatische jeugd namelijk.

first pregnancy it got worse..I'm not sure if I want another child
Did not know then I had lipoedema but knew something was wrong. Could not conceive and had suspected endometriosis. Was offered IVF but I did not feel comfortable with it, something with my body felt wrong.
Decided not to have any more children
Miscarriage, several failed IVF attempts. I believe we might all be estrogen dominant (thyroid, infertility, metabolic disorders, fibroids etc. and it might come from a malfunction of the pituitary gland?)
We decided to have children after the Liposuctions
Only had one child
I got worse during every pregnancy
My relationship Broke after diagnose and I am very afraid to get children cause the risk of getting worse (i dont have Any but have had miscarages
afraid increasing the stage of lipedema but i have just one kid
I (we) decided to have children AFTER the liposuctions has been done
i could not conceive any more children i only have one
Geen kinderen meer. ...
Unsure to have them or not
Weighing options now
We might have adopted if I were in better health. I knew that I could not have a baby by the time I married this husband.
Erg getwijfeld over een 4e zwangerschap ivm steeds flinke verergering na een zwangerschap. Uiteindelijk toch voor gegaan!
I was too sick to have children. Extreme obesity. Doctors warned against it.
Fearful of consequences
I am not sure right now what to do, I am scared.
I had a lot of problems dating and my self esteem was very low. I didn't date appropriate men to marry and have a child with until it was too late. My current partner would love to have a child, but I'm already 51.
decided to only have one
had twins, but do not want to get pregnant again
Our daughter was stillborn at 24 weeks. We have decided to not try again for fear of the lipedema progressing. The pregnancy and trauma triggered a major change in my body.
Only had two because I was afraid I wouldn't be able to care for any others
We decided not to have a third child
I believe that the DD and other ailments affected my physical ability in NOT having children. I have had dogs instead!
Adopted because I thought pregnancy would make me larger in the limbs
I already had a child when I found out. Now I am worried about having more.
I have not had a long term relationship that led to marriage/children because of the lipoedema
We twijfelen nog of we kinderen willen.ik ben enorm bang dat mijn benen door de zwangerschap nog dikker en lelijker worden en dat dit blijvend zal zijn
Ik wil eerst mijn lipoedeem behandeld hebben d.m.v. liposuctie omdat een zwangerschap anders teveel risico's met zich meebrengt (gewicht, zwaar voor het hart)
I have been unable to have children.
I am worried that pregnancy will make my situation worse.
Decided to cease fertility treatments since the hormones were causing me to have

pain and added swelling in my legs

Only had one child because of condition Dr. suggested not to have any more because condition would probably worsen and could cause a lot of complications

I was diagnosed with unexplained infertility; we adopted

during pregnancy very tired during the day. I felt my body could not handle pregnancy again. extremely tired my veins hurt

We weten nog niet of we het aan durven

Statistics 36 : What activities are affected (influenced) by your Lipedema

	1) Never	2) Little bit	3) A lot
36.1 Getting up / opstaan	35.48%	38.93%	25.58%
36.2 Going to bed / naar bed gaan	56.26%	27.76%	15.98%
36.3 Shower/ douchen	61.82%	23.78%	14.40%
36.4 Getting dressed / aankleden	40.21%	36.91%	22.88%
36.5 House cleaning / huishouden	27.46%	36.76%	35.78%
36.6 Job / baan	29.41%	33.53%	37.06%
36.7 During sport / tijdens sporten	13.58%	32.93%	53.49%
36.8 After sport / na het sporten	21.68%	32.56%	45.76%
36.9 In hot weather / bij warm weer	9.75%	25.51%	64.74%
36.10 Long standing / bij lang staan	5.93%	20.33%	73.74%
36.11 Daily activities / andere dagelijkse bezigheden	14.40%	47.04%	38.56%

Added comments:

- Standing from seating position, when walking fat bulges hit causing tripping.
- Ik heb soms last van stijve gewrichten bij het opstaan en lopen, maar weet niet of dit komt door de lipoedeem.
- Very self-conscious about appearance of legs in public.
- trap lopen
- My lipoedema means I cannot do certain jobs, i.e. I could not sit at a desk all day, so it has affected my career.
- Shopping
- I am in a wheelchair due to not being able to walk much distance, nor stand for long periods of time.
- I can no longer work. It is very hard to drive more than 20 minutes. It is hard to sit.
- Vaal stijf en pijnlijk
- If this is Lipoedema then it affects all. Pain is causing major lifestyle change, I cannot maintain my lifestyle. Neurologist says I have regional pain syndrome and is having me try drugs. I have tree like legs with no shape but since I have had vascular problems-DVTs-they are assuming all this has to do with that. But vascular surgeon says to find rheumatologist. They say fibromalagia, but it's only my legs. My legs are so sensitive it bothers me to wear socks and sneakers.
- My husband supports us, I don't know what kind of job I would be able to do.
- Mostly in winter I am limited in what I can do, I am stiffer than in warmer periods /

met name in de winter ben ik beperkt in wat ik kan doen, in de zomer heb ik de minste klachten.

- Cold, wet weather is awful.
- I have a part-time PCA - personal care attendant
- skiën vindt ik heerlijk alleen door de conditie van mijn benen die ontzettend snel verzuren ondanks gewichtverlies in het verleden en ondanks training. Dit vind ik erg lastig en zorgt voor minder plezier
- I am unable to do any thing much now, i am hoping when the weeping stops I can go swimming at the pool
- I am unable to work or play sport at this point in time
- I avoid activities because I know it will be painful or I have no appropriate clothes
- voornamelijk bij het vinden van een baan.
- Alles kost veel moeite. Ben Veel moe, weinig energie.
- Bij het aankleden word ik steeds geconfronteerd met de aanwezigheid vd dikke benen. Ben ook beperkt om leuke kleding te kopen. Baan: werk in de verpleging, zomers belastend door de warme omgevings temperatuur. Lang staan geeft op den duur drukpijn . Ben onzeker door mijn lipoedeem en de Hachimoto
- Lipedema prevents me from leading a normal life.
- I am 70 and I am experiencing increasing lack of mobility, pain, I am becoming a disabled person.
- kleding kopen
- As I have Dercum's also, it is difficult to sort what is from lipoedema and what is from DD
- I am pretty much homebound except for doctors appt. I need my husband to do many things my life really is dependent on him.. I do as many things in the house that I can but all sitting down and not much on the cleaning very hard to do. I want my life back !!!!
- Disabled by the condition. Had to leave work because of mobility issues and pain
- due to pain and lack of mobility
- I have problems sitting, for example in long meetings.
- Ik heb vooral last van zware benen en dat belemmert bij allerlei activiteiten zoals sporten, trappen lopen, enz.
- It affects every area of my life. I take Tapentadol and Gabapentin for pain, but I am still in permanent, considerable pain. I also have flare-ups when I can't walk at all. I cannot take part in sports at all. I used to be an athlete and I competed for my school at county level. I had the ability to go further (I was a Pentathlete), but lipoedema brought it grinding to a halt. I've had to select an option for sport to progress with the questionnaire, but I'm unable to participate at all.
- Verre reizen is mijn hobby. Zwachtelen van mijn benen is noodzakelijk in het vliegtuig en ook tijdens busreizen
- Tijdens sporten pijn in de benen
- ik kan niet frictioneren zoals ik wil
- Ik heb mijn levensstijl aangepast op mijn lipoedeem. Gelukkig kan ik veel zitten tijdens mijn kantoorbaan. Wel moet ik opletten om voldoende te bewegen maar dat lukt aardig. Alleen bij activiteiten waarbij ik lang moet staan of veel doen is het lastig. Zo ga ik bewust niet naar de jaarlijkse sportdag. Of lange wandelingen maken.
- Rokjes dragen (representatief kleden), bikini, korte broek dragen. Winkelen voor broeken, laarzen, schoenen. Aantrekkelijk voelen, zelfverzekerd voelen. Geen invloed qua pijn oid.
- Ben stijf als ik uit bed kom, loop dan houterig. Kan niet alle kleding aan ivm

vetophoping bij knieën en heupen. ook dikke bovenbenen. Ga vroeg naar bed, kindertjes bedtijd. ben dan doodop.

- Alle bezigheden kosten mij veel moeite, energie, pijn. Ben beperkt in activiteiten, per keer max 20 minuten. Nooit kunnen sporten b.v. dus geen goede spierontwikkeling, geen uithoudingsvermogen of geen kracht en conditie (nooit gehad), ondanks medische training therapie, vaak fysio.
- Problems nearly have disappeared since my 3 liposuctions. Before it was worse.
- Zorgen voor veel afwisseling, geen zware dingen meer doen, gewicht beperken, maar wel blijven bewegen.
- Activiteiten zoals douchen met name emotioneel, niet echt fysiek.
- bloot rond lopen
- I use a wheelchair and have help for 8 Times' day
- I cannot stand or walk longer thsn 15 minutes without a short break .Neither can i lay on the couch nor sit long
- minder energie
- if i am tired it is bothersome trying to move legs up and down....
- walking up stairs
- Nearly no more social life, I isolat myself
- Sitting, lay down on the side
- I am not able to sport because I suffer from Chronic Fatigue Sydrom sinecure the age of 17. I do walk a bit and ride my bicycle for Aboutaleb 15 minutes
- Ik krijg last van lang zitten ipv lang staan
- Somethimes when I haveto stand up, after a long periode of bureau work.
- My 'sport' is walking around 70-80km per week
- very limited mobility
- Vaak vermoeide benen
- Ik zit dd lipodeem al bijna 2jaar thuis. ben nu redelijk stabiel en hoop weer werk te vinden.
- Sitting unright in a firm chair -- I carry a pillow to church to put behind my back or the lipoma hurts.
- Met fitsen met snel lopen of lang lopen
- Everything us very affected
- My day is constant pain and I can only function on any project for a short time. Standing or sitting for more than five minutes is almost imposable without re - adjusting or lying down.
- It has immobilized me.
- Lipedema is stopping my normal life. No one will hire me, not able to stand or walk enough to do my own shopping, not able to afford help. Have gone 181 days without a shower due to lipedema.
- I was totally disabled by my Lipedema by the time I was 60. Getting liposuction has brought me back a great deal of my prior level of activity. I'm still healing from my surgeries. I wish I had never had veins ablated in my legs because I have problems with venous return.
- I am 61 and have just had a total knee reconstruction.
- weet niet wat door mijn ziekte komt of door de lipodeem
- Clothing and cleaning myself are very difficult - one major issue is getting the skin dry, I will lay out in towels for a while to fully dry off and stop the skin from being clammy (still damp)
- moeilijk lopen , erg moe veel pijn onbegrip.
- Don't work anymore can't standpoint enough

- becoming increasingly less mobile
- I used to like being in a choir but can't do it because we stand to sing. It takes a long time to get dressed in the morning with layers of compression. My legs are tender and bursting feeling by the night time. I can't do much in the evenings. I hate being in queues. I no longer like going to museums and art galleries because you have to stand up and move slowly around the gallery.
- I have severe pain with my lipoedema and this hinders a lot of things in my daily life.
- been wearing compression for years now
- snel pijn bij sporten snel koud en krijg het niet meer warm lang staan is heel vermoeiend
- Na lang gezeten of gestaan te hebben op een punt, dan doen de eerste paar meter in beweging komen door te lopen, pijn aan de benen. Zodra ik in beweging ben en opgang gaat het over naar normaal.
- Long sitting is my worst problem -I have to lie down a lot
- I've had lower leg swelling for 20 years so my knees and ankles are suffering under the weight now and give way occasionally
- sport niet en heb ook geen baan meer
- I always feel ashamed. This disease has affected my entire life path.
- I had to quit work. Idk how much was the Dercums
- Is een wisselwerking. Je weet nooit hoe je lichaam zal reageren op een activiteit. Als ik met goed voel en ik dan teveel onderneem krijg ik de dag erna vaak de rekening gepresenteerd en voel me de dag erna vaak ziek/malaise gevoel. Dit geldt voor werk/privé en op het gebied van sporten.
- 100% afgekeurd. Kon mijn super leuke baan niet meer volhouden. 80 % breng ik liggend door helaas!!
- None
- ik heb weinig spierkracht in mijn benen
- Meer dan 500 mtr. lopen is een groot probleem. De benen verzuren onmiddellijk en worden dan loodzwaar.
- It affects activities such as dancing, sitting for a longer time, walking and standing for a longer time. In terms of dressing, it affects the choice of clothes (sleeves too tight, for example), not the act of dressing.
- Depending on the amount of swelling involved and the amount of rest I receive. Good vitamins help with the energy and strength from day to day.
- Some problems associated with age.
- I getting a bit of swelling in hot weather. It affects what sports I would do as I wouldn't show my legs.
- my legs are so large, I have trouble buying clothes, finding seating that is comfortable at home, restaurant, airlines, cinema etc which stops me from going out/travelling. My size has damaged car seats after long term use, sofas in my home. It stops me joining in activities because I hate how I look. I can't go to spa days with my girlfriends - all sorts of activities where someone of a normal size would just not think about it. I can't bend down to garden, do household chores. I have given up horse riding, motorbike riding and so on. My life is so much more curtailed and I fight depression constantly. I have even thought of killing myself and ensuring that there is no body so that some poor souls don't have to carry my overweight coffin
- A lot of pain in legs
- I also have problems with chairs - both the discomfort of squeezing my tender hips and thighs into a too small chair, and the anxiety over encroaching into someone else's space in a plane, train, cinema or theatre.

- Kan geen huish.taken verrichten als gevolg van polyartrose en osteoartitis.lipoedeem maakt lopen moeilijk.
- Warm weer beïnvloed mijn leven in erge mate. Beweging ook, maar kan gelukkig over het algemeen nog redelijk goed bewegen.
- But you know: I am 74 years old !
- Lipedema affects every aspect of my life it makes everything i do all that more difficult
- Soms erg moe waardoor huishouden blijft liggen. Daardoor ook vroeg naar bed en moeilijk opstaan.
- de kracht gaat uit het lichaam .
- gauw erg vermoeid
- I am permanently and totally disabled.
- Ik zit in de WAO
- ik ben snel moe, krijg dan pijn
- Er is een voor en na mijn knieoperatie
- Ik heb altijd last van mijn lipoedeem.het beheerst mijn leven
- Badminton ben ik mee gestopt ivm last van mijn knieën
- ik kan niet lang achter elkaar fysiek bezig zijn, raak gauw vermoeid.
- It affects my whole life.
- Sommige vragen heb ik beantwoord uit psychisch oogpunt.
- Days vary some worse then others but everything I do is affected by me having Lipoedema
- My legs, the inability to bend my knees and move easily, the pain with standing, rule my life.
- at cold weather too
- I have been disabled since 1997 and unable to work. I dealt with extreme extreme almost how do I say it world record breaking obesity from this disorder, I gained 400lbs in late 90s and went from low 200s to almost 700lbs. I am in the low 500s now but life was severely impacted. I am in pain a lot.
- My legs are so big . The weight of them makes it difficult to move smoothly.
- always self conscious about appearance
- Eerder opstaan doordat ik wel even bezig ben met het aandoen van de therapeutische elastische kousen
- I feel just a general ache and awareness of the condition in my arms and legs all the time. Hard putting compression on and brushing against things. I find that my legs start to ache really quickly when walking/on feet at work.
- difficult with knee arthrosis and oedema
- Ik heb het bijna altijd koud bij het naar bed gaan en kan dan zelf niet warm worden. Tenzij ik een half uur onder de douche sta. soms blijft het dan nog steeds koud en duurt het gerust een paar uur voordat ik in slaap val. Vooral mijn bovenbenen en voeten zijn ijs en ijskoud.
- De therapie/sporten en opletten op voeding kost veel tijd.
- is it my lipedema or obesitas? putting on and wearing stockings stockings very affecting
- Fysiek nog sterk waarschijnlijk door mijn gezonde baan als schooltuintuf -hele dag tuinieren. Maar psychisch gaat het nadelig werken, voel me lelijk, onbegrepen snel bestempeld door onwetendheid anderen en angst voor toekomstig lichaam.
- traplopen ,fietsen
- Pijnlijke huid tijdens sporten, bv bij hardlopen of aerobics.
- Cant do job anymore very difficulty has stopped me doing normal things afraid of

falling again

- I try not to let it get me down, but it can when my legs won't do what I want. They have given way.. I lost my job because I couldn't do it any more.
- I quit my job teaching do to the fact that I couldn't stand all day. I was struggling to even get in the building to my office. I was also having such horrible brain fog or problems finding words, recalling anything. Prior to being sick, I could remember anything numbers, programming codes, you name it. When I was teaching a ton and getting my Masters Degree.....I was really sick. I could barely lift my arms or get around. I was loaded with water and didn't even know it. I was really struggling. My husband says that it affects every part of my life.
- Wearing clothes like shorts or dresses
- Climbing upstairs
- Foot and ankle pain in worst affected leg (Lipo-lymphoedema)
- My pain is not from movement at all. Sporting does not affect me .
- Flying, being on a boat, sitting for long periods.
- I am 50 yrs old and bedridden
- alleen als ik last van zwellling (lip/lymfe oedeem heb in knieen heb
- My walking is slow, hot weather affects leand wrists have difficulty typing. Hard to bend down weak knees and ankles cuts never heal.
- Sitting with my legs hanging down becomes painful due to a feeling of swelling and pressure.
- Job = Retired. But I do a lot of volunteer work -- mostly sitting at computer writing, editing, creating newsletters and websites.
- I need knee replacements for both knees
- ik kan alles maar met moeite
- I just realized I have this after seeing pictures on the internet. I had liposuction twice and it did not work. I am very concerned that this will get worse.
- sociaal leven! zoals niet uitgaan niet winkelen geen leuke dingen kunnen doen met je gezin.
- I struggle to do even the simplest things I get out of breath and my mobility is very poor
- Walking up stairs, wearing certain clothes bc of the compression.
- Lipedema affects every aspect of my life psychologically despite being stage 1
- koud weer is pijnlijker dan warm weer
- Don't work anymore
- Sitting down for a longer period of time. Traveling. Everything that has something to do with running or jumping.
- I am retired and I have never played sports.
- My knee pain limits my mobility but i force myself to be active anyway.
- I don't do sports.... poor balance.
- I have had to stop work for health reasons
- My legs and arms hurt all the time
- Bij het aankleden bedoel ik meer de keuze van kleding..heb moeite om leuke kleding te vinden die passen!
- Walking and finding comfortable shoes
- I trip and fall a lot because my legs are heavy and tired.
- Bij het zwemmen wordt het niet beïnvloed maar bij het fietsen en lopen wel, mijn werk heb ik er op aangepast. Dit gaat super zo
- It's impossible for me to feel smartly dressed for job interviews etc because my sizing is so odd; I have avoided sports for years because I've felt embarrassed and

clumsy; at school I avoided sports because I was embarrassed about getting changed in front of others.

- REACHING HOLDING ARMS FOR ANY LENGTH OF TIME AND CARRYING ANYTHING

- I am able to do what I need to do. My legs do not interfere with my activities/life. The one thing I notice is that sometimes I feel as though I am slogging through water or mud while walking. This makes my walking slow, but at least I can walk.

- door overmatige transpiratie ben ik sociaal vaak geïsoleerd doordat ik erg nat ben in mijn gezicht en romp. Het transpireren ook niet ophoud. Bij warm weer of inspanning extreem zweten.

- It affects how I dress and my self esteem somewhat

- Flying is a problem

- Finding clothes!

- I have just found out that this is what i have suffered with for 25 years. I am so depressed about the size of my legs that at times i feel suicide. The doc tors just think I'm fat and put me in touch with a dietician but my legs are huge and out of proportion. They are tender and saw and bruise at the slightest thing. I want someone to help me as this is ruining my life.

- Ik zou God danken als er een medicijn tegen was! Ik schaam me zo voor mijn lichaam al vanaf dat ik 13 ben!

- It's extremely hard to get motivated when you have "weights" on your legs and elephant legs to walk

- Summer months are the worst and most painful.

- Standing or sitting with legs down feels like I have thousand little needles inside my calves.

- I have refused to do alot of things like wear anything that shows my legs because of embarrassment. I have cried and prayed for years to make it go away. It hurts for my kids to touch my legs. Always in pain legs feel tight get red and hard..they are heavy and ugly! I just wanna feel normal look normal..

- Standing for long periods of time is the worst.

- Very self conscious about how large my thighs are compared to the rest of my body.

- I think psychologically gaining all this weight and unable to lose it with this disease it has been difficult to get dressed in the morning when nothing fits anymore and you don't want to shop for bigger sizes.

- Walking and stair climbing feels like I have extra weight tied around my legs.

Running is uncomfortable and hindered.

- I have a pretty active full life

- I find that I just don't do things that involve physical activity as my legs often ache so badly and the swelling increases to the point that I'm very uncomfortable. Takes several days for swelling to subside. Only water aerobics exercise can be done without consequences.

- The ankle and leg fat is uncomfortable and restricts how much I can walk or stand. Therefore my activity is restricted.

- Bruise very easily

- I have avoided sports so that people will not see my legs and hips.

- I am gaining strength from my exercise program, which allows me greater mobility and less problems with daily living

- Mine are worse the heavier I am.

- i am currently bed bound by my lipoedema.

- Restricts what I am able to do-it is getting worse as I get older.

- after extreme physical activity, and going up stairs bother me the most.
- I used to swim and sail and do things I love, but now I am so embarrassed by the excessive fat from my thighs to ankles that I keep my legs hidden as much as possible. I am 5 ft 4 inches weighing 130 lbs., which is slightly overweight. My mom had extremely fat legs and arms. Tremendous dimpled fat hung off her arms and legs. She was not a very active person and was 5 ft. 3 inches and weighed 160 lbs. I am very active and have never tended to be heavy. I did have very straight column legs even when my legs were not fat. My mother's mom and her sister, my great aunt, were extremely heavy and had difficulty with very fat legs and goiter (hypothyroidism).
- Difficult to find pants/boots that fit. Sometimes in hot weather I have strange honeycomb shapes under my skin (maybe not Lipedema?)
- Spend a lot of time in my daily life preparing my meals or doing sport or compression bandages. Also affects the way I dress, eat, and socialize, even as I relate to potential mates, which I avoid, including intimate relationships.
- I get to point where I have to rest with feet up during day. I had a boss who kept making negative comments about obesity - in the end I resigned my job.
- I am in need of a doctor for this condition in Tennessee, USA.
- Major thing especially at work is sitting for long periods of time. Chair cuts into back of legs.
- heb hulp in de huishouding fractuur van rug en Sjogren
- Work in retail so stand 8 hours per day, 4 days a week.
- I live with unbearable pain in my upper and lower limbs everyday. Please help me ~
- large thighs put weight on knees
- It affects every aspect of life
- Need two knee replacements. That is my biggest problem at this time.
- I can't stand for longer than 5 mins in one spot. I have no body confidence. I am single and probably will never have another relationship again because I feel gross about myself.
- Altijd vermoeid en op dit moment niet kunnen werken
- I very rarely wear skirts above ankle length I always wear trousers or long skirts
- I cannot stand or walk for any period of time before my legs start to become painful. It seems with every year that passes everything is a bit harder and very disheartening
- I am most frustrated with clothing. 1st because it is struggle to find and then put on daily compression, 2nd My choices for comfortable -attractive clothing and foot wear is dictated by my condition!
- It has ruined my life and made me completely unattractive to men, misunderstood and judged harshly and even bullied by family and strangers (my friends seem to accept me anyway, thank God). I cannot find shoes that fit, and am forced to go around barefoot, so I avoid leaving the house now. I can't find clothing that fits, so I feel badly about the way I look. A relationship with a man is absolutely impossible - so love is out of the question for me now. I cannot do ANY of the active, outdoors activities I used to enjoy, and avoid being with other people. I often think about ending my life and have to talk myself out of it. But as the disease progresses, my quality of life is worsening, and I am more and more depressed - it sometimes feels it's not worth it.
- Lipo has blighted my life especially the horrendous size of my legs. I hate them and I have never liked what people have been cruel enough to say to me. 56 years I waited for a diagnosis, by then all too late I'm pissed off that my life has been ruined

by this, now my daughter and granddaughter have inherited too...how cruel this all is!

