

Why is Lipedema Advocacy and Awareness Important?

What is Advocacy?

Advocacy is the proactive and strategic pursuit of supporting a cause, idea, or group, often with the aim of influencing policies, decisions, or public opinion. Advocates work to bring attention to issues, promote positive change, and champion the rights or interests of individuals or communities.

This can involve raising awareness, engaging with policymakers, mobilizing communities, and utilizing various communication channels to convey a persuasive message. Advocacy extends beyond mere expression of support; it involves a deliberate effort to drive systemic or social change, address inequalities, and ensure that voices that may be marginalized or overlooked are heard and respected.

Advocates for lipedema awareness may operate in diverse fields such as medical and healthcare settings, body positivity and mental

health, research and education, social justice and disability rights, women's health, fitness and wellness, policy and insurance, community building, fashion and apparel, or public awareness and media, to name a few. Honestly, with LegsLikeMine, I dabble a bit in all these areas – I just can't help myself.

Collectively, advocates are, or will be, working towards fostering a more equitable and just society. Advocacy and awareness play a crucial role in addressing the challenges associated with lipedema for several reasons:

1. **Providing Early Diagnosis and Treatment:**

Increased awareness ensures that healthcare professionals are more familiar with the symptoms and characteristics of lipedema. This, in turn, facilitates earlier diagnosis and intervention, potentially improving treatment outcomes.

2. **Reducing Misdiagnosis:**

Lipedema is often misdiagnosed as obesity or other conditions. Advocacy efforts help educate healthcare providers about the distinct features of lipedema, reducing the

likelihood of misdiagnosis and inappropriate treatments.

3. **Improving Access to Information:**

Advocacy initiatives help disseminate accurate and up-to-date information about lipedema to both healthcare professionals and the general public. This empowers individuals to seek appropriate medical attention and make informed decisions about their health.

4. **Enhancing Treatment Options:**

Increased awareness can lead to advancements in research and treatment options for lipedema. This includes exploring new therapeutic approaches, surgical techniques, and lifestyle interventions tailored to the unique needs of individuals with lipedema.

5. **Addressing Stigma and Body Image Issues:**

Advocacy efforts contribute to reducing the stigma associated with lipedema. By fostering understanding and empathy, it helps individuals with lipedema feel more supported

and less isolated. This, in turn, can positively impact mental health and body image.

6. **Supporting Research and Funding:**

Advocacy is instrumental in securing funding for research on lipedema. Increased financial support can lead to a deeper understanding of the condition, its causes, and more effective treatment options.

7. **Community Building:**

Advocacy creates a sense of community among individuals affected by lipedema. Support groups, online forums, and awareness campaigns provide platforms for sharing experiences, resources, and emotional support.

8. **Educating Policy Makers:**

Advocacy is essential for educating policymakers about the challenges faced by individuals with lipedema. This can lead to the development of policies that support access to appropriate healthcare, insurance coverage, and research funding.

9. **Empowering Individuals:**

Awareness empowers individuals with lipedema to advocate for themselves. By understanding their condition and its implications, they can actively participate in their healthcare decisions and contribute to broader advocacy efforts.

Advocacy and awareness are vital components in improving the lives of individuals with lipedema. They contribute to early diagnosis, reduced stigma, enhanced treatment options, and a supportive community that empowers individuals to navigate the challenges of living with this condition.

Why I Wrote This Book

To Inspire and Share Actions You Can Take to become an Advocate for Lipedema Awareness

This book contains so many ideas, big and small, that we can take to advocate for lipedema patients and spread awareness. I'm a part of several different lipedema organizations, and from what I've seen, many are trying to tackle pieces and parts of advocacy, yet none are owning the full picture.

For example, the Lipedema Foundation is focused on funding research, different surgeons share pieces of information on their websites, a variety of patients share their stories on social media platforms, several countries have started and run lipedema patient support groups and education sessions, etc. But none of us are working from a master advocacy plan and the information is scattered, without a comprehensive approach.

Don't let what I'm about to say scare you off. This guide is very comprehensive with a set of strategies that patients, medical professionals, friends and family, social media influencers, and others, can collectively contribute to as part of a larger effort. My hope is that

you, in whatever position you are in, will look through the book, and find one or two things that spark your interest and that you'll begin to take on.