- I don't do sport, I have become increasingly immobile, using crutches and a wheelchair. I have seen 10 consultants in last 3 years, they do not know why I can't walk. Prof Mortimer thinks it is due to lipodema
- Ik bedoel hiermee dat ik me altijd bewust ben van mijn zware benen en daar heb ik enorme last van. Voel me er i gelukkig door
- Lipoedeem beïnvloed al mijn activiteiten
- The way lipedema affects/influences my activities is primarily psychological, because I feel self-conscious.
- I'm fighting to stay mobile.
- My life has progressively become more limited. I suffer from depression, and most of all shame about my condition. I do not participate in many activities, either because I can't do them, or because I feel so ashamed about the way I look. I love to swim, but won't be seen in a bathing suit in public for fear of humiliation. This condition has devastated me, even though I try very hard not to let it. It feels like a constant and endless battle I am waging. I feel like I am slowly drowning. I cry as I write this.
- I have problems sleeping due to the intense leg pain but carry on normally throughout the day. I don't let it affect anything I do.
- I have lost some mobility and am not able to continue my normal daily activities or go on activities with my family. I do not attend church or go shopping any more. I cannot wear the same type of clothing as I did before Lipedema took over.
- I was just diagnosed three weeks ago. Can't find a doctor in St. Louis to treat me, so I'm just doing what I find on the internet. Need HELP!
- very depressed and this disease really affects every part of my life now at age 63; Social Security Disabled 1 year ago
- Belemmeringen komen ook door andere aandoening, hypofosfatemische rachitis. Weet niet precies welke aandoening voor welke belemmering zorgt
- Ik heb ook last van fibromialgie sinds ongeveer mijn 35ste dus weet soms niet of oorzaak fibro is of lipoedeem.
- Kledingkeuze. Nooit rokken of jurken aan.
- There are areas of my job which I can no longer do, or find difficult to do, and which I hide from my employer. This is extremely stressful as I don't know how long I can hide this or what will happen when I'm found out.
- afwisselend, veel pijn en dan weer even niet.
- Hard to find pants to fit. Legs ache, sore to touch, large veins and spider veins, stove pipe legs now in arms too
- I am disabled so do not work. My neuropathy is advanced
- It's hard to do anything physical.
- I was always small until I had the 3 kids then I was unable to lose that weight but was still only 165 instead of my 125 I held that 165 until I developed cellulitis then I gained rapidly up to the 309 that I weigh now. I find myself still thinking in my mind that I can move and do like I use to but I can't and that makes me depressed.
- I have just had a total knee replacement which has not healed properly and that is when they found the Lipedema
- How I feel about how I look
- Would have loved to have normal size legs. Felt very self conscious especially when teenager
- Finding clothes to fit the large legs
- More swelling in hot weather, compression stockings very uncomfortable in heat

- I don't do more than I absolutely have to and shopping, I use a mobility cart.
- cannot get swimming any longer through embarrassment
- Working out six to seven days a week, stretching and massaging my legs every night before bed, stretching throughout the day (especially when working seated at a desk) and elevating my legs in the evening, restricting calories, cutting out sweets and alcohol ENTIRELY (sugar is a MAJOR problem with lipoedema!), and going on a medicine called Vyvanse have all reduced fat, smoothed out my body somewhat, made my ankles and feet smaller, and made my mobility like that of a child. It takes a lot of work. But stimulant medication should not be overlooked for treatment of this condition. While it takes time and effort, and I have a ways to go, I've lost 170 lbs. without surgery in the last 13 months. I have gone from a size 34/36 to an 18/20 on top and a size 24 in pants. I wear a smaller bra band size at age 34 than I did at age 10! My shoe size went from 11W (a size I'd worn since I was around 13 years old) to a 9.5/10B. My wrist went down 1/2 inch on each side, as did my ankles, which was phenomenal. My knee pain and back pain, which were previously debilitating, are virtually non-existent now. This condition can be helped. Not made perfect, but helped by this type of lifestyle. I have had NO surgery of any kind, including plastic surgery or weight-loss. I am under the care of my fabulous family doctor for this, and he is a godsend for looking past simple diagnoses and searching for answers to deeper problems. So many women are put on SSRIs, pain medicine, sleeping pills or benzodiazepine medication, when they ought to be on something that is NOT a downer. Please don't overlook the possible link between depression, ADHD, obesity, and lipodema- I believe there is something there, lurking in the brain. Neurotransmitter activity should be studied deeper in the case of lipodema.
- I am extremely disabled at this point. I use two canes to walk and cannot stand for more than a minute without extreme pain. I have great weakness in my legs which makes it impossible for me to do any housework or cooking. I no longer drive my car.
- I can't keep a job since my legs got extremely fat because my clothes do not fit.
- Kan helemaal niet tegen de zon en warmte dan zwel ik nog meer op ,gewicht doe al 4 jaar koolhydraten arm . Niks helpt .als het mis gaat is het meer als 10 kilo vocht per dag
- Had bilateral knee replacements 8 years ago, as well as hysterectomy 18 years ago. Lipolymphedema became worse. replacements beginning to fail
- I do not work. Retired
- The disease has stolen my life and left a once active independent person inactive and dependent on others.
- my appearance, very embarrassed by huge ankles etc. Please find the underlying cause of this disease so it can be cured! wrapping is a waste and insurance will do help with cost.
- standing house work
- Recently I have been bandaged from my toes to the top of my thighs to help with the lymphedema. Everything is hard right now. Two more weeks to go :)
- I am also disabled due to a congenital spinal condition, curvature of the spine and my right hip did not develop properly, also have arthritis, both conditions diagnosed in 2007. Also have hyperparathyroidism
- Will not wear shorts
- I take my time doing things, I have slowed down a bit this year as I fell a couple times when I got overtired .
- I am not very active, but my legs are what gets most tired first. I get achy and need to sit a bit

- as it had gotten worse i had become more frustrated with my efforts at the gym and being super concious about what I was eating - guilty when i eat..but that was before i knew what it was. I am scared however of what it could lead to since there really is no cure
- Ik spreid huishoudelijke taken tegenwoordig over meerdere dagen, en bedenk me een paar keer voordat ik een dagje uit ga, want ik weet vooraf dat dit erg pijnlijk wordt (en een aantal dagen duurt, voor ik weer enigszins hersteld ben.)
- Waar ik een beetje ingevuld hebt is een heel klein beetje op dit ogenblik.
- Ik pas mijn bezigheden aan aan de toestand van mijn lijf op de dag zelf..
- Ik heb stand werk fulltime
- Legs get really sore - if I go to a concert for instance - I'm in agony next day
- Heb geen constante pijn en daardoor voornamelijk de beperkingen van overgewicht.
- Vermoeidheid en zware benen spelen bij mij een grote rol in mijn leven. Weinig spierkracht.
- Ik heb een fysiek zware schoonmaakbaan 4,75 uur staan, maar daar heb ik geen last van in mijn benen. Bij mij is het van groot belang dat ik compressieleggingen draag, waardoor ik maar eens per 2-4 weken echt vermoeide pijnlijke benen heb.
- I work on my feet all day which exacerbates symptoms.
- It has affected my social life drastically .

Statistics 37 : Do you need special help, tools or devices when:

	1) Yes	2) No	3) Sometimes	4) I think in the future
37.1 Taking a shower	9.41%	79.46%	6.12%	5.00%
37.2 Going to the toilet	5.60%	85.66%	4.48%	4.26%
37.3 Getting dressed	5.90%	78.79%	9.93%	5.38%
37.4 Walking	15.83%	63.63%	12.02%	8.51%
37.5 Sitting	7.92%	79.61%	9.34%	3.14%
37.6 Your job	14.56%	69.60%	9.19%	6.65%
37.7 Taking care of your house	21.43%	56.98%	14.79%	6.80%
37.8 Taking care of your children	6.80%	82.45%	6.50%	4.26%
37.9 Traveling	22.33%	56.76%	15.46%	5.45%
37.10 Driving your car	9.93%	75.65%	8.89%	5.53%

Gegeven Toelichtingen

- Retired no problems sitting down just getting up from sitting anywhere.
- Compression leggings.
- Do not work
- I can not work anymore. It is very hard to drive. I don't know what device would help me do that. (This question is faulty in that there is no answer for if you don't have children)
- heb hulp in de huishouding, ben afgekeurd voor mijn werk

- Mn steunkousen/panty en hulpmiddelen om deze aan te trekken
- Ik draag steunzolen
- Ik durf geen auto meer te rijden
- I do not have children
- Mobility is down to 5 mins standing no more then 1 hour sitting with my feet on the ground before I must elevate them, walking is painful and leaves me breathless.
- If I had children I would need a lot of help. Unable to drive a car, travelling I need time to get to my destination if I am walking
- Ik heb steunkousen
- steunkousen kan ik niet missen
- I hire a housekeeper to look after my home because I cannot do so myself.
- I have had to give up driving recently as my legs and the pain in them make it difficult to control the brake and clutch in a manual car and I can't afford an automatic one.
- I got used to it so much, I'm not quite sure about which activities I just don't perform because of lipodema
- I had to quit my job because of neck pain and then Dercum's and Lipoedema hit me after neck surgery
- I need to have my bathroom redone and I can't afford it the tub is very high and it's very dangerous getting in and I also need to sit as standing is not an option.. So very depressing what average people take for granted I would give anything to be able to just hop in and get a shower and it not take me an hour and exhaust me by the time I'm through. HELP
- I prefer a bar in the shower to help with balance. I am very wide. I need wide seats for work and driving.
- steunkousen
- Do not work. Children are adults.
- I can no longer work or drive a car. My children are grown up and live away from home.
- I can drive but have problems getting in and out of the car and always drive an automatic
- I need compression garments to work. I'm a teacher so I'm often standing up.
- My children are adults. I would not be able to take care of a child now.
- Vliegtuigreizen, busreizen: zwachtelen van de benen
- have no car in the immediate family so travel on public transport can be difficult
- Steunkousen
- I wear compression stockings daily as well as flight stockings for traveling.
- sokken aan uit doen is erg moeilijk
- Geen grote dingen. Met auto rijden blijf altijd steunkousen aan en 2 paar sokken. Verwarming aan. Lopen ook kousen, soms ondersteuning fijn.
- Blijven bewegen en steunkousen
- Ben te moe
- Auto rijden gaat niet meer op langere afstanden, tot max 15 km en niet op de snelweg. Kinderen heb ik niet. Baan: ik hoop over 20 jaar met vervroegd pensioen te kunnen, even volhouden nog en dat kost heel veel energie. Kon al afgekeurd worden, wilde dit pertinent niet! Mijn werk is mijn leven.
- Omdat we een eigen bedrijf hebben, en het werk soms tot s'avonds laat duurt, heb ik vooral bij warm weer een lymfapress moment nodig om ook s'avonds door te kunnen gaan.
- V.w.b. het werk probeer ik voor zoveel mogelijk afwisseling in houding te zorgen

(kantoorbaan) en zorg ik dat ik geen zware spullen meer draag of bukkende of knielende houding aanneem. V.w.b. het huishoudelijke werk heb ik 1 keer in de 2 weken een poetshulp; voor de rest hou ik het zelf bij.

- steunkousen

- i have my own shower seat that is high i do not have to bend my knee so much i can reach down bathe myself but getting into the tub that is out of question..... i can walk so far so good just slow.... no running at all..... i can drive no problem here as long i can get in and relax a bit.... it is that long period of time sitting so still for so long my legs hurts like heck to move then when i move it hurts again when i stop.....

- Always use a wheelchair at airports

- Kinderen heb ik niet evenals een rijbewijs dus de antwoorden zijn niet van toepassing

- heb een rollator en een mobiele scooter.

- I cannot or do not do some of the questions answered yes

- Not sure whether using another chair in front of my legs to put my legs up counts as a special device, after a while? And my children are grown but taking care of other people's kids and grandchildren is definitely difficult for me

- I am retired from work

- I have a Master's in accounting, but have not been able to land a job due to memory and word usage problems that make me unable to remember things I need to know and words I'm trying to say. I feel like an idiot. I no longer search for jobs due to intimidation resulting from my poor memory.

- Because I am now suffering Neuropathic issues (due for testing this month) I need more help, where as I coped a lot more before these issues. The Lipoedema makes the struggle with the Nuro issues harder to deal with. Having had weight loss surgery back in 2005 and losing 113.83kg

- elastische kousen

- I have to rest frequently. I get breathless. I sometimes use hiking poles for walking.

- I use walking aids and have another person who cares for me and physically helps with things around the house etc...

- I wear my compression garments almost daily so that helps with the swelling and pain

- I do not drive much. I have no children.

- compression stockings the whole day

- Steunkousen.

- I walk with a stick, have a grab rail in the bath/shower, swivel seat in the car

- Bij het vliegen draag ik speciale sokken ivm vochtophoppingen

- Moet steunkousen dragen, vind pijnlijk en mezelf te jong dus trek ze niet aan....

- I'm still young - 40. My mother has all of these problems.

- My kids are grown & I had to quit work. My husband left because of my pain & dx

- Geen hulpmiddelen nodig. Heb een kantoorbaan, en heb wel een voetensteun zodat ik de benen kan laten rusten en de kousen niet knel gaan zitten. Heb geen kinderen, bewuste keuze i.v.m. lipoedeem

- Wil geen hulpmiddelen om achteruitgang te voorkomen!

- ik draag soms steunkousen ter ondersteuning

- ik ben nog maar 14 jaar (nog geen kinderen etc.)

- Zolang ik niet veel hoeft te lopen kan ik alles doen.

- I can't work anymore. Classed as disabled.

- I don't have a job, i am sickwritten

- I have started to need to use a scooter - like at a fair or a convention like event.

Walking isn't so much the problem, it's standing for a long time.

- Please note that I had several liposuctions on my legs and arms.
- Can not sit for long periods of time. Get really stiff sitting or standing for long periods of time. Hard to find cloths to fit if swollen and hard to get on sometime.
- I am retired so no job and have never had children
- I have recently had to get approval from my employer for business class air travel as the anxiety over aeroplane seating in economy class was getting out of control.
- heb geen baan
- Ik hoop het in de toekomst ook niet nodig te hebben, al houd ik soms mijn hart vast. Laten we hopen dat de zorgverzekeraars o.a. liposuctie gaan vergoeden, zodat onze klachten een stuk minder worden.
- heb al jaren dikke steunkousen (aangemeten) die ik aan moet, anders heb ik veel last van mijn benen
- KAN NIET TE LANG STAAN OF ACHTER ELKAAR ZITTEN, DUS BIJ REIZEN OF WERK, MOET IK DAT GOED AFWISSELEN,
- verzorgen van kinderen niet van toepassing, ben al lang oma.
- I live alone and have help with household tasks provided by the County as I am disabled and live on the edge of poverty. I am alone most of the time and feel disconnected.
- Geen werk, kinderen en kan niet reizen en heb geen auto
- I am unable to work. My children are at an age that they are driving and independent. They are quite helpful with my care. Because of the care my spouse and children give me, I am able to live in a way that most people outside would not know i\m disabled. If I\m unable to shower, walk or dress I simply stay home. If I need assistance, my spouse and kids help me with whatever I need. I am getting to a point that I will need assistive devices in the near future if I desire to leave the house more often?I\m just not ready to do that yet.
- My mobility is much better since losing weight however it is still difficult at times ,causing pain,I can not use my knees well ,my back hips shoulder knock hurt
- The toilet must be high or I cannot use it, and I need bars to help me rise from it. I use a rolling walker to walk at times, to steady me and so that I may sit when I am not moving. I cannot sit on low furniture. I cannot sit on delicate furniture. I sometimes take my rollator walker so that I have a seat that I know will hold me. I stopped working September 30, 2012. I do not keep my house very well. I get too tired, or I do not want to stand, or have trouble working at the sink because of shoulder and neck and rib pain making breathing difficult. I do not have children, but my dogs do not get the walks that they need. My husband wishes that we could travel more. We must bring so much when I go on trips! The car is full of my things! I cannot imagine flying or taking a train. I often have to stop running errands because I cannot drive any more because my legs or heels hurt. I must then go home.
- Multiple Sclerosis causes most of this, I have limited mobility.
- Een aan-/uittrek hulpmiddel voor mijn therapeutische elastische kousen, bij zitten en dus mijn baan heb ik de kousen nodig
- ik werk niet meer ben ZZp er , kinderen zijn de deur uit
- I am not restricted in everyday life. I often wear compression stockings.
- Mijn huis is al aangepast
- can't bend or sit on knees while doing houswork. have sit on butt.
- Zou steunkousen moeten dragen maar dat is niet haalbaar in mijn werk-hitte
- children grown up
- I gave up driving because of spasms in my legs. These have settled down now, and

I'm thinking of driving a bit. (I'd get out and be less depressed.)

- At one point, I had to use a cane to get around. I am now free of that, but have a few knee, ankle, hip, and back problems. When I have a bad flare up I need a little assistance.
- I have to stop when we are in the car for a lot of hours
- Flight tights
- I have to use a wheelchair going through airports as the walk is usually too far. Pushing a supermarket trolley really helps.
- I do not have children
- I have trouble getting out of a chair, walking in the morning, opening containers and moving quickly.
- I have had to retire from my job early on disability.
- bedridden
- Weak lower back hot weather legs burn up at night.
- I take a bath in tub, use handrails, have no children
- Having problems reaching with lipoedema in lower and upper arms. Toileting, shower, dressing, etc is a hassle
- I use a mobility scooter. Also have a bench and hand-held shower head in shower.
- My legs swell when flying.
- Have trouble because of my knee getting down steps
- Need strong compression socks during flights as I feel tremendous pain without as altitude climbs and have feared at times an embolism as pain is so bad
- No children
- I do use gloves when I put on my compression garments.
- Yes items are resolved
- I am retired and my children are grown.
- I don't have children. I am on early retirement and applied for disability.
- I am unable to work
- My mother also has Lipoedema and now has to use a cane to get around.
- Vind het moeilijk een onderscheid te maken in specifiek lipoedeem klachten en mijn bekkeninstabiliteit
- I do wear compression hose daily. Didn't know how to fit that in, above.
- No I do it all through the pain. It takes longer than it should to do things but I grin or cry and bear it. Things have to get done.
- Having a harder time walking, thinking I might need a cane. I feel embarrassed about this being 40yrs old and a woman.
- steunkousen aantrek hulp
- Compression stocking especially with travel and exercise
- Compression garment and orthotics for my shoes to support walking.
- One time, on a very long flight from Hawaii back to the East coast, my legs were so swollen I couldn't believe it. I had never seen anything like it. I took an indoor cycling class when we returned to get the blood flowing.
- steunkousen
- currently bed bound by lipoedema
- Managing at the moment-problem getting worse as I get older
- I'm still pretty physical at this point, but my thighs and legs are very large and I'm afraid they will get bigger and cause me to lose mobility eventually.
- I wear compression stockings daily at work and always on airplane trips.
- Compression socks
- I always use compression stockings. Only in summer with hot weather I substitute it

- for compression bandages at night and more sports always with compression.
- I use a garden kneeling stool to get to floor level chores. I use a sock aid and a grabber/reacher aid - due to osteo-arthritis in hips.
- Heb regio taxi
- Again, knees are biggest problem, but knee problem has been worsened due to weight/lipedema.
- This disorder will only get worse with age. I have a back complaint now. Getting heavier will only graduate the problem over time
- I do not drive.
- Use a cane and/or walker with a seat sometimes.
- I currently am able to take care of myself however my ability to get around on my own is becoming more compromised as the disease goes untreated.
- "Taking care of your children" is not applicable to me - I have no children (I wish I did).
- I am now disabled thru this disease so I need help with certain things but try to help myself as well...I don't give up easily.
- Driving - I need an automatic - driving a 5 speed gets very painful on my legs and lower back.
- I do not do as much nor am I able to worksitting or standing. No children ever.
- tot op heden.. zelfstandig te doen
- It's too painful to kneel, and when I do I lack strength in legs so it's difficult to get up from kneeling. Weakness also makes it difficult to lift or carry young children (nieces not my own). Seat belts on planes are becoming tight across lap.
- Raising my children it was hard and I worked long hours and on my feet. I did not know until my late 40s it wasnt my fault my legs were so fat.
- I use compression socks/tights when flying due to the extreme swelling I get in my lower limbs.
- I ve always been active and eat sensibly.i cycle and walk.my calves seem firmer and better than when younger but knees and general leg bigger and now upper arms are flabby.
- Up until a year ago, almost all of these were very difficult for me. Vyvanse and a strict lifestyle changed all of that.
- I no longer work or drive. When I did work, I brought my own padded chair with wider, deeper seat to keep my legs from becoming numb and painful from the pressure on the thighs. I also used a scooter to get around the campus which was large. I needed to work in several locations but could not walk that far in a timely manner. Needed to use the elevator as the stairs were/are too difficult for me to use and the ramps in the older building were too steep for my weak legs to use safely and without pain.
- I don't need extra help for any of these activities yet, but may in the future. I'm still not sure of how this condition progresses.
- Ben bang voor de toekomst .val de laatste jaren erg veel.
- Experiencing foot fractures as a result of weight on feet
- Do not work Do not drive My children are adults
- I have had to give up my job and now work from home with much less money
- I can no longer drive or do my job.
- son is now grown, I am disabled and unable to work or drive
- ik heb geen kinderen, als ik die had zou ik hulp nodig hebben i.v.m.vermoeidheid
- I am trying to strengthen my legs with exercise. My main concern is the emotional toll. So humiliating !!! People look right at the legs!!!!

- have answered
- cannot sit for long periods as legs become uncomfortable. Need to rest when walking a lot - legs get tight and back hurts. Take aisle seat on planes so I can get up and walk
- I am stubborn, and have not given in to using assistive devices, but I am getting to the point where I am thinking about using help.
- don't have children
- I do not have any children, I live on my own, as my husband didn't want to look after me.
- I don't have children at home so I answered no. Retired.
- bij lange wandelingen gebruik ik nordic walking stokken. Ok draag steunzolen
- Kan niets zonder steunkousen.
- Mijn werk is te zwaar geworden ook mede door rug/heupartrose. Word nu begeleid maar passend werk. Activiteiten lukken wel, maar alles beperkt in tijd. ongeveer 30 minuten.
- Leven is behoorlijk aangepast mn wat betreft duur van beweging etc. Therapeutische elastische kousen helpen enorm met als oedeemtherapie! Kwaliteit van leven is daardoor veel beter.
- Ik heb geen kinderen
- Can not drive without pain.

Statistics 38 : Which family members also have Lipedema

38.1	Nobody else	34.70%	
38.2	Mother	30.82%	
38.3	Daughter	12.94%	
38.4	Sister	16.60%	
38.5	Granny	20.64%	
38.6	Maternal grandmother	13.09%	
38.7	Aunt(s)	22.06%	
38.8	Niece(s)	9.72%	

Statistics 39 : Do you have Lipedema pain and where is it located

	1) No pain	2) Little pain	3) pain	4) heavy pain
39.1 Arms at night	63.37%	22.44%	10.18%	4.01%
39.2 Arms during the day	58.10%	27.71%	10.40%	3.79%
39.3 Legs at night	17.61%	33.06%	30.53%	18.80%
39.4 Legs during the day	9.88%	31.05%	36.40%	22.66%
39.5 Feet at night	50.07%	24.44%	15.53%	9.96%
39.6 Feet during the day	36.18%	30.16%	20.58%	13.08%
39.7 Shoulders at night/	57.21%	22.66%	13.67%	6.46%

39.8 Shoulders during the day	54.90%	24.81%	14.93%	5.35%
39.9 Hips at night/	41.98%	25.56%	19.09%	13.37%
39.10 Hips during the day	42.27%	27.71%	19.69%	10.33%
39.11 All places during the day	51.71%	26.15%	16.05%	6.09%
39.12 All places during the night	54.31%	24.37%	15.01%	6.32%

Statistics : If you have pain how would you describe it.

40.1	Achy / pijnlijk	59.58%
40.2	Crampy / kramperig	31.20%
40.3	Stabbing, sharp / stekend, scherp	30.39%
40.4	Pressing / drukkend	56.76%
40.5	Burning / brandend	40.42%
40.6	Inapplicable / niet van toepassing	4.09%

Other answers:

- klotsend gevoel
- heftige groeipijn
- zwaar
- Has resolved after lipo
- Tingling, numbness
- The pain changes constantly.
- Creepy crawly, spasms, burning,
- stretching at the skin
- moe/lam
- Er zijn dagen dat ik geen pijn heb, maar ook dagen dat ik veel pijn heb. Dit is vooral afhankelijk hoeveel ik mijn benen belast en de weersomstandigheden hebben ook veel invloed.
- Throbbing Bruised
- Vermoeid
- like acid soaked gravel in all my fat
- "pokey", annoying, intermittent (on top of the regular constant achy-ness)
- Groeipijn/spierpijn-achtig
- zeurend
- vermoeide benen en zeurende constante pijn
- it's all those at different times during the day
- also nerve type pain
- Zwaar gevoel
- like toothache
- throbbing, joint pain
- strak
- like bones ache and like skin is sore
- burning, achy, crampy, pressing
- onrustige benen

- Zeurende vermoeidheid
- Zeurende pijn
- alsof er duizenden mieren door mijn benen lopen
- F,hle mich sehr geschwollen
- once in a while when i get bump ouch like heck! sharp then it fades.... just achy feeling after a day at work when i rest it goes away little then it comes back i just gotten used to it....
- Like you ran a marathon for 24 hours
- Like the legs are blown up very very much.
- muffled
- Benen voelen aan of ik een marathon heb gelopen
- boiling wather/milk inside my leg
- Een soort heftige constante spierpijn.
- Throbbing dull knees pop
- My lippy pain disappeared with liiposuction. However I do have leg pain caused by venous insufficiency at times
- zenuwpijn na inspanning overdag
- Like a feeling of pressure ... Like my legs are sausages in a fry pan about to burst.
- Stabbing pains when my son leans on my legs
- Ik ben de pijn inmiddels gewent, weet niet meer hoe het is om zonder door het leven te gaan.
- I don't have pain. I don't eat sugar, carbohydrates, MonosodiumGlutamate, Gluten. When I do, I get pain. But with discipline and not eating any of those things I rarely get pain.
- Like insect bites stinging
- only have pain if I bump my legs or even if the Chihuahua dog stands on them
- absterbend
- Like a strangling from within my legs
- artrose dus pijn bij bewegen
- Swollen, uncomfotable, tight
- tintelend, brandend, moe, stekend, zwaar, alles tegelijk eigenlijk. Meest te vergelijken na een kramp.
- Havy.
- I have a lot of what might be called pressure points in my legs. A cat stepping on my leg might sake want to scream.
- all of them but in different areas of my body, sometimes all
- I have achy pain with occasional stabs of pain
- Sometimes tingling or tight. Sometimes Like a dull toothache.
- verzuring
- pressure
- bij stoten of een lichte aanraking ga je door de grond, zo pijnlijk
- Onrustig
- vermoeiend
- prikkeldraad gevoel
- Like a bruise; sometimes a little itch
- veel pijn bij druk, dus altijd op kussen zitten
- Here is also the difference before i started to be treated everything ached
- hard, moving
- zeurend
- water-logged

- constant mini shock waves
- shoulders painful but nog lipedema
- het kan per moment of dag wisselen
- zeurend
- Mixture of all at times.
- No pain
- Tenderness when pressed
- Pressure
- Pain upon pressure (touch)
- All three
- feeling my legs are too heavy for my body. Feeling legs will burst
- alleen is mobiliteit beperkt van knie door vochtophoping en vetafzetting boven knie
- Umfortable restless legs at night get very hot dontwear clothing
- "tingly" or "creepy" feeling in muscles that eases with movement or sleep
- sometimes dull, sometimes sharp.
- tingling, restless, numb
- Burning constant down to a pressure pain
- s
- I have pain from any type of touching/pressure 24/7. Sometimes I have pain during the day and when I do, it is very bad upon retiring at night. The pain comes from within and radiates out. It can get pretty bad.
- My knees feel as if a knife is plunged into them and weights are wrapped around them.
- heavy, dragging, pulsing, sometimes sharp
- itching
- There's not a day that goes by where i remember what it felt like to go through the day -without- pain.
- like tiny needles pressing from inside out of my calves
- Feels like my fat & skin are bruised all over
- Long lasting
- Constant ache.
- constant I calf pain, feels like twisting crushing deep aches
- Onrustig. Kan ze niet stilhouden
- tingling
- usually a heavy,leaden numbness sets in prior to the pain symphony
- heavy,hard to walk
- I only feel pain when someone grabs my lower legs too hard. Or if I get a pedicure or massage and they rub too rigorously.
- it varies greatly, and i have noticed humidity plays a large part as far as increasing the pain. as humidity rises so does pain and pressure in legs
- It hurts when anyone leans on my thighs or pokes my legs
- bij aanraking
- It is nagging, with the choices each occurs at different times
- kinda varies but is constant
- My legs feel like heavy rubber objects. Loss of sensation at times.
- I feel bruised all over. Worse in my legs.
- Jumpy legs
- It is a combination of heavy aching with a feeling of pressing and if I have been walking for a while my feet seem to burn
- Strong, overwhelming

- Heaviness and trig tend pressure
- Benen druk pijn en restjes legsel, voeten stekend. Kloppend en brandend.heup enkel aan een kant, stekend , pijnscheuten branden en zeurderig
- It is so intense and it feels like it is right down to the bone.
- tightening
- Pins and needles and !legs and feet are on fire!
- Zeurende drukpijn
- Heavy like filled with cement
- heavy
- Throbbing
- skin is stretched tight and hurts
- Throbbing, very bad in groin too if I don't wear compression stockings every single day
- I have achy, pressing and burning pain all the time. The crampy and stabbing pain are intermittent.
- Voeten brandend
- throbbing
- I also have Dercums
- Pain in the hip is horrible at times.Doctor will not acknowledge that there is a problem.
- Heavy
- tingling
- zomer ook brandend en veel rechtstaan fel drukkend
- tingles sometime or just a discomfort
- de pijn in mijn heup kan vaak stekend zijn maar is niet continue aanwezig! en de drukkende pijn ook niet.
- gevoel beestjes onder de huid en zware benen
- Like toothache but then in the body. Some sort of nerve pain.
- pain when legs or arms are bumped or pushed on

Statistics 41 : Do you take pain medication

Yes / ja	26.52%
No / nee	39.30%
Sometimes / soms	32.32%
Inapplicable / niet van toepassing	1.86%

Added comments:

- Tylenol w /codein
- Anti-Inflammatory.
- Vicodin or naproxen
- Ibuprofen
- Vicodin, Norco, Valium, Baclofen
- Ibuprofen or Naproxen
- Gabapentin & Tramadol
- Tylenol, Flexeril
- Tramadol

- Vicodin, Butrans patch, Lyrica, topical creams
- Pain killer
- ketoprofen
- My doctor won't prescribe. Says they on him for prescribing pain pills and people getting addicted. He is a rheumy and doesn't understand pain management. I lay in bed and cry I hurt so bad.
- Fentanyl en naproxen en paracetamol
- Tramadol and paracetamol
- I take warfarin so can't take Advil and Tylenol does not help. I take muscle relaxer.
- Ibuprofen or paracetamol
- just over the counter stuff
- Tylenol, advil
- ibuprofen, sometimes valium
- tramadol/paracetamol
- naproxen
- Paracetamol
- Co codamol Gabapentine Amtryptaline Others
- 2 jaar geleden ergere pijnen gehad heb toen endermologie ondergaan waardoor de pijn veel minder waren. Nu ik 15 kg ben afgevallen worden de pijnen steeds minder. Eerder vermoeide benen gedurende dag.
- Tramadol
- Paracetamol and codeine
- brufenbruis of aleve 475mg
- naproxen
- Oxycontin mostly -I keep the dosage very low (~30 mg/day) - some Fentinyal for breakthrough pain (25 mg patch cut in half)
- Paracetamol codeine
- Tramadol
- I cannot take regular pain medicine anymore (allergies or severe intolerances.) I use essential oils and supplements.
- co codamol
- CoCodamol
- ibuprofen
- Hydrocodone, naprosyn
- advil
- Oxytocin
- aleve
- paracetamol
- Panadol Osteo
- Ibuprofen
- Paracetamol met codeine
- Ibuprofen 400mg
- Zapain
- De pijn geeft aan wat ik wel en wat ik niet kan op een dag.
- Paracetamol voornamelijk.
- Ich m'chte so lange es geht noch auf Tabletten verzichten. Ich habe Angst vor den Nebenwirkungen auf Dauer.
- ik ben allergisch voor pijnstillers die helpen
- Percoset
- "ibuprofen 400"

- Co-Codamol, Tramacet
- Anti inflammatories
- I take RUTIN supplements.
- Metformine, simvastatine, lisinopril, paracetamol, b12, D
- Aspirin & paracetamol
- Advil
- Ibuprofen
- Norco 10/325
- Paracetamol
- oxycodone as needed gabapentin as needed clonazepam as needed I don't like to take a lot of medicine so I take pain meds when I can't stand it anymore.
- Ibuprofen or Ketoprofen
- novalgin
- paracetamol en soms diclofenac als het echt te erg is
- Co codamol
- Butrans 10mg or 20mg skin patches. 30/500 cocodamol tablets if and when required
- Magnesium bij verkramping
- Valoron (but for my fibromyalgia)
- Gabapentin, Amitryptiline & Voltarol
- Ibuprofen, Novalgin
- paracetamol ibuprofen diclofenac
- Buprenorphine patches Dihydrocodeine Gabapentin Fluoxetine
- Co codamol
- Tylenol muscle relaxers Fiorocet
- Tramadol 3 x 50 Mg per dag
- 300mg Tapentadol per day 900mg Gabapentin per day
- Ibuprofen, diclofenac
- Tramadol met paracetamol
- amitriptyline 50mg at night and 10mg during day when needed
- Ibuprofen
- Voltaren
- Paracetamol, aleve
- I hate medication and I try everytime to go without it.
- Paracetamol or anti inflammatory
- paracetamol
- Ibuprofen
- diazepam 5 mg s'avonds voor het slapen gaan 10 mg
- paracetamol z min mogelijk
- Doe snachts soms steunkousen aan..
- alleen paracetamol. Ben erg allergisch voor voedingsstoffen, materialen, hooikoorts etc. Ook voor SNAID's en ook ontstekingsremmers, pijnstillers.
- Morfinepleister en paracetamol
- Ibuprofen
- Ibuprofen 800
- ibu 800
- Ibuprofen
- Nurofen
- Panodil 2x4 Dolcontin 5 mg x2
- Ibuprofen

- zaldiar
- aspirin, arnica montana for muscle.... aleve.....
- Pijnstillers paracetamol
- Ibuprofen
- Diclofenac
- Paracetamol
- Tilidin 100
- Ibruprofen
- Ibu 800
- paracetamol
- Ibuprofen800 Novalgin 500
- Zapain
- morfine pleisters
- Ibuprofen
- aleve and vicadine at bedtime
- Panadol or codeine
- Paracetamol.ibopruferm werkt beter naar is niet bevorderlijk vd lip/lymfoedeem
- paracetamol 3000 mg a day sleeping pills 50 mg 1 at night shortly attending a pain clinic
- paracetamol en pleister 1x in de week 10 mgr.Butrans.
- paracetamol
- Paracetamol
- Morphine Dilaudid Oxyconton Hydrocodone
- Tramadol
- I am very sensitive to nsaid and other pain releivers, I have given up on drugs that make me feel worse or not right in the head. I stick to asprin just to taked the edge off..and flexeral for muscle relaxtion.
- Meloxicam, tylenol
- Lìrica, Ultracet
- prescription
- Nurofen 400
- Naproxen
- Paracetomole. Panadol
- Ketoprofen
- Pijnstillers
- Ibuprofen of diclofenac
- paracetamol
- Valerian, Paracatmol
- Excedrin
- Co -codamol 30/500 plus paracetamol if needed for pain relief I take 125gm thyrozine daily seratide 150mg daily benaflorize 10mg inhalers 2uniphillin at nite1tablet sleeping tablet nebulizer if needed had hole in heart born with it
- Voltaren anti inflammatory, nurofen
- Paracetamol
- Paracetamol or ibuprofen
- diclovenac
- asprine
- Loratab
- Voltaren
- codimagnyl, ibuprofen, cannabis oil

- Diclofenac sodium 50 mg can have 6 a day
- butrans 20 triptazol
- Vaatverwijders voor nachtelijkekrampen
- Ibuprofen
- methotrexaat 10mg diclofenac 50mg foliumzuur omeprazol
- Ibuprofen
- ibuprofen, paracetamol
- Ibuprofen 400
- vochttabletten
- Methadone & a muscle relaxer
- Ibuprofen
- paracetamol met codeïne soms en trental sinds 3 maanden
- Lyrica Mobic Panadol Osteo
- Tramadol Paracetamol
- Ibuprofen / paracetamol
- Paracetamol
- Tylonel
- ibuprofen codeïne
- ibuprofen
- paracetamol
- Paracetamol, ibuprofen
- tramadol and aspirin
- paracetamol
- Ibuprofen, flexeril, etc
- paracetamol
- paracetamol
- paracetamol
- Panadine forte
- paracetamol
- Dicyclofenac
- paracetamol
- Tramadol
- Diclofenac
- paracetamol in overleg met huisarts
- ibuprofen en diazepam.
- Ibu 600
- Celebrex Panadol Osteo Cymbalta Lyrica Norspan 20 patch Endone
- Diclofenac panodil
- Ibu profen 600-800mg
- Morgon and stesolid (i have more diagnosis...)
- Paracetamol met codeïne
- Naproxen
- Ibuprofen
- norco, baclofen
- Diazepam
- I take Savella twice per day (for other pain conditions as well) and Norco occasionally
- tramadol hcl 50mg tablet
- Panadol and Ibuprofen
- Hydrocodone

- .hydrocodone, Lidocaine patches
- Don't like medication
- Diclofenac
- Co dydramol and sometimes tramadol
- pijnstillers
- Ibuprofen paracetamol
- Paracetamol
- Voltaren
- Paracetamol of ibuprofen
- Paracetamol
- Paracetamol, ibuprofen oid
- Paracodd
- oxycontin
- Tylenol
- Percocet, Tramadol, Neurontin
- paracetamol
- TRAMADOL EN DICLOFINAC
- Vicodin at night
- Paracetamol, diclofenac, tramadol
- morfine pleister diazepam paracethomol codiene .
- Paracetamol/Ibuprofen
- Hydrocodone
- Arcoxia
- Tramadol, lyrica
- paracetamol
- Diclofenac
- Tramadol
- Panadine
- Panadine
- ibuprofen
- Tylenol
- Aleve
- I'm only given Lortab. At best it will only take the edge off my pain. Otherwise my pain gets at levels that cause me to vomit and I'm unable to eat.
- Ibuprofen
- Lyrica 100mg 3x daily
- Tramadol
- Paracetamol
- Paracetamol/Arcoxia
- Paracetamol
- Co-codomol
- Tylenol
- No, because I'm allergic to all pain medications
- Oxycontin
- Lyrica
- Co code mol
- Aleve
- nsaid -Aleve opiate - rarely - Norco
- Pain killer
- I may have to soon.

- paracetamol
- paracetamol, diflofenac
- Paracetamol
- Paracetamol
- paracetamol
- paracetamol, naproxen , tramadol
- tylenol pm
- Anti-inflammatory
- Overgevoelig voor veel soorten medicatie.
- ibuprofen of paracetamol
- Ibuprofen
- Cymbalta, fentanyl patches, and much much more
- Ik gebruik medicatie vanwege de reuma die heb.
- Ibuprofen 600
- Over het algemeen reageer ik niet op pijnstillende medicatie, alleen morfine maar dit gebruik ik zo min mogelijk
- paracetamol
- Ibuprofen/paracetamol
- Panadol Osteo, Meloxicam . Panadeine
- Aleve
- Advil
- mexolcam
- ib
- Ibuprofen
- Tramadol .paracetamol
- paracetamol
- Naproxin
- Brufen and paracetamol
- Co-codamol 30/500 Naproxen 500
- I take Hydrocodone three times a day. They also give me a fentanyl patch to wear daily. This really helps me. The fentanyl patch is 25 mcg and the Acetaminophen and hydrocodone bitartrate 325 mg / 10 mg. I visit a pain clinic once a month and my regular doctor every three months and Dr. Herbst once a year.
- Aspirin
- 800mg ibuprofen
- Oromorph, Tramadol, Paracetamol, Gaberpentin.
- Nurofen
- Codeine, ibuprofen, paracetamol
- Advil
- Paracetamol & ibuprofen
- Ibuprofen
- Lortab
- Ibuprofen if mild pain, Tramadol if bad pain.
- gabapentin paracetamol fentanyl patches
- Paracetamol and codeine
- Paracetamol codine
- Panadol
- Tylenol or Ibuprofen
- Morphine, Tramadol and paracetamol
- Co-codamol

- Penadine osteo, glucosamine and fish oil
- hydrocodone and compounds
- Panadol
- Panadeine Forte
- Tramadol 200 SR Lyrica 75mg Norspan patch 10mg & 5mg
- tylenol
- Lyrica Tylenol
- Ibuprofen
- diclofinac paracetamol
- Paracetamol
- Aspirin
- Advil
- Aspirin, Aleve
- Indocin
- zalidan
- Co codimal
- Motrin
- Ibuprofen, 400 mg
- medicijnen helpen niet tegen de pijn.
- Oxycodone, Methadone, Gabapentin
- Butrans patch, norco, dilaudid
- Hydrocodone Advil
- Paracetamol and codeine
- Aleve
- Various
- Aleve or Advil
- Ibuprophen 800
- Tramadol codamol pain compression nit farrow wraps day stockings
- Omeprazole Ramipril Have taken lots more in the past
- Vicodin
- Ibuprofen
- Aspirin
- Ibuprofen
- Tylenol PM, Vicodin
- I take gabapentin for the neuropathy in my feet.
- MS Contin, Roxycodone, and Robaxin(
- I do essential oils, tart cherry juice, honey and cinnamon and coconut oil.
- tramadol/paracetamol
- Ketoprofen
- Whatever is available
- Ibuprofen
- Tylenol
- Ibuprofen or Meloxicam
- Norspan patches Oxycontin Panadol Osteo
- Not allowed anti inflammatory eas so take tramadol
- Paracetamol
- Ibuprofen, Tylenol
- Norco 10-325
- Tylenol
- Aleve or Tylenol

- VOCIDIN
- Co-codimal
- Ibuprofen and paracetamol for joint pain but not for other lipoedemic pain.
- advil alieve
- diclofenac
- Tylenol and Advil
- Metformine 2x daags omeprazol 1x daags temazepam 1x daags ascal 1x daags simvastatine 1x daags furodantine 1x daags fluoxetine 1x daags
- ibuprofen, magnesium
- parasetamol
- I can only take acetaminophine as i had rny (gbs) ib 2008.
- Naproxen sodium (Aleve) Muscle relaxant at night
- usually ibuprofen
- oxycodone and fentanyl
- Celebrex. Cortisone shots in knees. Ibuprofen and acetaminophen
- Paracetamol/coffeine
- Aleve
- Ib
- antiinflammatories Muscles Relaxants
- Aleve
- Lodine
- Ibuprofen
- Fentanyl, hydrocodone, ibuprofen800
- Panafon osteo
- Ibuprofen
- paracetamol
- Co codemal
- Naproxen
- Aleve, Advil, or Meloxicam
- Naproxen
- Mexiletine, Dilauded, Tizanidine
- Ibuprofen
- advil or tylenol
- Ibuprofen rarely
- Magnesium (latent tetany)
- Advil
- Tramacet, Flexiryl
- Nurofen
- Vicodin, neurontin, cymbalta, tramadol
- mobic, panadol, panadine forte (when it is really bad) lasix when i can't remove the fluid over a few days
- Paracetamol
- Sometimes hard to be taken seriously to get appropriate medication that's effective.
- Ibuprofen
- hydrocodone, then changed to oxycodone
- Tylex
- just glucosamine for the osteoarthritis in my knees. I have a high tolerance and refuse to take a lot of pain medication
- Paracetamol maar zou wel zwaardere willen
- Ibuprofen