My larger hope is that as we all unite at the global level, we will use this book as a guide to set up a very comprehensive advocacy plan, with every part of the actions we can take assigned and committed to by individuals and organizations. That's how we get stuff done.

To Share My Personal Experience, (and Probably for my own Therapy)

I am the result of a not-yet-mature recognition of lipedema as a legitimate condition. Having had lipedema that was present during countless medical exams for conditions like infertility, obesity (including two bariatric surgeries), and other co-morbidities that often accompany lipedema, lipedema was never brought up by any of the medical professionals I'd worked with. I ended up self-diagnosing my condition before I was able to meet with my doctor for assistance.

This was after a worker at a foot brace specialist's office who was caring for me asked me about my LYMPHEDEMA, which led me down the rabbit hole of looking at pictures, going online, and asking opinions.

Some kind lady on the internet saw the lipedema in my legs in my shared pictures and told me about it. Thank God for that lady! Of course, once I knew the word 'lipedema' I was off to the races to figure it all out.

Only when I walked into my doctor with the diagnosis, some brochures with pictures and information on lipedema was the doctor able to help me with the referrals I specifically asked for and was able to get in for surgery. If I hadn't asked her for the specific referrals, we'd still be using the internet to figure out what to do next! (Side note: I now overshare my personal story on LegsLikeMine and its social media presences as a pay-it-forward from what the kind internet lady did for me a few years back.)

Even after the referrals, I had to cobble together a treatment team that crossed half a country and for the most part, practice self-care. I still take occasional visits to a lymphedema therapist when the swelling conditions get out of control. There was no doctor who recognized lipedema in me early, offered a referral, or then integrated, long-term care to manage my condition.

And now still, there is no drug to take, no magic elixir to fix the problem. I've had three surgeries and need more, which I haven't fully committed to pursuing yet. So, for me, conservative therapies rule the day. I swim at least 200 minutes a week, wear compression, use a

vibration plate, take supplements, use a pump, and do Manual Lymphatic Drainage. My mobility is impacted significantly, due to the effects of now-gone fat pads that stretched out my connective tissues in my knees.

I'm doing all I can to prevent lipedema from progressing further. And honestly, there is not enough real research yet to prove that doing these things will keep Lipedema from getting worse over the course of my lifetime, but I am doing everything I can. I need research to be done so I can keep walking for the remainder of my life and get a full night's sleep every night without pain waking me up. Not a bad request, really.

Before I was able to self-diagnose due to the assistance of Dr. Google and some very caring and compassionate colleagues in the patient world, I went for two decades with the condition as it progressed, hiding my legs, swelling, weight cycling, taking an abhorrent amount of over the counter pain medications. I tried all kinds of self-imposed treatments like tools that are geared towards breaking down fascia via torture (ha!) (I won't say the name because I really don't want to be sued) that ultimately resulted in my being covered in black and blue bruising with no relief from the fibrosis.

But now let's tell the other part of my story that I haven't shared publicly yet.

My Career

I haven't shared this part of my story yet, as what I think was the final chapter just played out. Frankly, I haven't been in a calm enough headspace to share without loss of emotional control. But I think I'm better now. I guess the next few pages will tell.

It took me a while to find a surgeon who would see me due to my weight. When I did finally find a surgeon who would see me, at over 300 lbs. and holding, I had a significant, illegal, adverse action happen at my career in a US government agency, which happens to be led primarily by men (it reports at being 76% male). To not dwell on this sore subject, I was in an a very high upper management position performing a temporary detail for eight months, managing hundreds of employees and millions of dollars in budget.

When I asked off for three weeks of sick leave to receive lipedema treatments including complete decongestive therapy, physical therapy, preop testing, aquatic therapies (for the hydrostatic pressure) exams, and visits to specialists to check off the list leading to surgery, after a surprise 'blowout' of my legs (one of them doubled in size out of nowhere, after an over the top, super stressful day at work), my second level

manager, let's call him Dick (not his real name, but, appropriate) was not happy about my taking leave, despite my having more than adequate sick leave available.

My second level manager, Dick, never said it to me personally, but he didn't believe that I had a legitimate medical issue, even though I'd provided medical documentation and was legitimately going to treatments daily, and that the detox process of decongesting made me ill as toxins that had built up in my legs over twenty years released into my body, almost like having the flu.