- Ketoprophen
- panadol
- Alieve
- Paracetamol and ibuprofen
- its not prescribed for pain
- Naproxen
- tylenol
- Paracetamol
- cymbalta4525091503.html
- Tramadol
- medicijn allergie
- Vultaren
- Zaldiar en meloxicam
- Aspirin/caffeine/paracetamol
- Tylenol
- Pain killer for musclesg
- Muscle relaxer or ibuprofen
- Tylenol ,Gabapentin, Naproxen
- morphine
- Paracetamol
- Tylenol
- Diclofinac, naproxen
- Cymbalta(generic) for fibromyalgia and oostearthritis, Triamertene for water retention, Alleve for arthritis
- Tramadol hydrochloride. Amitiptyline.
- 1 Aleve daily
- Co-codamol or paracetamol
- Anadin extra, co-dydramol and tramadol I am not allowed anti inflammatories due to kidney transplant
- tramadol paracetamol
- ibuprofen, tylenol In the past was prescribed Trimadol for SI pain and it worked well on my general arm-leg-shoulder pain too
- Aspirin
- Ibuprofen
- Diclofenac
- Not able to take pain meds because of bad interaction with my heart meds.
- Naprosyn
- Tramadol
- gabapentin
- Gabapentin, duloxetine, ibuprofen, paracetamol
- Naproxen, obuprofen. Have taken codeine.
- Ibuprofen
- Paracetamol
- NORCO
- Vicotin
- Duragesic patch Oxycodone
- Tramadol
- Co codamol
- Aspirin, Ibuprophen
- hydrocodone as needed

- Advil on occasion. It helps most of the time. Occasionally, not at all.
- I am on a Butrans Pain Patch. 15 mcg/hour. It is changed every 7 days. I also take an extra strength pain reliever when needed (500 md, 2 tabs, 3 times per day)
- Aspiring, Ibuprophen.
- Advil
- Motrin
- Advil
- Tramadol, lyrics, paracetamol, naproxen
- Celebrax, Ibuprofen
- Hydrocodone, Advil, and hydromorphone, PRN
- Tylenol
- Ibuprofen 200 mg x 6 (1200 mg/day)
- Ibuprofen
- Alive, ibuprofen
- Ibuprofen
- Diclofenac 50 2xdgs. 4 paracetamol. Pijn medicatie is voorgeschreven voor hypofosfatemische rachitis .
- Ibuprofen
- Foster
- Prednisolin, salofalk, calcium (ivm colitis ulcerosa)
- Paracetamol. Ibuprofen.
- noni juice and grapeseed extract
- Paracetamol and Ibuprofen. Have tried Codeine and Gapapentin but they had no effect.
- Ibuprofen
- Advil
- Vicodin
- Neurontin, Voltaran, Flexiril, Lamichtal, Ultram, Lyrica, Elavil, (Hydrocodone when needed)
- neurofen
- Tramadol
- Oxycodone, ibuprofen, naproxen sodium
- Tremadole for my knee
- Panadol
- Ibuprofen
- Fentanyl en tramal clonidine
- Ibuprofen
- paracetamol
- Celebrex,
- Tylenol, aspirin, others
- Aspirin
- Daflon Inneov
- ibuprofen 800 mg x 3
- Diclofenac
- Hydro codeine
- Ketoprofen
- norco
- advill
- Ibuprofen
- Naproxen and flexible

- Paracetamol of naproxen
- Co codamol
- Ibuprofen
- Naproxyn Co-codamols
- preganalin diclofenic co codamol
- acetaminophen
- Oxycodone and Morphine
- gabepentine, keppra, paxil
- Tramocet - although about to up medication
- Tramadol paracetamol iodine amitriptyline as I also have a back & knee. Problems as well
- Ibuprofen or tylenol
- Ibuprofen
- Aleve
- IB 800
- Ibuprophen
- aspirin. Stay away from pharmaceuticals!!
- pandol
- ursodeoxycholic acid (biliar problem/not specified in my current diseases question)/omeprazol/bezafibrate/ tramadol 50mg/day (pain after mastectomy)/Q10 at high doses (diagnosis of mitochondrial myopathy acquired, not severe/ I forgot to tell in my current diseases
- Panaidene Forte Endone
- Paracetamol
- Just panadol
- Neutontin
- Nothing, so far, helps with my pain, and some make it worse
- IBU 800
- Muscle relaxers
- aleve
- Ibuprofen
- Alieve, Naproxen
- Paracetamol, Noratryptaline
- Advil
- Aleve
- Tramadol maxicam
- Endep Mersyndol
- Advil
- strong medication for arthritis and fibro
- ibuprofen 2x 400 per keer
- Percocet
- Naproxen en paracetamol
- Ibuprofen
- wel gebruikt in het verleden
- Advil
- 1000 Mg paracetamol
- heb allergie voor pijnmedicatie
- Tramadol paracetamol
- Naproxen
- Ibuprofen/ paracetamol

- Meloxicam
- Euthyrox , Fluoxetine , Paracetamol CodeOne , Oxycontin
- Paracetamol
- Naproxen, Paracetamol, Paracetamol/coffeine
- gewone pijnstillers ibuprofen
- Acetaminophen
- morphine 15mg and diclofenac 75mg
- I've tried Aleve, Ibuprofen, and vicodin

Statistics 42: About having a job

	1) Yes	2) No	3) Inapplicable	4) No but it will	5) No but I did have
42.1 Do you have a job	60.03%	24.00%	2.23%	1.34%	12.41%
42.2 Did the Lipedema make it difficult to find a job	23.77%	51.04%	19.84%	4.01%	1.34%
42.3 Did you ever lose a job because of the Lipedema	15.38%	72.73%	9.88%	1.41%	0.59%
42.4 Does or did the Lipedema giving you problems at work	46.06%	38.11%	9.81%	4.46%	1.56%

Comments to Gegeven Toelichtingen

- No really an issue
- More from others not understanding and bullying
- I cannot have a desk job as the swelling and pain in my legs gets too much. This limits the work I can do!
- Mobility on an office campus setting is exhausting.
- I have been an interpreter for 20 years. I occasionally do a job but I mostly can not work because I can not drive to the jobs and I can not take jobs where I have to sit for a long time.
- I am trying to get better but have not worked since August 2013
- Veel pijn en krachtverlies
- Can't stay sitting for too long.
- I am retired
- Ik werk momenteel veel achter een balie, maar dit is een sta balie. Omdat ik ontzettende rugpijn kreeg (balie was ta laag voor mij) heb ik nu een kruk. Deze ontlasten mijn benen ook ontzettend wat heel prettig is. Door deze oplossing kan ik gewoon 38 werken. Mijn werk weet trouwens heel weinig van mijn aandoening. Heb ik het liever ook niet over overigens.
- Lang staan, zitten en lopen. Beperking in mobiliteit en pijnklachten
- Ik ben n doordouwer
- I was a hair colorist/cutter
- Since 2 years I have been working from home as a naturopathic/health practitioner so it is easy to work around my complaints, previously I had a stressful job as a manager at my husbands company managing 60 staff, my complaints were heavy and all the time because I was constantly going over my limits and did not listen to

my body. this has now reduced by 90%

- A molecular biologist with brain fog can be problematic.
- Combination of Lipedema and Dercum's Disease caused me to have to resign from my job. I am now on disability.
- people don't understand that it affects thinking and motivation
- Dr took me off with work and wouldn't let me go back
- voor mij persoonlijk zorgde de lipoedeem ervoor dat ik's avonds totaal afgebrand was en dat ik veel vermoeide benen had en veel pijn. Ik stond voor de klas. Dit is echter niet de reden dat ik ermee gestopt ben.
- Had to leave work taking early retirement, unable to work the hours standing up
- it doesn't matter whether I walk or sit, either of those I am unable to do for anything longer than half an hour
- Getting in and out of chairs and the car was very painful to hips and especially knees
- Ben door de lipoedeem niet mijn baan kwijt geraakt, maar heb er door wel moeite om wat anders te vinden.
- Werkte in de kinderopvang dit ging niet meer, fysiek te zwaar. Nu bezig met ander werk, vanwege beperkingen erg lastig iets anders te vinden.
- zware benen veel oedeem s avonds na het werk
- Durch die andauernde manuelle Lymphdrainage und die Rehamafnahmen hat man oft Ausfallzeiten.
- xxx
- Lipedema limits my job opportunities because I prefer to work from home. I am a Web developer so I can get work this way, but many companies will not hire me.
- Retired with very part-time work - mostly at home, a little at a venue with stairs - now getting difficult to continue
- Advies van de arboarts was een parkeerplek onder het kantoor met ruime uitstap. HR doet daar niet aan mee als er geen europese invalidenkaart getoond wordt. 100 meter in eigen tempo zonder laptop ed. meezeulen kan ik goed, 700 meter met alle spullen niet. Kennelijk ben je volledig in orde als je niet heel duidelijk niet in orde bent. Ik denk niet dat ik nog lang werk waar ik nu zit, nu ik sinds een week geen recht meer heb in de parkeergarage onder het werk te parkeren. Dat is voor bezoek, werknemers parkeren 700 meter verderop. Of 800 meter als je later begint en dus geen plekje vooraan in kunt pikken.
- Needed a special chair without armlegs
- I currently do not work, the pain of this would and will make a difference for the type of work I will be able to go back to.
- Too much sitting causes lymphoedema. Too hot in summer so legs and feet swell
- I kept breaking my foot by just putting pressure on it . I was diagnosed too late and the past 8 years I've just tried to eat healthy and elevate my legs
- Sitting too long, standing too long, too much physical activity.
- Had it all my life but lived with it...Did not know I had it. Told swollen ankles (it) was high BP and given diuretics for years and years.
- Ik heb enkel partime gewerkt. Ik werkte onregelmatig en ik ben hier ivm lipoedeem mee gestopt. De onregelmatigheid en de aard van het werk was fysiek te zwaar
- Lang staan toen ik ik een winkel werkte. Vooral met werk weer gaf dat problemen.
- I am a full time student. Lipoedema causes problems moving around campus. I used to be a care worker. I am unable to work in care now that I need care myself. I am not physically capable of the demands of care work. After my degree, I hope to become a primary teacher. I will be unable to stand in the playground, but I hope to

be able to teach sitting down.

- used to nurse ,pain and leg size made long shifts impossible
- ik werk parttime en dat helpt
- Niet op mijn werk, maar ben daarna doodmoe
- Was verpleegkundige. te zwaar. Ben manager in de zorg geweest, werd ook te zwaar. B.v. ook veel met de auto naar afspraken/vergaderingen. uren zitten. Concentratieproblemen door pijn b.v. In het verleden waren overleggen en evrgaderingen nog niet rook vrij was ook een groot probleem wat er bij kwam, heb COPD (mee geboren, astmatische bronchitis, had dauwworm bij geboorte).
- ik werk fulltime in ons eigen bedrijf en merk dat ik niet meer dezelfde inzet heb als voorheen, vanwege de vermoeidheid in mijn benen
- Vorig jaar in de ziekte wet terechtgekomen. Ben nu met reïntegratie bezig en werkgever zal hierin genoodzaakt mee te werken wat niet altijd gemakkelijk is.
- Kantoorbaan, dus dat scheelt veel.
- met vocht opgezwollen, dikke benen, door lang zitten
- Colleagues do not have understanding
- I work in an office and i cant sit long so i have to stand up and walk a bit at least every 30 minutes
- my sister owns a cafe... i just do dishes prep food for the day cook for the day then ii go sit down when not busy as i am getting older i noticed that i have more pain as to walk all the time now but i do it for as long i can walk i walk..... even i am in pain i just go slow....
- Long Standing and walking as an air hostess.... horrible
- vanwege de vermoeidheid depressie en pijn kon ik niet altijd op m'n werk zijn
- Ik heb in een winkel gestaan waar mijn bazin het beter vond voor mijnbenen om niet meer hele dagen te staan. Baan kwijt...
- Ik ben kapster en was daarvoor afgekeurd maar wil het toch weer proberen maar dan met minder uur.
- ben Ziekenverzorgster geweest en 30 jaar een boerin met koeien samen met mijn man is helaas overleden.heb een miskraam gehad en heb een zoon en een dochter.
- I had to retire.
- I had to stop working in my early 60s because of Lipedema pain. Could not sit in front of my computer at all without unbearable pain in my legs. Since my liposuctions i am able to do a limited amount of work sitting in front of my computer. Probably a couple hours a day.
- Heb eigen groothandel gehad en ben nu webshop aan het opstarten.
- Even though I was in charge of disability services I was hands on and found it physically painful when having to stand for any period of time. More so than a lot of my clients
- The lipedema gave me a lot of trouble while going to school because I could not remember things very long. Now I do not remember the things I should know to be able to work. Now I have not been able to land a job.
- Uniform were an issue, jobs with lots of standing were excluded, also lots of sitting was painful as was lots of walking
- Couldn't do job due to disabilty now . Need job sitting but again can't seat to long painful to get up also can't climb stairs
- I was scared and insecure of my body, ashamed. I didn't want to do any job where I would have to wear a dress, or shorts, or swim suit, or a uniform that would expose my legs. I had very low self esteem.
- ben eigen baas

- long sitting in an office job with lipedema is worse.
- heb een zittend beroep, staand (bv in een winkel) zou wel problemen opleveren
- Ik krijg alle ondersteuning en tijd die ik nodig heb voor therapie bezoeken, dokter bezoeken enz.
- I quit my job two times because of lipodema - i was too tired and got stressed, and finally had a depression. As soon as I could get a pension I quit jobbing.
- I was working as a nurse, I left to get treatment after a virus after pregnancy brought out my symptoms, I was in too much pain to go back to do long shifts
- For my day job I'm ok. For my opera singing I have been discriminated against because of my strange body proportions. Following the advice of my singing teacher 10 years ago I got liposuction on my hips which made my silhouette more normal.
- Kan niet te lang staan en veel trappen lopen
- I was fired & lost my disability insurance despite a dr note wanting me to put my legs up for a day.
- Sitting at a desk and typing all day.
- Incapable of working now
- Ben door mijn lipoedeem minder gaan werken. Ik werk 30 uur. Zodat ik 1 dag vrij heb om het huishouden te doen. Heb een burn out gehad, doordat ik de combinatie full-time werken en prive niet kon volhouden door mijn lipoedeem. Veel pijn, onvoorspelbare vermoeidheid en prikkelbaarheid etc.
- I was a teacher and the job required a lot of standing. I retired at age 60 when wearing garments created difficulties with loss of my leg muscles.
- Poor appearance in skirt in office work. Pain from standing too much.
- retired nurse
- None
- I was unable to walk while pregnant and had fainting spells and threw up 4 times a day. My gallbladder also played up and had to be removed.
- Sitting for long periods is very hard on my body.
- nog maar 14 jaar. Ik ga naar school, wat soms echt moeilijk is omdat mijn benen niet willen meewerken en er geen lift is alleen trappen(veel!!)
- wisselend moet ik steeds opstaan en van kantoorplek naar receptiebalie lopen, de ene keer gaat dat beter dan de andere> pijn, stijfheid, hielspoor
- Het is niet alleen het lipoedeem bij mij, ik heb namelijk ook een erfelijke nierziekte die mij beperkt.
- Can only work part time full time would be too much on my legs
- But now am i medical leave
- I was already sick and not having a job before this diagnose
- I'm looking at changing my employer, but my legs are worse now since my hysterectomy. I'm afraid it could influence getting a new job.
- difficulty sitting behind the computer/desk, absences due to liposuctions/recovery, etc.
- I had to quit my job, due to mobility problems
- I am terrified of losing my job due to my health issue. I can not afford to live on a lower income. Stress really affects my legs & body so much.
- I am now retired, but looking back, lipoedema certainly affected how I did my job. I suspect I was judged in my job by how I looked - I was a senior manager - and I continue to be judged as being stupid because I am overweight.
- Walking on stairs
- Increasingly I am finding seating in meeting rooms uncomfortable. The chair arms press against my hips and thighs and it hurts.

- Ik ben door de lipoedeem van baan veranderd.
- Nobody knows at work
- I am on disability because of Dercum's Disease and lipedema. I can no longer be a special education teacher or paraeducator. I would have to be able to lift, transfer, hold, change and help with PT students.
- zat in de zorg, maar kon door toenemende beperking en klachten bij dit bedrijf een kantoorbaan krijgen
- WERKT IN DE HORECA, MAAR WAS VEELSTE ZWAAR, DODOENDE WERD MIJN CONTRACT NIET VERLENGD
- Ben verpleegkundige. Nu al Max 5 dagen achter elkaar werken, anders kan ik lichamelijk niet genoeg herstellen. Af en toe zit ik op kantoor ipv aan bed voor fysieke ontlasting.
- ben afgekeurd.
- ik werk in de zorg en het is de vraag hoe lang je dat kan volhouden met lipoedeem
- I was forced to leave my job due to Lipedema. I was not treated fairly and it was clear they did not want me there. The psychological impact of being treated like that as well as the physical toll became too much. I was losing sleep and had to take more anxiety medication and it became unbearable. I tried to fight it but finally decided it was time to go.
- ik ben te moe, onberekenbaar daardoor
- Inmiddels met pensioen
- I quit nursing due to the inability to stand for long hours
- Leg swelling
- I left my job because I was unable to continue functioning. My employer was very kind and considerate. It was very difficult needing to leave my job. I loved working and miss it very very much.
- I work from home ,I stopped working in schools as this was getting too difficult ,I am a carer of children.
- I was slow to move through the halls and out to my car, to load my walker and get in my car. I could not stand and talk to people, I had to bring my walker and sit to talk to people. I had to push my walker, plus the wheelchair of the nursing home resident I was visiting, and that slowed down my work. I could not just stand and take notes anywhere, I had to find a spot where I could sit and set things down. I could not consider taking a job in a hospital because I know I could not stand to do the work or there would not be room for me to have my walker with me. My size and my added walker made a lot of jobs impossible for me to take. I had a lot of trouble with word finding. The jargon of my profession and the names of medications were particularly hard for me to remember under pressure! I always felt that I could not show my true abilities because I could not say what I was thinking because of word finding problems.
- I was disabled by age 28. I was discriminated even before my weight gain worsened when I was in 200s at more mild levels of lipedema. I could barely even get jobs due to my body shape and was mocked even though I had a university education.
- steeds meer pijn
- appearance issues - comments about weight, etc.
- ik werkte in de zorg en doro het moeilijke lopen, bukken ging het niet meer , ook de uniform broeken pasten nooit vanwege dikke benen
- I am a mature student at the moment
- In het verleden heeft dit zeker een rol gespeeld.

- Ik werk als leerkracht in de bovenbouw van een basisschool. Kinderen maken opmerkingen over je uiterlijk. Dit heb ik vaak moeilijk gevonden.
- het kost wel veel tijd de huidtherapie en dat gaat ten koste van werkuren.
- sitting a lot is painful, but i dont bother my employer with that
- Je bent beperkt in de bewegingen en snelheid van bewegingen.
- Zittend beroep; moet regelmatig gaan lopen, ook al is dit niet echt nodig.
- Ik werk thuis als coupeuse. Heb zittend werk wat wel slecht is maar kan mijn eigen tijd indelen.
- Tijdens slaapdiensten niet kunnen slapen van de pijn, moeizaam trap kunnen lopen, kort lontje hebben, emotioneel zijn, concentratieverlies
- If I had a job where I had to stand all day I know that I would feel very uncomfortable by the end of the day with my calves swelling
- I do modify what I can do to complete my job
- werk niet meer
- I started volunteering to teach and have been very active lately.
- I worked for over 40 years not knowing I had Lipoedema, even though I knew, my body was all distorted. And I used to get very embarrassed at work, as I did not like people looking at me. My work colleagues where fine, it was members of the public, that I would be very conscious about.
- Sitting for long periods and very hit office
- Pain and the time required to treat - had to go part time
- I have a stool under my desk to put my feet on
- I am retired
- Sometimes I'm in pain at work. I just take pain killers a lot,
- I have to sit for long periods at work so by the end of the day my legs are very heavy, Yahtzee, and swollen.
- part of my job involved long hours of driving and this caused my legs big problems. Also i had to dress brides and lifting them into the dress became to painful as the dresses are heavy and my arms and shoulders couldn't cope. I had to stop tying the grooms shoes (Kilt Costumes) as i could not get back up and my knees were dreadful. I closed my business down not to let brides down due to a lot of time being spent in bed with pain.
- I had to leave work as I was unable to stand for long periods (I was a cook) at the time I didn't know I had Lipedema
- early medical retirement
- Wrists get swollen and achy cant type air conditioned room
- Multiple sclerosis at age 26 caused disability
- Walking = problem. Hips so wide that most chairs with arms do not work for me.
- I use a walker. Grateful that my employer understands about the lipedema.
- I was a truck driver for 20 years
- Disabled
- Problems caused by aching legs.
- I am self employed
- I was an elementary school teacher (kindergarten and first grade). I had to stop teaching due to my Lipedema pain.
- Degeneration of both knees at age 62. They do not want to operate on right knee.
- My company required the ladies to wear knee length dresses, and did not want me to wear compression hose, therefore, I was told it wasnt going to work out, even though I was employeed for over two years and was the best employee
- I swell really bad during the day due to just sitting at my desk

- Can't kneel, sit down cross legged, run, or walk as much as I would like to. Limited in style of clothing due to comfort, size, and need to cover up.
- I ENDED UP QUITTING MYSELF.
- Occasional exhaustion makes me stay at desk more than I should instead of getting out to shop floor. Stairs hurt my knee..and during physical inventory each year being on my feet all day counting parts takes a toll on me for days afterwards
- Put me in pain
- Knee problems meant that I had to give up nursing. Now retired
- trappen lopen gaat moeilijk
- I was unaware of it possibly being Lipedema and my employers are not aware of it either.
- Ik ben met pensioen na 30 jaar gewerkt te hebben.
- General pain and difficulty walking.
- Kan niet meer staan, kleine problemen op werk ivm kantine schoon houden
- I was on a disability from work with something else and now can't go back because of this.
- Stand and. Squat alot
- It is just uncomfortable to stay sitted with legs down.
- I did leave a job due to my butt being very large and my manager made jokes about me. I found another job.
- After standing or walking Its painful hard to stand up or pick up my feet. Sometimes they go numb!!
- I have no way of proving if it did or did not affect hiring practices.
- lost my job due to my bipolar disorder, now on SSDI
- Makes me feel uncomfortable when meeting new people as I think they notice my disproportionate body and heavy legs
- gives me problems because of the discomfort and pain. I avoid walking whenever I can.
- standing is a big problem to me
- Do not like wearing shorts ever so really struggle in the heat.
- i have a great job however the thing i'm finding hard is their uniform doesn't cater for my lipedema
- I dont work outside the home
- I don't even own shorts and never wear skirts (unless ankle length) so no one really knows I have it in the work place unless I disclose it to them.
- job required long hours of sitting, almost impossible to sit for more than 30 mins without pain.
- I did not have lymphoedema/lipodema when I started this job but, due to age, will probably not be able to get another job due to age/health
- At one point I was over 300lbs and I ended up quitting a job because of all the walking/stair climbing required
- I am a full time college student
- maar het werk werd steeds zwaarder
- I avoid travel to work and I get up many times during meetings. I avoid working lunches and sometimes I have to take hours in my therapy (in Spain and in my office is usual working until 8 pm)
- Negative comments about obesity from a past boss, frequent comments about bariatric surgery. I always felt my body image placed me lower down the employment queue, whether it actually did or not. Am now self-employed in an entirely different

work sector, have some limitations due to physical flexibility, but get round most things.

- retired when i got lipedema
- Difficult to stand, walk any length of time
- I have an office job and doing a lot of calls
- geen problemen op het werk, maar werk wordt wel beperkt -> arbeidsdeskundige wordt binnenkort ingeschakeld al ben ik zelf creëer genoeg om oplossingen te vinden. tijdens mijn werkperiode is lipedeem ontstaan en ik heb een vaste aanstelling waarbij je er niet zo snel uitgewerkt kan worden. passend en geschikt werk eerst.
- legs ache and swell over the day
- Additional weight on hips and knees. Had a hip replacement two years ago.
- My legs swell during the day. I have to get up and move around to keep my circulation moving or my limbs become heavy & cold to the touch even on a really hot day.
- I have not had a job for 45 years.
- Retired
- Retired now. Owned my own business for 30 years
- I have my own business. If I did not, I do not believe it would be possible to find work. Sitting at a desk for long periods makes the pain in my legs worse. I Could not perform well on a job that I would need to stand all day.
- Ik kan mijn sport trainingen bijna niet meer volgen op het werk. Ook moet ik een politie test lopen. (Over kasten rennen en springen, aantal rondes)
- I have a very low paying job with very long hours. It's the only job I've been able to get since I lost my other low-paying job 7 years ago because of lipedema-lymphedema problems. I am living far below the poverty level and have been for 15 years. Very difficult, and most of my money goes for medical bills, prescriptions and fruits & vegetables for a healthy diet - none left over for fun ever. SO HARD.....
- I just do a little work from home transcribing audio files.
- No comment as I coped
- I am a primary school teacher. I can sit, move or stand as I need to. Now I use a wheelchair or crutches I can't move around the classroom easily
- Tired legs in the afternoon.
- Difficulty standing for long periods of time. And sitting for long periods of time isn't good either
- I just had to retire early due to the pain , swelling and limited mobility it caused- I loved the career I had had
- Ik werk in een atelier winkel waar ik veel sta en ook zit
- Contributed to job performance negative impact
- As stated before, the difficulties were primarily psychological due to self-consciousness.
- I work in the health field, and I have definitely felt some discrimination regarding my condition. I also feel less credible as a health practitioner due to my condition.
- I retired prior to lipedema
- Sitting; laid me off due to too many visits for pt and related illnesses....but they said it was due to no business in the education field of enrollment in a college.No it was not as I look back.
- Na langdurige mantelzorg voor echtgenoot, Parkinson 19 jaar, wilde ik graag werken maar tot op heden nog niet gelukt. Veel vrijwilligerswerk gedaan en nog. Laatste betaalde baan werkbegeleider vluchtelingen werk ex-amaproject
- Werk al 40 jaar bij de Spoorwegen.. Die kijken bij interne sollicitatie niet zo zeer

naar uiterlijk of leeftijd alleen naar geschiktheid. En volgens mensen die mij kennen straalt ik schijnbaar iets uit waardoor dikke onderlijf minder opvalt.

- I can't spend as much time standing and walking as I should. I can't kneel, or get up from a kneeling position. I have to go up ladders but I've almost reached the safe weight limit for the ladders and am embarrassed to tell anyone that I'm too heavy to use the ladders..

- I am now self-employed, but when having gone to interviews previously, I've always been aware of my appearance, i.e. sometimes it's harder to get hired when you're fat.

- I worked for over 25 years in petroleum equipment industry on feet a lot, a lot of lifting and also desk work, then in retail on feet a lot and working with elderly. Legs always swelled and painful. Compression or support hose hurt so bad to put on and take off.

- I work in heavy construction, walking on concrete and climbing ladders spend all day on my feet and legs.

- Sometimes the pain affects my mood or ability to deal with stress.

- ik kan niet meer werken vanwege het oedeem, te moe, te veel pijn

- I just do one day hairdressing freelance no problem

- fluid build up behind knees makes hard chairs very uncomfortable. Also, I cannot bend my knees enough to pedal a bike because of knee fluid build up.

- Retired before it got bad

- I'm in college full-time now, which takes a lot of my time up. But I worked full-time for fifteen years prior. In the last five years or so of working, the lipodema (and fibromyalgia, which may or may not be related) made working more and more difficult. I also could not seem to lose weight, and was in CONSTANT pain.

- I am on disability retirement since the age of 49.

- Geen baan sinds 28 jaar

- I believe I lost a job due to my weight, but I did not lose the job because I was incapable of doing the job. I believe the boss laid off the person who weighed more in his eyes.

- Becoming harder to travel by plane and sit in long meetings as pain increases for several days after

- Lipedema & Dercums together caused me to be unable to work and I have been dx with Dercums and am now on disability

- I am having a few mobility issues

- I only work part time

- with my feet hanging down I sometimes feel pain and have a difficult time standing up at first and walking. I didn't know it was lipedema until recently

- have to put my feet up if I can at times

- hard to say if the problem caused issues regarding being employed. I 'dress for my problem' and dress very well. I also did a very good job and what I did (Health IT/ telehealth)

- I did have leg pain when I was working but, I did what I had to do.

- I am retired on medical grounds but this is not due to lipodema

- Sitting at my desk gets more uncomfortable as the day goes on

- im not working anymore. i can not handly work and being a mother

- Ik ben werkzoekende, maar kom nog niet eens op gesprek, dus de lipoedeem kan niet de reden zijn

- Ik werkte in de verpleging dat was veel te zwaar, waardoor ik me vaak ziek moest melden. Dat resulteerde uiteindelijk in ontslag.

- lipoedeem zorgt ervoor dat ik minder flexibel ingezet kan worden. Zorg voor

anderen is zwaar. Ik zit nu in een traject waar naar passend werk word gezocht.

- Lichamelijke vermoeidheid maakt het zwaar.
- Ben nu zzp er wat heel goed bevalt.
- Aanpassingen voor "staan" rolkruk en lokatie zodat ik niet veel hoef te lopen
- I never fit in any chair.
- DIFFICULT TO STAY ALL DAY LONG SITTING AT DESK: CAUSING PAIN AT HIPS, THIGHS, LEGS
- I am self employed .
- I am not able to walk as much as I need to. Also, the pain gets too unbearable at times.

Statistics 43: Did a surgery worsened your Lipedema

Yes 24.03%
 No 28.42%
 Inapplicable 47.54%

Statistics 44 : Did your own GP (doctor) have knowledge about Lipedema

	1) Yes	2) No	3) A little bit	4) I do not know
44.1 Lipedema knowledge	8.31%	64.54%	15.65%	11.50%
44.2 Willing to help	37.24%	25.82%	21.36%	15.58%
44.3 Willing to learn	28.64%	28.19%	17.14%	26.04%
44.4 Takes you seriously	41.91%	25.15%	19.36%	13.58%
44.5 Gives information about Lipedema	5.64%	73.81%	8.61%	11.94%
44.6 Gives mental support	20.25%	52.30%	13.50%	13.95%
44.7 Gives diet advices	21.22%	55.64%	11.05%	12.09%
44.8 Gives lifestyle advices	20.47%	56.16%	11.28%	12.09%

Statistics 45 : Did ever a GP or specialist said to you that Lipedema was "bullshit"

Yes / ja 30.12%
 No / nee 69.88%

Statistics 46 : Did ever a GP, docter or specialist treat you bad because you have Lipedema or because beeing overweight

Yes / ja 45.13%
 No / no 41.36%

Sometimes / soms 13.52%

Added comments

- None of my drs knew or cared about what caused it.
- Dat was de aanleiding dat ik van huisarts ben veranderd.
- I have had doctors tell me to exercise and lose weight. the nicest one said I had ideopathic edema. No doctor will try to help due to fat stigma.
- Some years ago I was accused of being lazy and overweight. I did not accept this accusation and made sure to correct my (then) GP.
- for many years my symptoms were not taken serious I was overweight I was to lose weight I did just not in my legs so I was told I had an eating disorder and mental issues... just wish they would have sooner realized I did not make the pain and problems up and had diagnose the Lipedema in combination with PCOS and a gluten-, histamine, sorbit-, fructose intolerance much earlier it would sure have been much easier
- GP was unaware of Lipedema and only considered obesity and accused me of poor eating habits
- My Lupus doctor told me I was just fat & needed both a diet & a shrink.
- When I was looking for a diagnosis, doctors would deny seeing symptoms, sometimes treating me badly.
- I have found everything about all this on my own
- Had obisitas vindt hij en wou mij niet opereren
- Bij uitkerings instantie het UWV wel . Die mensen hebben er echt geen kaas van gegeten . Ik heb Fibromyalgie , Hypermobiliteits Syndroom en Lipoedeem
- My doctor will not tell me I am fat
- heb zelf een medische achtergrond. Moet vaak in de verdediging tav mijn overgewicht. Heb ook wel excuses gekregen van UWV arts vanwege zijn gebrek aan kennis. Specialisten zijn vaak minder toegankelijk voor mijn motivaties. Mijn huisarts heeft meeste kennis opgedaan via mij, werkt vaak ook mee omdat hij vindt dat ik een beter inzicht heb als hij. Heb echter eens een invalster gehad die het arrogant weglachte, daar ben ik boos weggelopen en gewacht tot mijn eigen arts weer dienst had.
- Not applicable, I have never seen dr about it
- During pregnancy an OB told me that I needed to lay off the kit kats, learn what vegetables are and get off my butt. Said this in front of my friend. I was gaining around 2-3 pounds a week due to the lipedema.
- Ik kwam voor behandeling aan mijn spataderen, en de dokter zei dat dit ook wel kon komen doordat ik dikke benen had.
- Orthopeed vond dat ik maar moest afvallen zodat mijn benen dunner werden. Dan waren de gewrichtsklachten een stuk minder... hij wist dat ik Lipoedeem had.
- Ik heb mijn huisarts alles geleerd ! En informatie gegeven ! Ze hebben toen zelf op de site alles nagelezen
- Niet direct slecht behandeld maar nadat ik aangaf dat ik sporte en oplette met wat ik eet. Kreeg ik het antwoord ieder pondje komt door het mondje. Door het mondje ging de schijf van vijf!!!
- Told me to go to Weight watchers and Curves Nothing is wrong with me I'm just fat and depressed Told me that blood just pools in my fat legs, I asked her Do your legs do that? She told me to run.
- I was not diagnosed till I was 50, and I am still being told my main problem is

obesity, despite having a diagnosis

- gynecoloog zei dat ik na 3 miskramen maar eerst de cola en chips moest laten staan, ik wist toen nog niet dat ik lipoedeem had
- Yes, yes, yes & yes!
- all the time, especially from age 11 until 2011 when diagnosed, although a few doctors were much more understanding during this time
- Men placht er een opmerking over te maken, deze pareer ik direct. Met succes. Als men speculeert dat ik 'iets aan mijn levensstijl moet doen' zonder te weten wat deze is, zeg ik: jij concludeert adv mijn dikke kont dat ik ongezond leef? Dit zegt meer over jou dan over mijn levensstijl. Werkt direct.
- Mij werd de schuld gegeven en ik zou maar beter mijn best moeten doen. Het zou tussen mijn oren zitten.
- From the time I was 18. Weighed 140 pounds at 5'3" small top large bottom. When expressed that I didn't eat that much was called a liar
- I had been treated for obesity for many years by my GP and my Dietician, both were shocked when they found out what I had, I then was treated a lot better
- Ik moest maar afvallen.
- I have been told not to bother with anything and just go into a nursing home because there's nothing anyone can do for me. You can't have lipoedema because I've never heard of it so it can't exist, what you have is lymphoedema.
- A fat female GP said that the NHS had better things to spend its money on than pandering to women who need to lose weight.
- Door te zeggen dat het door overmatig eten kwam en dat ik maar moest sporten (in het begin).
- Jaren geleden ging ik naar de arts omdat ik voelde dat er wat mis was met mijn benen. Moest maar afvallen voor dat ze dure onderzoeken zouden doen. van 2 verschillende artsen gehoord.
- leer er maar mee leven is dikwijls de kreet
- Man soll dringend abnehmen und dann w,rde es einem auch wieder besser gehen.
- meerdere keren
- Have left many doctor's offices in tears because they were dismissive and unwilling to listen.
- Most GP's assume you are obese due to over-eating
- De arts die me slecht behandelde was overigens niet mijn huidige arts en de adviezen over leefstijl zijn gericht op obese mensen. Maar afvallen moet toch wel kunnen, ik ben 40 kilo kwijt en ik zou niet weten hoe ik er meer af moet krijgen.
- Leaving me without treatment. Saying you have to learn to live with it.
- I am at normal weight.
- My doctor didnt have enought knowledge, passed to a specialist and that one was just remove and remove without any info... although a new doc, has worked with patients on the east coast but he has a kind of attitude that it cant be painful etc.
- Being overweight, didn't exactly treat me badly, just suggested weight loss.
- when I was younger I would diet and still not lose weight and I was basically told I need to be truthful with myself... they acted like I lied about what I ate...
- Some g p s just said I was fat and to diet.
- Knee surgeon said couldn't help because BMI was too high = obese=sent on diet and exercise course for 12 weeks. Failed to lose enough for him to help with my badly arthritic knees. Now using sticks & wheelchair.Have a Lot of pain. Unable to walk far even with sticks. Knees constantly give way. Upsetting !!!
- Bij n reumatoloog kwam de ziektegeschiedenis ter sprake en daarmee lipoedeem.

Ik heb toen aangegeven dat ik twijfelde over diagnose en zeer teleurgesteld was over t doorlopen traject en gebrek aan begeleiding en behandeling. Hij werd boos, later bleek zijn vrouw dermatologe te zijn. Na t uitkleden nam hij ook visueel de lipoedeem op op een manier die kleinerend en vernederend was.

- You must do a diet, than you loose a lot of weight in the next 6 month

- Said it was obesity to begin with

- Most of my life I am now 64 ...even a headache was because I was big?

- The first time I went to a GP, I was told "Face facts. YOU'RE FAT. Stop wasting my time and yours and go to a gym." I did and I made myself work. I have spent 10 -15 minutes explaining lipoedema to various hospital doctors, only for them to either offer to refer me to the weight loss clinic, or to say, "I don't know how you can lose weight, you just have to do it."

- mother took me to a specialist when aged 15 because something was obviously wrong he said "of course she has pain she's fat" I didn't have the courage to return to a specialist until I was 23 and then told I had primary lymphoedema the lipoedema was not diagnosed until I was 35

- he said: adipositas obesity due to high calory intake eat less. be more active/exercise more

- not serieus genomen

- Huisarts wist tien jaar geleden niet wat hij met m'n rare benen moest, afgelopen jaar opnieuw gevraagd en doorverwijzing gevraagd en gekregen. Hij kende nu de term en nam het serieus.

- dr Fleur, gespecialiseerd in lipoedeem van de onderste ledematen. Wouw geen papier op maken voor mijn invaliditeit (66%). Moest mijn plan maar trekken, dat ik niet kon werken was haar probleem niet. Wenend buiten gegaan !!!! Teleurgesteld, hebben 4 maanden gezocht naar een dokter, dan drie maanden moeten mijn benen in wikkelen samen met lymfedrainage en dat allemaal voor niks!!!!

- Ik moest 20 kg afvallen, zonder dat de arts keek waar het vandaan kwam.

- In het verleden en recent nog. Revalidatie afdeling Erasmus MC. Ze weten niet wat het is! Ook bij chirurgie en internist. Gewoon minder door het mondje mevrouw.....

- maar zowel huisarts als vatenchirurg noemen het lymfoedeem, ipv lipoedeem, en ik vermoed dat dit is omdat lipoedeem niet erkend wordt door verzekeringsmaatschappijen en zodoende niet vergoed.

- I am not overweight

- Wegen des bergewichts. Da war das Lip^dem noch nicht bekannt.

- Ik heb niet veel overgewicht

- Maybe, but I have not noticed or ignored

- Always been told to Los weight and all fat People have pain

- One said lipedema doesnt exist and that i am just fat

- wel gezegd dat ik een maagband kon nemen, terwijl ik vol met vocht zat.

- i have been big all my life my family doc kept saying lose the weight , you will feel better but all the blood work i had taken came back health normal ranges....

sheesh..... kept getting the same saying..... "lose the weight it will go away"

made my sister very angry ! so search for new doc.... she found dr. swartz of kansas city that was about three four years ago trying to figure out what is happening with my legs i was getting odd shapes my sister search online came across lipoedema and went from there soself taught.... i got help liposuction tumescent to remove

the fatty tissue from my knees that i could walk..... i was fighting to walk i had walk like a duck swadding side to side and now i walk straight forward wonderful

feeling!

- overweight
- Very bad!!
- bij vaatonderzoek niet serieus genomen
- Bullying, harmful, vicious--many.
- after my knee surgery, my chirurg advised me to lose some more weight, just after I told him I had lipodemia and that it would be wise for him to educate him about this because a lot of women with knee problems have lipodemia, wich causes this knee problems. (My sise is 40 nl) This is not really very bog or obese! can you imagine that he said that?! 4 weeks afther tis happened I had a new appointment with him and I had a good conversation about this badly communicated consult.
- My GP made comments about me being lazy at getting rid of my post baby weight.
- Ze kijken alleen naar de buitenkant en zeggen dat je toch maar naar n diëtist moest om af te vallen.ik kwam 10kilo aan dd schijf van 5! En heb anorexia ontwikkeld.
- The question about other members in the family did NOT include males. My 41 y.o. son is TOTALLY disabled with Dercum's Disease.
- specialist eerst maar eens afvallen.u hoeft niet weer terug te komen en een diatiste zei het zelfde
- bij het UWV GOEDGEKEURD VOOR 40 UUR WELISWAAR ZITTEND WERK MAAR 40 UUR IS VEEL TE VEEL
- I had an endochronologist tell me that if I was not so fat....at that time I was 150 pounds, that I would not have any pain. He was an Idiot!
- Too many times.
- Huisarts in opleiding heeft me op mijn verzoek doorgestuurd naar ziekenhuis voor bloedvatonderzoek, bezoek dermatoloog en internist. Toen ik daarna naar lymfdrainagespecialist wilde en om verwijfsbrief vroeg, moest dit maar wel het laatste zijn. Was na jaren er tegenaan hikken nog maar net begonnen.
- I had stand up argument with one specialist who later went away ,researched and then apologised.
- When I tell doctors I have Lipedema, some of them roll the eyes and say that I am just very overweight. When my mom wanted to get manual therapy, the therapits said, they have never seen such a fat person. Also the GP from the health insureance who had to see my mom to allow her a rehab said she was too fat and has to lose 60pounds before he would send her to rehab (when she was in rehab some years before, she ate 1200 calories and gained 3 kilos in one week, she could only eat 800 calories).
- Not my current GP. A previous GP told me that if I was to lose weight my legs would be normal and that there was nothing wrong with them. That I just cheated on diets and that I must be constantly eating to get that big.
- neemt je niet serieus
- Overweight for years
- Dismissively
- Always told to lose weight, eat healthier.
- Before being diagnosed with lypheodema by my GP everytime I went to him with the pains and swelling he would just say "it's because your fat!" The pain was so bad I was on morphine tablets and they made my legs swell more but, when I told the GP that since starting them the swelling has got worse I was told "don't be silly, if anything swelling should have gone down!" Obviously this was all before he diagnosed Lypheodema and before lipoedema was diagnosed as well.
- 18 jaar geleden zei een plastischchirurg, je krijgt na liposuctie alleen nog meer

putten en duiken!

- I am not overweight
- Ik had een tijd lang last van veel braken en de arts vertelde me dat ik er niet zo druk over hoefde te maken want ik had nog steeds een hoog gewicht.
- I was being told to loose weight as I was fat
- I went to a famous plastic surgeon in Vienna, Austria Dr. Milesi. She almost threw me out of her office in disgust with comments that there wasn't anything she could do for my condition.
- Wist niet wat het was
- Many, dr Sarah Kramer was the most hurtful. The last was my cardio dr said my heart issues were from putting so much food in my mouth. Plus Dercums & lipodemia were not factors in heart tissue issues.
- They don't believe you have lipedema and they'll argue.
- toen ik nog geen diagnose had, had ik een slijmbeursontsteking in mijn heup, de internist zei dat ik eerst moest afvallen voordat hij ging spuiten
- Often !!
- Je moet alles zelf uitzoeken en dat is frustrerend. Je gaat zelf steeds op zoek naar nieuwe ontwikkelingen. Je vraagt je huisarts om raad en die weet ook niet waar hij moet beginnen. En soms krijg je wel een verwijzing en soms ook niet.
- Most people associate obesity with stupidity. I had a Gynacologist who always wanted me to believe that Lipoedema got nothing to do with overweight or the form of my legs.
- specialist zij dat ik maar niets moest eten om mijn over gewicht kwijt te raken
- No my doctor is amazing
- i.v.m. kniepijn
- i.v.m. kniepijn
- Heeft vanaf m'n 17-18 altijd gezegd dat ik te dik was en op dieet moest, maar nooit gezegd dat ik Lipoedeem heb. Daar kwam ik zelf ongeveer 2 jaar geleden achter via internet. Ben toen weer naar de huisarts geweest en hij dacht dat het niet zo was, maar wilde me toch wel doorsturen naar de dermatoloog als ik daar op stond. De dermatoloog zei; "Er is geen twijfel over mogelijk" !!. Kortom huisarts weet er niets van...
- An old rheumatologist said to me "we all have fat!"
- De dermatoloog constateerde dat ik "\"rare\" benen had.
- lipoedeem is medisch niet erkend, dat kwam ik bij mijn nierproblemen tegen. ik moest maar wat gaan afvallen zei de arts... hij moest 'ns weten wat ik allemaal geprobeerd heb! maar hij geloofde het gewoon niet. ook niet als ik alles op papier meenam. helaas.
- Ein Gef%flchirurg sagte, jeder Mensch h%otte Schw%ochen. Er k^anne nicht aufh^ren zu rauchen und ich nicht aufh^ren zu essen.
- So many times I can not even begin to tell you..... it is sad!
- I lost alot if weight (17 stone to 13 stone) and went to see a surgeon about removing a varicous vein he told me to loss another stone and tgen ehen I did he said no as my legs were fat and the varicous vein would come back
- Je wordt altijd direct op uiterlijk beoordeeld en de conclusie hebben ze direct klaar, zonder maar een vraag te stellen.
- Mijn vroegere huisarts zei dat er niets mis was met mijn benen. De diagnose was "ieder pondje komt door het mondje"
- I was told that lipodema wasn't really my problem then told that all I need is bariatric surgery.