Dick didn't believe that had a condition exacerbated by extreme, and chronic workplace stress. When I came back from treatments and surgery recovery, I was shocked, dismayed, and frankly, pissed off, to discover that my promotion had been cancelled even though I was still in the job. And the way I found out was not upfront, which cut a little deeper.

You see, in this executive position I was in, I would get weekly lists of pending personnel actions, and I'd seen my own promotion moving through the often-months-long process week after week (this is common). When I returned to duty after my three weeks out, my name was no longer on the personnel actions list, so I assumed the promotion had finally processed. But I never saw the promotion come through on my side.

The government is notoriously slow with HR actions so at first, I wasn't concerned.

A couple of weeks later I was having drinks and dinner with my first level manager (she was the manager between me and Dick), and she may have had a glass of wine that evening. We're chatting away and at one point in our dinner, she casually mentioned, "Dick cancelled your promotion because you took leave to treat your leg."

(Yet he had me keep doing the work for several months. In fact, I was travelling that very week I was having dinner with my boss, doing that high level, ultra-high stress job, when I could have been at home with my kids, you know, raising them.)

The second I learned what had happened through this informal channel, I filed an equal employment opportunity complaint and requested a list of remedies including having Dick to get retrained on how to handle medical conditions, sick leave and persons with disabilities. I also requested to be moved - to not work for this man again. I filed this complaint the very day after I discovered what had happened...because after receiving years of management training (the same training Dick got, in fact) I recognized that having a promotion cancelled because a human being took sick leave for a real medical condition, as a flat out illegal and adverse action.

One thing led to another, and I ended up requesting what's called Reasonable Accommodation (RA), to reduce stress in a variety of ways. This is a pretty common request. In my 18 years in a management position at the agency, I had granted Reasonable Accommodations numerous times for employees who had reported to work with all kinds of newfound conditions, like after having had heart attacks or broken legs, gone blind, or developed allergies, for example.

Accommodations we as managers could make were things like, restructuring jobs, providing, or modifying equipment, changing job schedules, helping someone move to part time employment, reassignment to other positions, providing interpreters, etc. I wanted a reassignment and restructured job, should be no issue. Over the years, I'd even mentored numerous new managers who'd had RA training, but needed confidence in navigating how to handle requests when they were uncertain of their ability to help employees through hard times.

The doctors in charge of our agency's medical response reviewed my request and medical documentation and fully agreed that I needed accommodation for reduced stress, in writing. Yet, sadly, after much negotiating, my request for accommodation was denied. At this point, I recognized I had been unofficially blacklisted in the agency. I'd made someone mad by filing legitimate formal complaints that should have been swiftly

addressed and reconciled. My decades-long career was in the trash.

I ended up retiring on a disability retirement since the agency couldn't accommodate my Reasonable Accommodation: a very sad and senseless end to a 28-year career in which I had won many awards, helped so many employees, led billion-dollar projects, and represented the United States at an international level. All because one man didn't believe that lipedema was a condition worthy of my using earned sick leave.

Interestingly, the last time I was in our headquarters offices in DC, to which I had traveled literally hundreds of times, was to receive the agency's Humanitarian Award for my work on lipedema awareness. And it is the last time I will ever be in Washington DC.

You see, this work, fueled by my dismay at my agency, had been ongoing behind the scenes while my legal endeavors were being processed, albeit not working for me. It's kind of ironic that the people I complained about and to were giving me awards, I guess. And although I have a folder full of awards and certificates from my long career that are hidden deep within the boxes I packed as I left my office, I keep this, lovely sparkling crystal Humanitarian Award out on my desk, three feet from where I sit every day, as a reminder to why I need to continue to be an advocate.

The way this story ends is also not the best. Not to get too technical into the complaint process (and I'm really condensing this down because this has been a few years in the making), but on the day I found out what had happened originally (that cancelled promotion due to taking sick leave for lipedema treatments), I filed every complaint I could find, a whistleblower, EEO complaint, administrative grievance, etc.

I was advised by someone in one of the HR departments involved that I had to redact all but one of the complaints at a time, and let its process play out so the processes wouldn't get mixed up. I lost on the first one in another long story – the agency promised me retroactive pay (and then ultimately did NOT meet their promise, but they got me to retract the complaint), and then I was unable to add it to the longer term EEO complaint, which recently was closed, despite all the appeals available being filed. And now of course I no longer work there and the statute of limitations for filing more complaints has passed. I got screwed.