- One told me nothing was wrong with me and if I lost 60 pounds I'd be fine.
- I was not overweight
- Doctors in New Zealand do not have enough knowledge of Dercums. I have been mildly overweight (74 kg), and since the onset of Dercums I am 95kg. The human population in general including doctors treat people who are obese with disdain.
- I almost died because they attributed all my illnesses to being fat, when it was vasculitis and lipoedema...and they still act like it is my fault.
- Constantly advising to lose weight to help my situation.
- a nurse at my surgery was unsympathetic about my lack of weight loss
- dermatoloog suurde mij weg dat ik gewoon moest afvallen
- Er werd om gegiecheld
- Internist zei dat lipoedeem onzin is en dat ik maar gewoon moest gaan afvallen....
- De arts die dat gaat doen krijgt ruzie met me, ik heb hier niet voor gekozen. Een patiënt met een andere erge chronische ziekte kiest daar ook niet voor.
- Constantly i have to keep justifying that i have a disease and that just because they have never heard of it does not mean it doesnt exist
- heeft gezegd dat ik vreselijke benen had.
- Many times over my lifetime I have been treated badly and told to lose weight and I have been on many diets and pills. I finally got Gastric Bypass Surgery in 2005 which helped a lot in proving I could not lose past a certain point and that my bottom half would remain out of proportion. I have maintained the weight loss after the surgery for nearly 10 years now so it is obvious something is not right.
- Ik voel me ontzettend onbegrepen . Verga van de pijn als ik er kom
- I feel judged and blamed for my weight
- I was told I was sick because I was overweight and that fat people get sick so I should lose weight and I would feel better.
- I was once told, "there is nothing I can do for you short of prescribing duct tape", implying I eat too much
- Moest eerst maar eens afvallen
- Moest het opzoeken wat het was en zijn commentaar was : Vervelend hÈ! Ik zei, verkoudheid is vervelend..dit heeft mijn leven verwoest!
- All my life I have been looked at as being a fat women and told to lose weight I have a phobia of all medical
- Yes severe discrimination during years I was not diagnosed, though in my case they admitted something was wrong and concerned about the degree of hormonal problems and rapid weight gain.
- Niet expliciet, maar je voelt het aan. Eenmaal bij een vaatspecialist: "er is niks aan de hand, u bent alleen veel te zwaar. U moet gewoon 20 kilo afvallen. Hierbij keek hij uitermate afkeurend naar mijn benen alsof ik bij een Miss verkiezing als misplaatste deelnemer verzeild was geraakt. Hij keek alsof hij vies van me was.
- During pregnancy I was told is was irresponsible and being selfish to staff
- Fashion disease, Illusion, lose weight and it gets better.
- eens vroeg een arts me of ik ooit gehoord had van Sonja Bakker en andere dieten. Nou, ik heb alles geprobeerd zei ik. En ik sport me suf maar het hielp niet. Ik had nog geen diagnose destijds.
- Ik ben zelf met de "diagnose" lipoedeem naar mijn huisarts gegaan, met een printout van Internet. Ik ben toen uiteindelijk doorverwezen naar de dermatoloog.
- maar ik heb wel een internist meegemaakt die niet eens wist wat het is
- de huisarts vidn het onzin de neurloog waar ik voor rugklachten kwam evt hernia kwam zei dat ik eerst eens moest afvallen en wat aan die olifant benen moets doen

daardoor kon ik moeilijk lopen

- my GP

- no knee operation because of FAT knees

- Ik heb een nieuwe knie nodig en ik had uitgelegd dat ik het knie gebied niet kon verminderen met een dieet. Toen gaf hij als antwoord dat ik maar een stuk darm moest laten verwijderen, terwijl ik in het verleden al een maagverkleining heb gehad.

- Vooroordelen: teveel gewicht = enkel ongezonde levensstijl

- Ik ben een keer bij een intern specialist geweest voor hulp voor mijn bovenbenen.

In de hoop dat zij lipoedeem konden vaststellen en voor pms achtige en schildklier achtige klachten. Ik werd door de arts (iemand die nog nooit zulke benen had gezien) als een soort curiositeit gezien en ik stond daar maar en hij zich maar vergapen.

Vervolgens werd er weer iemand bij gehaald en ze riepen maar dat het heel raar was en heel apart en het einde van het liedje was dat ik niet minder mocht wegen dan 85 kg. Dan zou mijn middel te slank worden en dan zou ik last krijgen van mijn organen en verder konden ze niets doen. Ik voelde me heel erg naar en bekeken en totaal niet serieus genomen. Laat staan dat ik het idee had dat deze arts wist waar hij het over had.

- i needed full leg stockings because of pain and fluid build up. was told: 'dat moet je niet willen' you don't want that and then got lousy product that didn't work. though it was possible. left it untreated for several years because of that

- Word gezegd dat je vetzucht heb en bekeken op een nare manier

- Mijn vorige huisarts zein niets over hulpmiddelen of preventie ik moest er maar mee leren leven waren zijn woorden

- jaren geleden toen ik nog niet wist dat ik lipoedeem had, heeft een arts tegen mij gezegt: jij hebt ook al dikke benen. Kortom: deze arts wist dus niks van lipoedeem af. Nu achteraf weet ik dat ik het dus al jaren heb.

- De meeste artsen luisteren niet eens goed naar je klachten, hun eerste commentaar is dat je te zwaar bent. Als of je dit zelf niet weet. Alles ligt aan je overgewicht en je wordt niet serieus genomen. Natuurlijk is overgewicht niet goed, maar niet alle klachten hebben dit als oorzaak. Hierdoor ga ik niet of nauwelijks meer naar artsen.

- When I first told my GP I thought I had Lipoedema she looked disbelieving and patronising. She didn't say so but I felt her look said . ."thats just an excuse for being fat"!

- He mildly suggested I just needed to exercise more - when I walked everywhere and played squash and nothing altered my weight!

- yes, was told when my daughter was born that with my level of obesity (undiagnosed lipoedema) I would be dead by the time she was 10 years old

- Heb geen overgewicht

- My original gp who is retired now said that I was fat and had fibromyalgia. That I needed to lose weight.

- For years I was told that I needed to diet, even though I watched what I was eating. I was also very active. But still get told you must be eating to much.

- I am not overweight much though....never been diagnosed by a doctor with lipoedema

- Knee specialist told me to stop making excuses and lose weight. GP told people if I lost weight I would be fine.

- While I was pregnant in hospital.

- Rolling eyes. "If you just loose weight...would feel better." Etc.

- Gave the action insinuating I overeat

- I was being scanned for my veins and the sonographer told me if i wasn't as fat she would get a better picture. I also over heard a lipo consultant call me the fat lady when he asked a nurse to call me back into his room. I turned down his offer of help after this comment. This was Not Mr Munnoch
- Whenever I went to the Dr about a complaint it was always my weight which was the problem.
- I have been gaining weight for years, and all I got was I need lap band surgery, I was told I had to stop eating so much by my dietician and doctor, either of them looked at my body or touched me I have not been examined by them, I was only examined when I was in hospital for Cellulitis 5 times in 2 years
- Always told to lose weight Obese! I could starve and still look obese in the thighs
- I have had a number of specialists growl at me for not losing weight on my bottom and legs, it was obvious it was more going on. I had a gastric band because specialists convinced me I was obese and it was best for my general health. When I failed to lose weight on my legs and bottom , he blamed me.. even though I was not cheating .I never went back I was so upset by his tone and approach.
- constantly be looked at as lazy, overeater, glutton. ALWAYS trying to get me to do bariatric surgery...HEARTLESS!!!
- Many specialists told me to eat less and join a gym. I knew something was wrong but they seemed unwilling to investigate. Interestingly when i was 19 back in 1989 i had a work medical. The female gp examined me and said mine was the type of fat that could not be lost through diet and exercise. She knew straight away but did not give it a name.
- This consultant is no longer in post he had mental health and I have training in this field.. Shouted and screamed at me. Made a formal complaint and he was placed on extended sick leave and then left the Trust. Had problems with my bladder and this Consultant retired!!!!
- My cardiologist mentioned my "obesity" once.
- Before I knew I had Lipedema, a doctor was quite nasty about my weight.
- I lost 160 lbs and specialist said I should have had the skin removed, because I didn't the fat is back. Doesn't believe in lipedema.
- Said the pain was in my head
- I had a doctor tell me to "lose 30 lbs then come back and talk to them" when I went to him for advice for weight-related issues. I never saw that doctor again.
- The vascular surgeon was very rude
- Always about my weight even though I have been on every diet going ...
- Ik heb jaren gewacht op een diagnose, maar ben jaren doorgewezen naar diëtisten, uiteindelijk werd mij gezegd dat ik me niet aan het dieet hield dus wilde mijn vorige huisarts me niet meer verder helpen met mijn probleem.
- Not gp they havnt a clue have told her given leaflets I get most help from my lymphedema nurse who I was referred to by a support group because they kept saying diet exercise more so am so grateful to that lady
- What kind of question is nr 45? If this is a serious survey, you would never write "bullshit"!! And why would a doctor call anything "bullshit"??
- I was told about lipedema 50 yrs. ago mentioned it to a couple of drs. they had no idea what i was talking about so I stopped mentioning it.
- They do not seem to know what it is in America
- voormalig huidarts vond dat de verdikkingen bij mijn leeftijd hoorde
- I feel GPs think everything is down to being overweight
- Ignorant. Skimmed info I brought and refused to believe it. When they do that I go to

their boss.

- Went to an endocrinologist he said I was just obese ,
- University GP attributed everything to overweight
- I was told the I was obese when I only weight 125 lbs. My PCP always tells my to just watch what I eat and exercise
- I was told at 130 pounds that my leg swelling was either fat tissue or water but that nothing could be done. It was likely genetic. Which upset me as I had lost 50 pounds to be so disappointed that swelling never went away. Now I regained the 50 and put on another 50. I am so depressed!
- DID NOT WANT TO TALK ABOUT IT
- Recently went to plastic surgeon Dr. Hanke in Indianapolis for lipo consult. He talked to me as if it had never occurred to me to diet.. and gave me simplistic dieting advice that I tried to explain had never worked for me before. He mentioned that I had some pretty good looks going on but really needed to weigh 145. His dieting advise included eating cheese and crackers as a snack. I have given up both dairy and gluten to help with inflammation.. which I tried to explain but somehow he assumed he knew better than me. For someone that dealt with lipodema before..he seemed to be an idiot.
- First doctor I saw had no idea what I was on about, and but it as being overweight, the only way I got the doctor to refer me was by taking a magazine article in of someone else with Lipodemea.
- Several unhelpful comments about my weight.
- Even after gastric bypass I never could lose the weight in my legs. The swelling actually got worse after the surgery. Another instance I broke my ankle, the ER staff could not believe/understand the size of my legs, as they are quite big near the ankle. Several of the staff had to come in to 'see about' my ankles and make comments about how I needed to lose weight.
- Zeer minderwaardig behandeld , zelfs weggestuurd ach mens dat zijn gewoon vetbulten omdat je te dik bent. Door meerdere artsen zeer slecht behandeld en zeker niet serieus genomen.
- ik word gezien als dikke lui person
- you are f%ot lose weight
- Had vaak met onwetendheid te maken.
- All told me that I was ok, I was healthy, lose some weight and here take this diuretic.
- Al jaaaren zegt mijn huisarts : tja afvallen he, en zij vraagt al 10 jaar : heb je al gefietst ?? Nee dus
- In het LUMC ziekenhuis denkt de internist dat ik obesiatas heb in plaats van lipoedeem. Hij weet niets van de ziekte. Verwijst me naar een dietist.
- Yes, I look like I'm very out of shape. It's so sad!
- A vein surgeon told me I had lymphedema and to just put on my compression hose; that I was lucky I didn't have cancer
- Told me to lose weight. Said most people had swollen legs in the heat. Gave a prescription for stockings but I cannot wear regular ones, they cut into my ankles
- Complaining about leg pain was told it was because I was fat.... As if fat people deserve a life of pain.
- Several drs said i just needed to lose weight. I have 40 lbs from upper body..my bones show up top no weight loss waist down. Ive have doctors say its lymphedema. That i was an odd case. That this was my cross to bear. To exercise. Ive been called fat but only butt down. Ive been told i dont know.

- Overweight
- Dr. Lee an E.R. doctor at St. Alphonsus RMC in Nampa, Idaho USA
- Generally the first thing I hear when I visit a new GP is that I must lose weight; if I did, everything would be better.
- I had a liposuction
- My vascular surgeon told me it is a neurological problem (I was app. 16 years old, my calves were not so bad like it is today). My neurologist told me the same - it is a muscle (neurological) problems..like cramps or something like that
- Didn't know about it and didn't care, different doctors different attitudes but none were interested in helping. In 25 years not one doctor ever mentioned this disease, asked every new doctor I had, most just said I needed to lose weight or exercise etc got down to 58kilos (I'm 165cm tall) and still they didnt know what the problem was.
- every GP i have ever seen has said you're just fat loss weight, go to the gym, diet change, take this pill... it wasn't until last friday that i meet a GP who cared enough to help me ...
- I would like to comment on all of the questions which refer to whether a GP diagnosed me: No, but once I saw a dermatologist (age 30) because I notice my ankles had thickened, my skin felt rubbery, there were sore fat lumps on my calves, and my legs were swollen even though I had just slimmed down to skeletal 52kg (I'm 168cm tall). I didn't know about lipedema then - so I had to do with my dermatologist's diagnosis: "you're just getting old" :O
- before age 55, no one told me i had lipodema, since i was diagnosed my regular doctor had never heard of it,
- Told me I was obese, told me I was overweight.
- Although my legs were heavy and disfigured, painful and often cramping uncontrollably, I was told by EVery doctor To "just lose weight.". When I tried to tell them nothing changed my legs, they were dismissive. " lose weight " I lost 50 pounds and my legs got worse and my weight increased.
- I was thin/fit/healthy before I had Lyme (with the exception of gaining a little bit of weight during college). When I got Lyme, I developed a thyroid problem and the lipedema became worse. Many docs thought I was overeating and didn't believe me. Mostly endocrinologists.
- myself and my husband are furious with the medical community and its unwillingness to learn about lipoedema. i found something that works. to get rid of the swelling. and i need a way to inform doctors who care about it. it doesnt cure it but it removes the fluid. and allows the legs to function again.
- Until diagnosis from Dermatologist, I was told that I was told being overweight was the cause not the effect.
- He kept saying "lymphedema" throughout my clinic visit. I had to correct him about 3 times until he finally said he didn't know what lipedema was. Yes he did talk about a weight reduction program. He did offer compression stockings but, neither him nor I knew if they would work. I didn't get them.
- Ik moet maar afvallen, dîten
- said in a laughing way that I didn't have venous insufficiency but just had mild elephantitis and could wear compression stockings and staff off my feet.
- I went to a vascular surgeon because I suspected something was wrong and he told me I should not try to "be perfect" and just diet and exercise more. :-(
- Endocrine (more than 25 physicians in 10 years) diagnosed obesity and always give me their diets, then accuse me of not following their instructions when diets do not work even though the follow scrupulously for months or even years

- A GP literally shouted at me to lose weight when I went for an emergency appointment in severe pain and told my health problem was my own fault. Four hours later a different GP had me admitted to hospital with cholecystitis.
- not sure yet
- Doctor that was diagnosing my fibromyalgia thought weight was cause of all my problems
- Longarts bij diagnose trombose met massale longembolien. Kwam door dik zijn en slechte conditie terwijl dit niet zo was.
- He said: that's the way it is, stop nagging and suck it up
- heb ik ook al jaren dezelfde arts die ik bijna nooit zie (1x per jaar met de griep prik)
- Never been treated badly, they just don't say much at all. They clearly don't know how to treat the condition Never been given any dietary advice or lifestyle advice.
- Because I had fat legs when I had treatment for varicose veins.
- Went to GP on three different occasions. On first two the GP advised either to stop standing for long periods then to stop sitting for long periods. It was only when I realised what the problem was that the GP looked into it
- When my legs first started to get big I had them photographed by an endocrinologist at the hospital where I had my transplant. After seeing the photos which were all professionally taken in a studio he told me that he couldn't help me but was going to use my photos in lectures. Others have just said it is something I have to live with. Easy for them to say.
- altijd dat ik teveel eet en weinig beweeg
- I have been trying to get my GPs over the years to recognize that my legs were "not right" . I was constantly referred to nutritionists, dieticians, gym memberships. one doctor told me that he had another patient who "also was not careful about her weight and her legs had also broken down" He told me nothing could be done, my fault for over eating. This was in 1996. In 2002 saw the female doctor in the practise and expressed my frustration by confessing a fantasy of taking a very sharp knife and cutting off the excess fat of my legs. She offered me Rx for anti depressants and helped to get me fast trackex for Roux n Y Bypass (July 2002 Mass General). I did Not get the Rx filled-knew I was not depressed. at 360 plus pounds, my surgeon said that I was heaviest patient he had ever performed bypass laparoscopically because I had such a "slim" midsection. In 2006 My legs, after initial small decrease, began to increase in size. I made appoint with same surgeon and asked to be "zipped out of fat suit" from my hips to ankles. He referred me to yet another Harvard professor-plastic surgeon. I used the term 'lipedema' at my appointment with her and she was VERY strong in her reply "there is no lipedema only lymph edema". She told me to call a massage therapist. Spoke with massage therapist who could not treat me because I had no Insurance.BUT she directed me to check with private clinics in Florida and Chicago area. She told me she had best training in world at Foldi clinic. When she told me about Foldi clinic in Germany, I contacted a close family friend, himself a surgeon in Germany and he set up my appointments and doctor visits in Germany to get diagnoses and opinions on treatment.
- Keeps telling me to get gastric bypass or wants to prescribe weight loss drug Qsemia. Doesn't accept that lipoedema is legitimate - still acts like I am making excuses for being obese despite telling her about diet and exercise.
- My original GP, and 2 cardiologists treated me terrible because of the lipedema & tried to belittle me into having gastric bypass surgery. I knew eating wasn't causing my obesity because I've attended 15 different courses in nutrition and healthy eating/weight loss, AND bought their books AND follow their advice, and have been

on a 700 calorie diet for 6 months on the advice of my cardiologist - and gained 25 pounds while on that 700 calorie diet. I kept food journals, weighed my foods, and met with a registered dietitian. My doctors accused me of cheating. I became so discouraged and angry that I quit going to the doctors for about a year. Found a new cardiologist and GP, who, although they don't know much about lipoedema, at least believe that I have it - it's pretty obvious when you look at me, my whole body & legs and feet. It is very difficult to be me - to live my life because of this problem, and if it continues to get worse, I don't think I want to. I am a very nice person, and very smart, and I treat people with compassion always. It is worth keeping me around - my life has value - I'm just suffering terribly because of this disease and I don't know what to do.

- When I had gastric bypass, the doctor treated me like I was fat and lazy. He told me to lose 15 pounds before the surgery.

- I was always treated as an obese patient and told repeatedly to diet, also told I wouldn't have a long life with my weight! I'm now 68 so up them...did better than they predicted! Medical profession years ago were mainly barstards to me!

- They have been rude, refused to look at or touch me. Described me as grossly deformed. Have told me I am obese. Have refused to look at papers describing lipodema. A surgeon refused to believe it existed and treated my knees incorrectly, causing lipoma underneath and for 3 years since I can't walk. Not interested in follow up, sent other doctors to talk to me. Blamed me, it is your own fault, you are fat.

- Until I received a diagnoses of lipedema in my 50's no physician had ever been able to identify the problem and always made it about being overweight- but losing large amounts of weight never changed the proportions of my lower body

- Mijn oude huisarts gooide al mijn lipoedeem klachten (ik wist niet dat ik toen Lipoedeem had) op mijn overgewicht, van een ontstoken galblaas tot een keelontsteking.

- They say that I need gastric surgery to lose weight.

- Dismissive. Usually told to just lose weight.

- Endocrinologist said it was just the way my legs were. nothing is wrong with them

- Doctor was rude to me and made offensive comments to me about my fat legs, saying I did not exercise enough or eat the right foods. Told me fat cannot hurt on me, and told me I bruise because I am clumsy.

- Many many times from the time I was young.

- I have a natural fear of doctors due to the constant shaming by them about my weight. No one understands this condition, and I have yet to find a knowledgeable or compassionate doctor in a big city like Chicago. I have felt so hopeless.

- i leaved in the UK for 20 years and the GP kept trying to get me in a healthy diet (which i already was) and simply did not believe i was eating little and exercising. so i was always treated as i was a liar.

- Before knowing I had Lipedema, all doctors would tell me I HAD to lose weight. I would diet and lose weight from the waist up, but never from waist down. They always said I was still eating too much or not exercising enough. I used to walk 4 miles a day!! Those days are gone.

- No one, for years, knew what it was. Originally doctors told me it was growing pains, then as I grew older, it was a mystery that no one could figure out.

- They told me I was not telling the truth about how much food I ate and how much I exercise.

- They are ignorant of the disease and say i am just too fat.

- I haven't seen my GP since being diagnosed, but I feel he will be supportive.

- No matter the complaint/illness, doctors always blame it on the "obesity".
- No but assuming their lack of knowledge weight loss was a recommendation for all my illnesses. I now know why I have been a sick kid and adult with a lymph system like mine WOW
- Al jaren onder behandeling van specialist in academisch zkh, aldoor gemeld en verzocht om onderzoek dikke benen. Niet serieus genomen, ik moest stress verminderen, echtgenoot, spataderen zijn diverse malen operatief behandeld, regelmatig mislukt. Ook reactie dermatoloog in ander zkh, dat behandeling geen zin had met zulke benen. Later bleek dat hij in het verslag wel lipoedeem had genoemd maar, Niet voldoende?, tegen mij. Op eigen verzoek naar NySmellinghe gegaan waar diagnose volgde.
- Bij vlagen soms een jaar last van knieën. Dan weer jaar niet. Ooit naar specialist geweest die zei, mevrouw heeft zwaar overgewicht en dus versleten knieën. Onzin want ik heb tussendoor ook jaren geen last. Ben er ook verder niet meer heen geweest.
- Told I did not diet correctly
- A consultant and an intern refused to recognise Lipoedema. The consultant wouldn't refer me to the lymphoedema clinic for an assessment for MLD as 'they don't treat people with obesity problems'.
- I went to see a doctor to get diagnosed with hypothyroidism. She accused me of being a fat hypochondriac, without actually saying those words.
- GP told me to use Google to find out about Lipoedema and treatments. When I asked for advice she just told me to try a holistic approach. But not spend too much money on different treatments. I was left to look up treatment options and make my own decisions.
- Ik kwam voor galstenen bij een internist die het alleen maar over mijn gewicht had.
- Drs in the US now days seem to think gastric bypass is the cure for all fat problems. Most GP's have no idea what it is and do not care to know. It's a shame because young girls will suffer the mental anguish and blaming themselves. I know I did. Never wearing shorts or dresses, god forbid a bathing suit.
- Most just say eat less exercise more and everything will get right diet they recommend is usually a low carb diet
- One told me that I should go to weight watchers, another said I was lying about exercising, I asked a third why, if I exercise and eat right are my legs so big and she looked at me and said "some people are just meant to be pudgy" she used the word 'pudgy'
- Te dik en lukt niet af te vallen
- It has happened several times, and I've been told to take the diet more seriously.
- One day he says: I am skinny I am so lucky. ? Make me feel worthless, and he doesn't know about lipoedema.
- The last time I saw a doctor about my legs, he said I was built for the fields!
- All he ever does is increase the dose of the water pill which pretty well confines me to the house.
- Just didn't take it seriously, told me weight gain was from menopause.
- All but two doctors that I've gone to in my life treated me TERRIBLY because I was overweight. They would automatically assume that I'm lazy, sloppy, stupid, and undisciplined. I have an IQ of 145 and a 3.8 cumulative GPA as an Honors student in college. I'm a member of Phi Theta Kappa International Honors Society and leader of my college's Student Senate Committee- and I'm in my mid-thirties! I presented at an Honors Conference with a solo project as a freshman, and have two more coming up

in the next few months (I'm a sophomore now). I assure you that I'm none of the things those doctors believed me to be, then or now!

- Incidences are too numerous to list.
- Internist vind het geen duidelijk lipoedeem endrocrimologe Vond het wel maar die heeft afgehaakt huisarts heeft nooit 1 mening .
- so many times I cannot remember
- Specialist gave no sodium, low fat, low carb 500 calori per day diet for 1 year. I gained 5 pounds. He said I did not follow the diet. He knew this because if I did I would have lost weight. He told me he was sorry I wasted his time and please get out of his office. He would not be seeing me again.
- My GP said I was just overweight and should exercise and diet - even though I already did this on a regular basis. I had to ask another GP to refer me to a Lymphedema clinic for diagnosis.
- being over weight
- Culpabilising about my obesity. I've lost 18 kg in the latest three years. Now, my BMI is 31. I realized about lipoedema when I began to have knee problems in one leg after menistectomy. I did not know about the disease, I thought it was simply obesity, but I realized it was lipoedema because of fat in upper legs worsening my knee problems. I did not care before because of breast cancer.
- Told me that since I was not employed, there was no excuse in not working out (exercising) eight or ten hours per day. The doctor who delivered my son told me that if I didn't lose weight, my son would never love me.
- Initially before i reasearched and found Lipoedema i was told for 10yrs just to exercise to lose weight
- accused me of overeating and laughed when I said I don't
- Living in Japan, I walk several km a day and live a mostly healthy lifestyle. A GP in Texas told me that 'I couldn't be doing what I said I was doing, or I'd be thinner. Stop lying to him'
- Dermatologist said I was just fat when I was sent to him about lipedema. ER physician said I had "Massive Legs!!" At 58 years of age, some finally told me and it was an advanced practice nurse
- All the time, for having big legs, lipomas all over my body. Was told I was a drain on the NHS, felt very humiliated.
- I was told by a previous GP I was fat and needed to lose weight and didn't believe I worked out or dieted.
- Dr. Just gave me a strange look when I mentioned lippoedema that's what the dr, called it 40yrs. Ago only a plastic surgeon in Burlington,Vt. Told me that's what I have and I would have to live with it.
- de huisarts niet, de specialist in ziekenhuis gaf me zogenaamd advies: mevrouw ik raad u aan om niet verder aan te komen! kwam er best wel bot uit
- have not seen a doctor about it
- multiple doctors told me I just needed to lose weight and the vascular specialist whom reviewed my doplar that was negative for vascular issues said that it just is the way my legs look now and pretty live with it
- i recently had a investigation. They did not know. The women who gave my my socks told my yesterday.
- Mijn oude huisarts was er van overtuigd dat met minder eten en meer bewegen het gewicht en omvang wel minder zou worden.
- Mij glashard gezegd waar assistenten bij waren je bent gewoon te dik als je niet te veel vreet gaan de dikke bulten van zelf weg.

- arts in Drachten Nij Smellinghe
- Krijg geen knie prothesen omdat mijn benen te dik zijn
- Maar mijn diltiste was negatief over een dieet die bij mijn tante en haar lipoedeem (overgewicht hierdoor) geholpen had.
- They don't give help because they say I have to lose weight first.
- just do not recognise condtion
- Several doctors chalked my issues up to being obese and said it was my fault for not eating right and exercising.

Statistics 47 : Do you, are you

	1) Yes	2) No	3) Sometimes	4) In the past
47.1 Wear compression stockings (flat knit)	37.22%	45.57%	11.74%	5.47%
47.2 Wear compression stockings (circulair)	24.08%	59.60%	10.19%	6.13%
47.3 Taking birth controle pil	15.95%	62.19%	0.52%	21.34%
47.4 Eat meat	78.95%	4.95%	14.55%	1.55%
47.5 Eat vegetarian	18.83%	59.08%	20.24%	1.85%
47.6 On a diet	38.85%	37.37%	17.87%	5.91%
47.7 Having a eating disorder	12.41%	75.70%	6.20%	5.69%
47.8 Have also lymphedema	41.43%	51.48%	6.35%	0.74%
47.9 Easily depressed	40.25%	37.30%	19.94%	2.51%
47.10 High sensitive	55.54%	28.29%	15.07%	1.11%
47.11 Manuele Lymph Drainage (MLD)	39.66%	44.09%	7.09%	9.16%

Statistics 48 : How would you describe, define the Lipoedema fat (feels like)

	1) Beans in a bag /	2) Styrofoam balls in a bag	3) Soft, smooth	4) Bubbly
48.1 Arms	19.87%	13.00%	46.97%	20.16%
48.2 Legs	26.07%	20.83%	15.88%	37.22%
48.3 Buttocks	18.61%	19.72%	25.41%	36.26%
48.4 Tights	19.20%	19.20%	28.88%	32.72%
48.5 Belly	12.70%	14.40%	48.74%	24.15%

Statistics 49 : Are you on a diet (or have been)

	1) No	2) Yes and it worked	3) Yes with temporarily	4) Yes and it never
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			result	worked
49.1 Low fat	39.04%	11.47%	26.18%	23.31%
49.2 Low carb	35.96%	22.57%	27.94%	13.53%
49.3 Paleo diet	86.32%	6.54%	4.19%	2.94%
49.4 HCG diet	92.13%	1.54%	3.53%	2.79%
49.5 Modifast	86.18%	2.13%	7.13%	4.56%
49.6 Weight watchers	56.76%	7.50%	23.53%	12.21%
49.7 Gluten free	78.82%	9.41%	5.74%	6.03%
49.8 Vegetarian	81.32%	6.25%	5.07%	7.35%
49.9 Atkins	74.85%	6.47%	12.79%	5.88%
49.10 Cambridge diet	89.85%	1.76%	4.71%	3.68%
49.11 No suger	61.69%	16.99%	13.31%	8.01%
49.12 Low processed foods	59.85%	20.44%	10.88%	8.82%

Statistieken voor vraag 50 : Do you have a (national) health insurance

Yes 83.58%

No 16.42%

Other answers:

don't know, just NHS

Public hospital

Private health insurance

Private insurance

Private self-paid insurance

I am on disability with medicare, medicaid

I have Medicare and a supplemental insurance.

Because I am on Social Security Disability, I have Medicare, and also have Medical Assistance (from the State)

Medcare

Private medical benefits

yahhh, health care mess, who knows.

N.H.S

Yes, Nr.49: I eat vegan.

Doesn't mean I can get any treatment though.

International private insurance in Sth korea

private insurance

Private health insurance bcbs

UK NHS

Self-paid private insurance

I have the Austrian WGKK and I work for the UNITED NATIONS and have their insurance called Van Breda who has denied my treatment (2 operations liposuction

for 12,000 Euros).

Just started & I have Medicare & Medicaid. Nothing but massage drainage is covered & only 12 physical therapy visits. The poor must just suffer in the USA

Private

State insurance

vraag 49. Ik ga binnenkort beginnen met het dieet van Yvonne Van Stigt

(koolhydraatbeperkt/ oervoeding/ paleo)

Medicare

i don't now

Medicare which won't pay for treatment.

UK National Insurance

nhs

Medicare, Medicaid

Private usa

Medicare in my case

medicare just started

Private insurance (usa)

NHS not private

Policy through the Affordable Healthcare Act Exchange

Not sure, we have Tricare through the military

State employee plan

on Medicare

I'm non Australian citizen => different right to resident. Have to pay for lot of treatments myself.

lipoedema not covered in Australia. my Dr needs to say it is lymphoedema to get cover

Medicare Tri care

Through my job

Medicare and United Health Care Supplemental

bupa

Private health insurance through my employer

NHS

on

medicare advantage plan with drug plan

n.h.s

aansluiting mutualiteit en hospitalisatieverzekering

Health insurance through employer

I have insurance through my job.

Thru my husband's job as a teacher

Through husband work

Regular

HMO

Medicare, government ins

Affordable Care Act; have private insurance thru employer

we have a national health plan supplemented by my husband's excellent health insurance through his employer (he is retired)

group from husband's job

didn't understand question, i do have insurance

bcbs ppo

private health insurance through my employer

.
 Not sure
 medicaid at the moment. new GP and he has never heard of lipedema
 I have employer provided health insurance HMO does not cover the lipoedema
 doctors in the US and there are none in my city.
 have medical insurance through my work
 National health service.
 I don't know
 I have insurance through my work.
 private health insurance - but treatment too expensive still
 I have health insurance, but I live in America, we have all different types of health
 insurance. I do have good health insurance.
 Ik ben niet op bovenstaande dieten maar meer gezond verstand eten...
 Medicare
 Self
 medicare
 Medicaid. My husband lost his job and we lost our good health insurance.
 Champ VA
 I'm in America. I have health insurance.
 I have private pay health insurance, Blue Cross Blue Shield, not a national or
 socialized health plan
 employer insurance
 B.u.p.a.
 B.u.p.a.
 B.u.p.a.
 B.u.p.a.
 I have insurance through my former employer: retiree insurance
 bcbs through husbands employer
 I have private insurance (Aetna)
 partial
 I have government insurance
 In japan I do, but in America I do not
 I have insurance through work
 nhs
 Private health insurancr
 I'm living in Australia but I'm not Australian. Will have to wait another 2 yrs to have it
 Mericare, USA
 NHS

Statistics 51 : Does the insurance cover:

	1) Yes	2) No	3) Partly	4) Inapplicable
51.1 MLD (manuele lympe drainage)	37.47%	28.21%	15.21%	19.10%
51.2 Compression stockings	46.14%	26.23%	13.96%	13.67%
51.3 Liposuction	4.11%	66.57%	4.63%	24.69%
51.4 All medications	31.01%	27.19%	18.96%	22.85%
51.5 Home adjustments	8.45%	42.10%	9.85%	39.60%

Statistics 52 : Did Lipedema change you personality

	1) Yes	2) No	3) A little bit
52.1 More lonely	39.18%	40.50%	20.32%
52.2 Easy depressed	40.87%	34.41%	24.72%
52.3 Quickly angry	27.88%	50.84%	21.28%
52.4 Sensitive	55.83%	24.14%	20.03%
52.5 Cry more	37.12%	44.90%	17.98%
52.6 More fearful	31.77%	52.75%	15.48%
52.7 Inferiority complex	51.65%	27.37%	20.98%
52.8 Stay more at home	51.80%	33.46%	14.75%
52.9 Always think about Lipedema	43.87%	26.63%	29.49%

Gegeven Toelichtingen

- Worry about my daughters getting it also NEVER go to the swimming pool and have not worn shorts in the summer for many years
- Makes me feel less feminine.
- I found out I ha Lipoedema by accident...I believe I have had it 25 years without diagnosis and have no idea how much I have limited my life because of it. One of the biggest concerns was I had to give up my hobby of flying gliders as I am too big to do it now and breach the weight restrictions. Also I do not have partners.
- It makes you feel self-conscious and ungainly, even at stage 1.
- Actively trying to improve the lipedema community
- Je vind jezelf niet mooi
- It's hard for me to sit up. I am most comfortable lying down.
- het heeft me ook sterker gemaakt
- Keeping myself able-bodied and functioning is a full time job.
- I am an extrovert, and am one to take action. A lot of times I get angry that people don't understand - sometimes, it makes me want to work harder. Also, I have had lipedema since age 11, and was 11 lbs, 15 1/2 ounces when born, so I guess I have always lived with being fat. Maybe I get more upset about it than I admit, it's just that I am so used to lipedema that it is like a different kind of normal than others.
- ikvoel me dikwijls minder dan anderen, terwijl ik toch veel bereik, en gemotiveerd ben in anderen en mijn werk. Cijfer mezelf veel weg, niet graag in mensen massa s. Graag buiten in de natuur en aan de zee in de wind,.
- Lipedema has taken away some of my independence.
- There was an adjustment period after getting diagnosis. I was upset when I was diagnosed, being told there was nothing that could be done. I don't believe that any more. I know help is out there and we're getting more help every day.
- This pasted 5 years i have had complete life style change due to this.. Fron the pain, the inabilities, and even the clothes that can and cant be worn et. physical contacts..
- I used to be outgoing and now I can't get out as I need an electric wheelchair and can't afford one and I can't afford to have my house remodeled to accommodate

me... very depressing

- I am by nature a positive and optimistic person. But this condition and society's judgements of obesity can wear you down, and cause you to pull back from social engagements without even realizing it...

- I feel blindsided and betrayed by my own body. How sad I am to say "I wish that I was just regular fat. People hear the words "Fat Disorder" and I feel that they tune out. I wish for more education for medical professionals as well as the public. And groups open to discussion in person. I am afraid of what the future holds for my body and if I have passed Lip to my daughter. Just saw a new facebook page for the later stages of Lipedema. I like this option as all people diagnosed do not face the same challenges. A facebook page is one way to connect, however many great things are said but they are lost due to the many next postings, unless someone saves them to the files. In the USA, is Dr. Karen Herbst really the ONLY doctor who can or is willing to treat Lipedema?

- je denkt eraan vanwege het ongemak

- Ge bent beperkter wat daarmee je levensstijl beïnvloed. Je moet keuzes maar ivm je gezondheid

- C

- Ik let altijd op benen. Als ik in de spiegel kijk, kijk ik het eerst naar mijn benen of ze misschien iets dunner zijn geworden. Ook bij anderen let ik vaak op de benen,

- I naturally have a very outgoing personality, but lipoedema has limited every area of my life, either because I'm unable physically to do what I want to, or because I would have to wear clothes that revealed it (e.g. swimming). There are times it affects me more than others. I still have an eating disorder and I have had 6 lipoedema induced suicide attempts. I had a traffic warden insist I wasn't disabled. He laughed and pointed at me, got his colleague to laugh at me, and in front of my whole street, he called me a fat freak. I used to live next door to a pub and the customers (male) used to yell out to me when I was on my mobility scooter, "Fat bitch on a scooter, coming through!" It gave me agoraphobia for a while. I used to get upset as I'm not fat, I have lipoedema. Now I realise the problem is fat-shaming and bullying. The one that upsets me the most is when we (and overweight people) try to feel good about ourselves, there will be loads of people saying we're not 'healthy'. They don't care about us, it's just another way of bullying by trying to make themselves look good. We know how we look, we don't need others to point it out. As I couldn't lose the weight by dieting, every time I was humiliated in public, I would go home and cut my arms with a razor blade to punish myself.

- ik voel mij niet 'vrij '

- In het begin gold voor alle punten ja!!!!

- Verergering na zwangerschap heeft zelfvertrouwen deuk gegeven

- Depressief: vroeger, ook angsten, grote onzekerheid, dwangstoornis en niet assertief zijn en minderwaardigheid complex (kan ook komen door traumatische jeugd en op mijn 43e PTSS was toen al in de overgang/menopauze en ik dacht dat het hierdoor erger was met de deprssiviteit (suicidedgedachten en daden).

- Since liposuction I'm lots more selfconfident!

- Voor de diagnose wél. Verschil met daarna is dat ik toen aan de slag gegaan ben met oedeemtherapie, hormoonbalansdieet en meer hardlopen. Nu ben ik meer dan 5 kg afgevallen, heb ik bijna geen pijn meer aan mijn benen, zien mijn benen er veel beter uit En zit ik veel lekkerder in mijn vel!

- durf niet in een badpak of jurk,rok, schaam me voor mijn lichaam

- i am adjusting to new lifestyle working on improving myself in good walking trying

to rid excess weight ...

- Isolated, heavy depressed, relationship problems
- I always had large thighs from puberty, hated how I looked and had to wear clothes to hide it. I have never worn a pair of shorts in my adult life.
- I do not like to go out in public - people stare at me and I look like a freak. If I were just fat it would be one thing but my legs look like a bunch of balls of different sizes all glued together. They are not shaped like human legs.
- I am not sociable anymore.
- Pain changed my personality more than anything.
- Being diagnosed gave me an explanation for my deformity - I went through Weight Loss Surgery and losing over 100kg before being diagnosed, I was over 30 when diagnosed and have carried the signs of lipoedema since before I was 10 (photos depict this) - the answers to the questions I answered with the mindset I had before diagnosis and diagnosis lifted a huge cloud from me - though I still carry a lot of the issues x
- I cried when diagnosed with lipoedema. Was brave with cancer and open heart surgery. Lipoedema the cruellest.
- Felt I had to reassess what u would wear
- Ik weet nu dat ik lipoedeem heb, het heeft een naam gekregen. En dat is fijn. Ik ben niet een zwakkeling, omdat ik niet kan afvallen. Ik heb een ziekte.
- I am 40 now. But when I was a teenager I HATED myself and my legs sooo much. I remember thinking that if I was ever raped, that would be ok but the worst part would be if the rapist saw my ugly legs. This shame is not normal. I have lived with this for 30 years!
- Always in pain & lost my finical & physical independence. I feel I'm a burden on society & am angry I must suffer pain with out hope of getting care.
- Maakt heel onzeker, naaste omgeving reageert gelukkig wel met begrip.
- I have the stigma of being very fat.
- None
- Mijn mobiliteit is beperkter geworden.
- De pijn/ongemakken bepalen alles wat je doet, de hele dag door wordt je ermee geconfronteerd.
- I feel stupid fat and ugly, and I wanted to kill myself because no one took my disease seriously.
- Try to keep my mind off of it as much as possible so that it does not control but I control it.
- Ik wil controle over mijn leven, en niet dat mijn lipoedeem mijn leven gaat regeren. Misschien dat het in de toekomst anders wordt, maar denk niet dat ik in 'negatieve' zin ga veranderen. :)
- It bothers me that clothes are a little bit difficult
- I suffer from anxiety, depression and panic due to other things in my life but it is made worse by Lipedema because i can't do what I want to do and feel isolated. I do not think about it much or feel bad about myself because of it..I feel vindicated since I know what it is as I always knew something was not right. I do not hate my body or myself like some and I am not obsessed with it. I would love to have liposuction to get rid of it so I could get around better and not have the pain and pressure. I refuse to give in to the whole thing..I waste enough of my life dieting and feeling like a failure..I eat for nutrition which is the result of the Gastric Bypass Surgery.
- I have never been able to move like regular humans do - to dance, sports, nature hikes. I feel like I have missed out on life. I feel like an alien at times when I watch TV

and see the "normal" people run on their little legs. I am nothing like them physically.
- I have Aspergers but I know the severe obesity and body problems impacted me in a very negative way.

- Nu ik weet wat het is voel ik me juist sterker

- Het positieve was wel, dat ik eindelijk wist wat er met me aan de hand was/is.

- I feel like my life is over and I have no future.

- Het lipoedeem in mijn heupen heeft er vooral voor gezorgd dat ik rot opmerkingen kreeg op straat of sexueel getinte aandacht van mannen. Die ik niet wilde. Hierdoor kom ik na 21.00 niet meer in mijn eentje buiten, ga ik niet naast een man zitten op een bankje buiten bij bijv. bushalte of trein. Ben ik als ik uit ga altijd op mijn hoede wie er in de buurt staat omdat mensen bij wijze van grap aan mijn kont moesten zitten. Ik voelde me niet mooi en was boos op hoe ik eruit zag en dat ik er niets aan kon veranderen. Het heeft ervoor gezorgd dat ik me ben gaan schamen voor mijn lichaam en dat ik nooit meer vrij kon bewegen omdat een ander er altijd iets over te zeggen heeft.

- Ik dacht dat het gewoon mijn bouw was.

- insecure, difficult to be motivated to try therapy since it may not work and very CONFUSED about information, diagnosis and what to do.

- Angst voor toekomstig uiterlijk en fysieke klachten -nu nog minimaal

- Hopeless Ugly

- kan moeilijk lopen dan zeg je vaker nee

- At first it did, but I have gone back to myself. I don't have confidence like I did, and never impose myself onto any one.

- At first it made me really sad. I felt like there was no hope for my future and that I would lose my ability to get around. I then found out that there was a difference that people like me could lose some weight and started changing my mindset of what was going on with me. I started working out even when I didn't feel good enough to. I started moving more and that really helped me a lot! When I started losing the weight it made me have less pain and pressure. I am still very sensitive to anything and can't always wear my compression. It hurts my legs to wear the thicker compression, so I wear some from the athletic store.

- I won't wear shorts or skirts or swimsuits in public if I can avoid it. My legs shame me.

- I have a house on the beach and I do not want to go, because I do not want anyone to see me in swimsuit..

- You wonder about how different your life would have been if you didn't have this condition or if it had been diagnosed earlier

- Since being involved in LASS and meeting others with lipoedema, I cope very well.

- I'm obese, that affected my self esteem more than lipoedema.

- Psychological reasons i dontvtell people as i fear they wont believe its an illness relationship confidence is a bigg issue, not feeling or llokibg nice in any outfit.

Sometimes i dont go out due to body confidence.sillmess

- I don't really think about it . I decided in my teens this is not a dress rehearsal this is my life I can cry about my body or be happy and just love it , it's the only one I got so I'm happy . The depression I feel at this time is due to the sudden loss of the love of my life , my husband of 39 years 7 months and 17 days . The last 2 months and 7 days are very depressing

- Ashamed of my legs

- Has changed the course of my life for the worse and made me so depressed that I didn't leave the house for 3 years between 2001 and 2004

- Poor body image - think it is most unattractive to men and unsexy
- I am more outgoing now that I am retired. I am physically less tired after being retired for 6 months. I am happier now.
- I have spent over 50 years hating my legs and having an inferiority complex because of them, without being diagnosed until recently. That's 50 years of self-loathing for something I didn't cause through over eating or laziness
- Can't begin to describe how profound the effect is it has had on my life.
- Embarrassed never wear shorts or a swimsuit. Avoid exercise in public places
- Always feel guilty and inferior. Missed a lot of quality time with my kids, low energy, low self esteem, couldn't move properly, balance was thrown off. The list goes on wouldn't be in pictures and hated being in public. I could cry thinking of wasted time worrying about what others thought or how I looked.
- Low self esteem affected every life choice i have made. There is no area of my life unaffected.
- I feel like I can never wear shorts, tank tops, or skirts in public. I love the beach and the pool but fear going to them due to people staring at my arms and legs. It makes you very afraid to go out in public.
- makes me very angry that it has taken 75 years for the American medical system to embrace and learn about it. I have been talking to MDs about it since I was a teen and never got any satisfactory answer. Here I am now, 60 years old and post menopause and losing weight is very very difficult.
- It's so sad there's nothing that can be done. Puts you into a very depressive state especially when everyone around you has beautiful legs...and you can't find anything to wear! It's maddening! =(
- I am very self-conscious of my legs
- Embarrassed to wear shorts, dresses, anything that shows ankles..
- Ive missed out on 12 years of experiences for fear of being made fun of and talked about. I recall when i was younger asking why couldnt i just cut off all the ugliness of my legs
- More insecure of myself, feeling more ugly and undesirable
- Just self conscious about my legs and arms
- Always worry what others think
- Not wanting to strip off in public i.e. Beach, swimming pool etc even though I love those places
- It stops me doing things that will involve me exposing my legs, I will not do it. Do not go to the beach, wear shorts, short skirts etc
- I feel I've always been ashamed of my body to some degree, and regret not being able to have fun swimming with friends. Especially as a teenager and young adult, my shape interfered strongly with my confidence to approach the opposite sex. I also overheard comments which made me sad.
- Only recently learned of lipodema and personality already very entrenched.
- To the previous question, I haven't tried to get some of the things covered by insurance so I don't really know. As for this question, I definitely have always hated my legs and am very self-conscious about them. I am looking into getting tumescent liposuction to fix this. In the meantime, I am likely going to do another round of HCG.
- condition has me bed bound currently
- I never wore shorts or dresses above the ankles. I have worn short sleeve tops, but I knew I looked horrible but oh well, I was hot!
- I feel very self conscious and embarrassed, feel my legs are very ugly and feel ashamed to let anyone see them. I wear pants on hot days to hide them and long

skirts.

- Since it is not an illness recognized in Spain as such, I spend a lot of time looking and proving new things which does that I always thinking about Lipedema
- Only recently diagnosed with lipodema, but from teenage years very sensitive about body shape.
- I had to go to a doctor to prescribe something for my depression
- Gevoel van schaamte
- I don't feel more lonely because my fianc  is very understanding and tries to comfort me.
- I have 0 confidence in myself. I never feel feminine. I hate my body. I sometimes wish I was dead.
- Hinders social life and physical activities - no swim suits or shorts or nice dresses
- The actual diagnosis was great!! After so many years being told it was my fault..It was freeing. I now know that there is a problem..and not caused by overeating
- I do my best to attend church and read positive things and to go outside at least once a day and breathe in some good fresh air. I also listen to music a lot and do artwork, which I enjoy.
- I have never felt 'normal' because of this wicked disease I feel like an outsider.
- Feel frustrated and I don't understand how quickly it has made me immobile and dependent on others. Odd, I hate the struggle for clothes to fit. I never look 'normal'
- When going through menopause I cried for an hour every day at 11.00am for 6 months
- I always have to choose clothing that doesn't show my legs and more recently my upper arms.
- Have always been reluctant to take part in group activities and social events.
- Cannot get as much exercise or go bike riding with my family. Cannot go for long walks with my husband. Do not go to social functions. Do not wear dresses, skirts or shorts. Do not go swimming.
- Even though I try hard to not let it effect me, it does tremendously. I constantly worry about it, and feel ashamed about it. I am filled with fear that someone will see my legs and judge me. I wear clothes that totally cover my legs to the tops of my feet. I wear long sleeves, even in very hot weather. This condition has completely changed my life, for the worse. However, I do admit that I have developed an incredible amount of compassion for all people with debilitating diseases, as my awareness has been totally heightened by having this condition.
- i can't avoid not thinking of it, the way i dress daily depends on that, now that i'm pregnant it is even worse
- Being newly diagnosed, and finding out what my future may be, my emotions have been a bit all over the place. I was a little angry at first, but I need to do what I have to to live my life!
- I've, literally, dealt with this my entire life. I know it's there, I know it's getting worse but it hasn't changed anything about me because it is part of me and has been forever.
- Emotional roller coaster.
- I stay home more because it hurts to stand or walk
- My life is not how imagined it to be; took me 3 years to find (I hope) a physician that knows his stuff regarding Lipodema and Lymphdema. Just recently found him he nailed the diagnosis nd will be seeing him again this Month of September for follow-up of PT and wrapping results.
- Kledingkeuze

- Self aware about size of legs
- I only found out about lipoedema today!
- The pain and creeping infirmity makes me angry grumpy and sad, I am ready to have surgery!
- Fear of the public. I think everyone is looking at my odd shaped hips
- I am fearful of losing my mobility when i age, to the point I am always trying to find a way to beat it.
- I don't know, I've had this condition for as long as I can remember
- Bad self steam
- don't wear dresses
- I havent been diagnosed only just heard of it. But always had much bigger legs than upper body
- Feel more irritable because of the constant discomfort in legs, groin from swelling. Irritable from always having to wear compression stocking -for 5 yrs
- just have less dress options and can't do certain things due to embarrassment
- I have no patience left for anything that isn't the norm.
- Ended in divorce
- Much more dependant on others
- I avoid beach and swimming pools
- At 11 I dieted to get my legs to look like other girls of course they never did. I was a very thin young girl.
- Some of these were applicable before i knew about lipedema but have always been self-conscious about my legs.
- ik heb nog zoveel vragen erover en mijn therapeut kan me ook niet veel vertellen
- I dont know what to do or where to go for help
- I think some of the mood shifts may be from the phentermine. which is not working anymore anyhow. it worked with increased gym time for about 2 months thats all but none of the weight came off my lower body
- een beetje was vroeger,nu kan ik heel goed met met ziekte om gaan!
- Ik weet pas sinds 2,5 jaar dat ik lipoedeem heb, ik ben nu 57, bijna 58.

Statistics 53 : How many yards,miles can you walk on 1 day consecutively

Less than 110 yards / minder dan 110 meter	11.56%
110 yards / 110 meter	4.67%
220 yards / 200 meter	5.86%
600 yards / 550 meter	8.63%
1200 yards / 1100 meter	12.43%
2400 yards / 2,2 kilometer	15.28%
4800 yards / 4,4 kilometer	9.82%
6000 yards (3,4 miles) / 5,5 kilometer	15.84%
12000 yards (6,8 miles) / 11 kilometer	8.16%
9 miles / 14,5 kilometer	2.61%
12.5 miles / 20 kilometer	1.19%
More than 12.5 miles / meer dan 20 kilometer	3.64%

Andere antwoorden:

I can walk all day, with compression, and massage afterwards.

It depends on how I feel and the temperature outside

I'm in a wheelchair, as I cannot walk much distance at all. To be fair, it's important to advise I also have Fibromyalgia, Dercum's Disease, & Lupus.

Wisseld per dag

I can do a lot one day and won't be able to for the next day(s). Can't pick a distance.

Hardlopen tot 15 KM wandelen nog meer.

It changes dramatically. I used to do lots of hiking, which I can no longer do.

Can't walk, use wheelchair

Used to walk miles every day

Wisselt heel erg wat voor een dag ik heb. Op goede dagen lukt 5 km, maar die dagen kan ik op 2 handen per jaar tellen. Ik kan 700 meter aan 1 stuk lopen of meer, maar ongeacht hoe veel ik loop, ik betaal er de 2 tot 3 dagen er na een zware tol voor.

Ik kan wel een eind lopen maar dan moet ik het daarna bezuren...

Unknown, walking on concrete or pavement is more challenging. Some days are better than others.

varieerd heel erg

Different each day

can only walk with a stick, loss of feeling in feet and pain in legs make balance difficult

Geen idee

als het pad goed is kan ik 18 km lopen anders 14km

Geen idee

Geen pijn bij lopen, wel mindere conditie. Geen idee hoe ver ik kan lopen, als moet best een uur of langer.

less then 9 miles

with rollator only and with pauses

I do not know, depends on my physical condition to. Sometimes I am completely exhausted after 5 kilometers, another time I can walk for more than 10 km.

i can only do about ten minutes then my legs hurts..... when i am not tired i can make it about twenty minute not long walk.....

I dont know

I have no idea

I can walk quite a distance but I'm always in pain...

never counted the kilometers

walk for 20 minutes, don't know distance.

I dont know

Torn meniscus prevents me from walking farther than a half mile at this point

Knee problems restrict me

As long as I had my stockings on

Ik kan een stuk lopen, maar hierna moet ik de consequenties hiervan ervaren. Dat betekent de rest van de dag met mijn benen omhoog en de dagen hierna rustig aandoen en veel rusten met de benen hoog.

My legs would get heavy but I could walk as long as I had to.

More with my walker

None

Can't walk without pain

weet ik niet

in mijn eigen tempo

Ik loop wel verder, maar dat kost erg veel energie

I dont know

Geen idee, maar kan nog wel door de stad sjouwen met mijn kinderen. Als ik moe wordt, of mijn benen willen niet meer zo goed ga ik wel even ergens zitten.

No idea

Tot een half jaar geleden kon ik niet langer dan een half uur lopen met veel pijn... nu ik volgens het oerdieet eet ben ik 27kg kwijt en kan weer uren lopen....

Weet ik niet.

Less on bad days

geen idee hou het niet bij

ik kan redelijk lopen met een rollator, zonder niet

1-2 m.

Geen idee maar ik heb het niet zo erg dus zou gewoon normaal kunnen lopen

Walk all day at work

geen idee

no idea

kan per dag wisselen soms is 200 meter al te veel

I don't know

More in the mornings, but certainly less as the day goes on.

On a good day. Other days it would be 200 metres

bedridden

I have walked farther but it was painful.

maybe 1 mile a day

I can walk around a large store like Sams if I have a cart to hold onto

Weet ik niet

No more than a mile

do not know

On a good day. On a bad day, I stay in bed

Nooit uitprobeerde maar ik denk dat ik meer dan 20 km kan lopen

three streets

Dit is heel erg wisselend naargelang de "staat" van mijn benen die dag.

3 km op de loopband

don't know

Differs

1 mile before terrible left leg pain, but can struggle through another 2 when hiking on a flat dirt road

don't know

niet geprobeerd

3 miles

Ik weet niet precies hoeveel kilometer ik op een dag loop maar het zijn genoeg. Ben zelf chemisch analist en heb thuis met mijn man een melkveehouderij.

I have no idea. I have a desk job M-F but I do exercise nights/weekends.

bed bound

I can walk about 2 miles before my R knee starts to lock up on me

I'm not sure

Depending of the day. I hike and sometimes I can walk more than 20 km, but I regularly walk around 10 km 3 times a week.

N/a. Post-stroke with balance and gait affected. Use cane and walker.

I dont know

What ever equates to 1.40 minutes of walking
 I keep active, I walk to & from work I try to keep motivated even though nothing I do makes any difference to the appearance of my legs. My mother is now pretty lame with the disorder. I fear I will end up the same.
 It is always painful.
 Varies good & bad days
 Unsure, used to walk a lot but now have foot problem
 Dat weet ik niet precies maar ik kan best een flinke wandeling maken
 1-2 miles
 Less than one city block.
 20 minutes on the treadmill at 2 miles an hour
 Inconsistent
 as little as possible
 200 meter gaat meestal we. Op slechte dagen minder op erg goede dag misschien iets meer.
 I could probably push myself to walk 3.4 miles but would the pain and fatigue would incapacitate me the following day. About 2 miles, at a slow pace, is a comfortable limit
 Never tried to walk more than 9 miles, so I may or may not be able to walk 12.5+
 I can walk all day but I cannot run at all...
 don't know - it varies
 less than 20 feet
 De ene dag goed lopen de andere dag zeer slecht.
 I play golf and do citytrips in vacations.
 1-2 miles
 I'm not real sure. less than a mile or two
 I can't even walk 10 ft!
 Less than 50 yrds
 3km
 Hard to say..I get tired and achy almost right away but can walk a decent amount.
 I can walk for like 5 km but get pain after 2 km. Also have to rest my legs for hours afterwards to get rid of the pain in my legs and feet
 unknown
 met behulp van nordic walking stokken
 Changes every day. Sometimes 5km and other days 500 meters is too much.
 30 min tot 45 min
 varies a lot from day to day

Statistics 54 : About Liposuction

	1) Yes	2) No	3) Perhaps	4) No but want to	5) It worked well	6) I am not satisfied (bad result)	7) It came back
54.1 Do you want to have surgical treatment of Lipedema (liposuction)	48.90%	18.13%	27.92%	1.90%	2.05%	0.44%	0.66%

54.2 Did you already have liposuction	11.70%	78.65%	0.07%	7.53%	0.95%	0.22%	0.88%
54.3 If yes, how did it work for you	1.97%	66.67%	8.55%	10.60%	6.73%	1.90%	3.58%
54.4 Would you recommend it	22.95%	43.35%	25.95%	6.29%	1.24%	0.07%	0.15%
54.5 Are you willing to go to an other country for it	39.40%	41.30%	17.76%	0.66%	0.80%	0.00%	0.07%

Statistics 55 : What would be your reason for having a liposuction

55.1	I never want a liposuction	12.50%
55.2	I want to be thinner	36.77%
55.3	I want to be more mobile	53.44%
55.4	I want to walk better	53.36%
55.5	I want to be able to buy clothes easier	53.22%
55.6	I want less pain	72.00%

Comments:

- I want to feel better about myself
- avoid fatigue
- To assist in the appearance of my legs, particularly ankle-thickened banding.
- I want to be able to wear "normal" jeans and clothes on my legs that match my upper body size
- less pain
- en geld genoeg!
- Om een betere vorm in de benen en armen te krijgen
- have less stress on hips knees ankles and feet
- It is too late - 70 years old
- possibly removing more lumps without multiple sessions.
- minder jeuk, je huid staat minder strak.
- Ik wil dat benen in verhouding zijn tot bovenlijf
- liposuctie kan niet is afgewezen door prof. neumann Erasmus MC Rotterdam te groot risico vanwege andere ziekten vanwege
- i have bulges that can never go away right now it looks like beanbag hanging onto me.... i hate it since i had lose so much weight almost seventy pounds then i started to gain weight those bulges came as bean bags.... trying to tone exercising pfffffftttt...nothing.....
- LESS PAIN !! play with my child..
- I want a normal life. I want less dates for lymph drainages. I don't want to wear compression anymore. I want to have a partner. I want to have a job, ...
- mag dit niet te hoog risico vanwege trombose.
- I want a better quality of life.

- mooiere benen
- I want to stop the progression of lipedema and llymphedema.
- Dat mijn benen er mooier uit zien
- better appearance
- I don't want it to get worse but will have to wait until I have had all my children
- i just want the part of me on me and not a sickness
- Niet in aanmerking, gebruik anti stolling
- I want to be able to get rid of the shame and go swimming again, wear skirts, look normal. I don't want it to get worse like my mother who looks like she has elephantitis.
- None
- I want to see the hard work I put in!
- Ik wil van mijn blubber armen, benen, buik en billen af.
- I want to live
- Verhouding armen/benen en lijf kloppend maken
- Me fijner zekerder voelen, zwemmen met mijn kinderen, preventief zodat mijn gewrichten het langer uithouden.
- It helps with my breathing and shortness of breath when fat was removed from my abdomen
- I want a baby!
- vind het enorm lelijk staan
- To have normal legs and not feel so conscious
- I don't want to knock things over when I reach for something because of this hanging fat coming down off my arm.
- Mijn benen ogen nu beter.
- Lipoedema and MS make walking very hard and very painful.
- I would like to have legs that looked healthy when wearing a skirt or dress, I have never worn them because of my big legs
- Ik zou het laten doen als ik daarmee een nieuwe knie kon krijgen
- Don't want to lose mobility Reduce deterioration of joints
- I want less pain AND I want to feel better about myself, which means wearing shorts when it is 100 degrees outside and wearing a skirt that doesn't come to my feet.
- When I had the surgery, I ended up getting DVT and pulmonary embolism which nearly killed me.
- I want to feel better about my appearance and have a better self image.
- I have had it but all of these effected me.
- I want to be healthy and look healthy. I work hard for it.
- It would be a last option.
- I want acl's to be easier
- Help my knee.
- Not convinced it has a lasting result.
- I want to have normal looking legs.
- I want to be normal
- betere verhouding tussen boven en onderlichaam.
- I want to look better. I want to limit damage to lymphatic system.
- I want my legs to have a normal shape
- I want to feel more comfortable when i sit on a plane. less spread!!
- To look normal!
- Not at all sure I would want this.
- I want to go out in public without feeling like a freak.

- ik wil vrij voelen
- Not have problems with heat/travel
- I don't want to do liposuction cuz it will come back and then I risk damaging more nerves.
- I have not considered it
- Feel better about myself
- I want to look normal and confident. I believe I deserve it.
- I want to ensure I don't develop lymph edema.
- I want to remove the adipose tissue which is a food source for the Lyme. I want to remove the fat to minimize my chances of getting a female cancer since I have the estrogen dominance problem.
- currently bed bound
- I want to just be normal
- Moet een knieprothese en een liposuctie is een verzoek van de orthopeed ivm infectiegevaar
- prevent it from getting worse over time
- It is uncomfortable but I wouldn't call it pain. I feel very ashamed.
- I want to feel better about myself
- With the veigns the doctors advices against it
- ik mag geen liposuctie ivm lymfoedeem. vraag 54 is dus niet goed ingevuld omdat er geen andere keus was. Geldt ook voor andere vragen in de 50
- need knee surgery joint replacement edema goes over incision sites
- I want to be healthier!
- I would like a more normal shape so I can live a more normal life & not hide my body in trousers all the time. I long to just wear a nice feminine dress.
- To have a more balanced body shape and reduce the progression of the condition.
- I want to have the life that others have - love, family, children
- I went to Germany for tumescent liposuction twice, last week and 3 months ago, I will go again in 3 months time
- I have always been VERY active. The ideal of not being able to backpack, run, hike, travel because of lipedema is absolutely devistating!
- I want to carry less weight, to walk better and be more mobile for health reasons
- Ik wil leren leven met lipoedeem, op een 'gezonde' stabiele manier zonder alle ongemakken die ik nu heb.
- I don't necessarily want to be "thinner." Rather, I would like to get rid of the bumps, the bulges, and the overall thickness of my calves.
- Less swelling in my legs.
- to be healthier n be able to care for my special needs daughter longer
- To stop the progression of the disease.
- frightened of surgery
- If i'll discover it is less risky (for lymfodema, for example)
- Shape of the legs
- Avoid long term complications
- I don't want to be embarrassed to swim with my children
- minder bobbelige benen
- I want to be able to play and do things with my 6 children. I want to look and feel normal. I'm only 37 but I feel like I'm 70!
- zit nog niet in die fase
- No pain, and hard feelings
- I need knee surgery done, and can't until I lose weight.

- Have had liposuction it shaped my legs
- Have had liposuction it shaped my legs
- Have had liposuction it shaped my legs
- Successfully had liposuction 22 yrs ago.
- I want to be independant again
- nothing
- Better outcome in the future
- I want my legs to look slimmer and normal
- I want control of my body back
- dit geldt voor de armen
- Ik krijg in maart mijn eerste lipo en in april en mei de 2de en 3de. De armen zijn daarna aan de beurt! Helemaal blij
- Om aanstaande klachten voor te zijn en om erger te voorkomen
- Vervolg operatie, knieprotheses
- Just to walk normal. I don't care what my legs would look like after liposuction.

Statistics 56 : Do you take supplements

	1) Yes	2) No	3) No, but I want to	4) No, it is to expensive	5) Sometimes
56.1 Vitamin D	40.42%	51.02%	1.10%	1.10%	6.36%
56.2 Vitamin C	24.12%	65.42%	1.46%	0.88%	8.11%
56.3 Vitamine B12	28.22%	62.06%	1.61%	1.24%	6.87%
56.4 Vitamin B11 (folate)	15.50%	77.70%	1.46%	1.17%	4.17%
56.5 Multi vitamin	36.84%	51.68%	0.95%	0.80%	9.72%
56.6 Selenium	15.06%	77.63%	2.70%	1.32%	3.29%
56.7 Bouchers Broom / Muizedoornextract	6.43%	87.35%	3.29%	1.32%	1.61%
56.8 Antioxidant, bioflavonoid	11.77%	80.77%	2.27%	1.39%	3.80%
56.9 Probiotics	17.84%	73.03%	1.39%	1.32%	6.43%
56.10 Q 10	8.48%	84.72%	1.83%	1.90%	3.07%
56.11 Zinc	12.72%	80.12%	1.46%	1.10%	4.61%
56.12 Omega 3	24.20%	67.18%	1.39%	1.39%	5.85%

Statistics 57 : Attending a Lipedema meeting (congres/symposium)

	1) Yes	2) No	3) No, but I will soon	4) No it is to expensive	5) No it is too far away	6) No I am not able (physical) to travel
57.1 Have been to a	19.39%	63.41%	7.36%	3.47%	4.81%	1.56%

meeting, congress, symposium in your own country						
57.2 Have been to a meeting, congress, symposium abroad	2.76%	83.51%	1.56%	6.37%	3.89%	1.91%

Statistics 58 : Where, would you think, medical research should focus on

58.1	Hormones / hormonen	71.27%
58.2	Diet / dieet	42.82%
58.3	Therapy / therapie	64.69%
58.4	Liposuction / liposuctie	58.60%

Most mentioned other answers:

Genetics / causes / DNA

Statistics 59 : About your medical data

	1) Yes	2) No	3) I don not know	4) Inapplicable / niet van toepassing
59.1 Are there medical data with your General Practicer	65.61%	17.06%	15.00%	2.34%
59.2 Do you have acces to that medical data	44.44%	24.70%	25.05%	5.80%
59.3 Are there medical data with your Specialist	57.04%	19.67%	13.80%	9.48%
59.4 Do you have acces to that medical data	34.89%	27.11%	26.26%	11.75%
59.5 Have you ever noticed that your medical information was not accurate	26.40%	48.12%	18.75%	6.72%