The psychology of all this happening in a career where I was front and center, smiling, receiving, and giving awards, hiring, mentoring, and representing was traumatic for me. I didn't share with my employees about this whole situation, ever believing the system in place, and the law, would protect me.

But behind the scenes, I pretty much crumbled internally from not only the burden of dealing with lipedema the condition I was still new to managing but knowing a workplace I had sacrificed years of travel away from my kids for, believed in the mission, represented, had basically turned its back on me. And I had to stand there and smile like all was peachy keen.

I would never want to be a part of this organization again as my heart was already lost, bitter, and useless to the agency, regardless of the legal outcomes.

When I filed complaints, the agency should have immediately jumped to support me, wrapping their arms around me to safety. They also should have crushed Dick, then retrained him to do better. But they didn't.

Government managers receive so much training, annually, on how to handle cases like this and how to foster people with disabling conditions. My former government agency, in fact socializes big, beautiful marketing campaigns advertising their "People with Disabilities" programs, saying they, 'actively recruit, hire, promote, retain, develop and advance people with disabilities.' They have disabilities hiring fairs and Disability Awareness Month and a coalition of persons with disabilities (I was an officer). But in my case, all that turned out to be a front and a fraud that looks

fantastic when marketed but was not implemented for a decade's long employee. Mindboggling.

When the rubber met the road, what happened was the agency bent over backwards to cover their own asses and find legal loopholes that I could not jump through without the power of a full legal team supporting me, not to help me. So, there you have it.

I'm going to rant a bit more because this is pretty therapeutic. So, bear with me.

Basically, this man we call Dick (it's not his real name, but it should be), unaware of lipedema or lymphedema, and obviously clueless about how to handle it, started a downward spiral of my career that will leave a bitter taste in my mouth for the rest of my life.

Incidentally, I wrote an entire book about my discrimination story in full detail, with real names, in fact. I have tentatively decided instead to not put that energy out into the universe and have paused its publishing. Not for Dick's sake, but for mine. Never do anything for Dick's sake.

Instead, I'll use my advocacy passion, my gifts, and my particular skills to write a different book to educate, and to teach how to spread awareness so this doesn't happen to others in the future. I'm also writing books for managers to be used in training, on how to handle

accommodation requests and employees who develop disabilities during the course of their careers. Nothing would be more satisfying to me than to have my former agency buy 17,500 copies of this book – one for every manager in the agency. See? All good things here.

We all know this wouldn't have happened were my condition prostate cancer, a heart attack, COPD, or a sports-related injury...or ANY disease that also affects a man (because there's published research on men's diseases.) And that's what really chaps my hide. Dick got away with demoting me for taking my earned time to treat my medical condition called Lipedema. He got off, Scott free.

Finally, before you say it. Legally, I've exhausted all my chances to be righted, so please don't send me emails with recommendations. I've missed the boat even though I had one foot on it. I should have hired that law firm I consulted early on but didn't.

I'll go to therapy, and Dick and everyone who knew about his and the legal department's handling of the case, get the satisfaction of living with their actions, and inactions, and if all is well with the world, its impending karma. I don't have time to waste fighting with them when I have a new purpose. Peace be with you, Dick.

I, on the other hand, need to move on and do good things in my life instead of walking around as a pissed

off person who can't focus (because anger makes one a little disheveled mentally). Anger, ironically, causes stress, which is bad for my legs anyway. It makes them blow up.

And now, breathe...and that's all I have to say about 'that,' except to say, I don't want this to happen to one more person, ever, so I advocate.

To Raise Awareness

Lipedema is often underdiagnosed or misunderstood, even within the medical community. Writing a book when there are still very few published on lipedema at all, allows me to add to the publications available widely, to raise awareness about the condition, helping to educate the general public, healthcare professionals, and policymakers about the challenges faced by individuals with lipedema.

To Advocate for Early Diagnosis and Treatment

What if my book happens to be the only lipedema book a doctor reads? I want to be sure it has enough information to validate lipedema, provide her with next steps, and to provide resources to her patient to get support.

For personal empowerment

Sharing my story and advocating for change encourages a sense of agency in the community and helps to break down stigmas associated with lipedema. It gives me something positive I can do, to change the outcome of my story from a sad ending to an amazing beginning with amazing results for the world.

To Provide a Mechanism and Tools for Community Building

Our community can become isolated due to lipedema's affect on mobility and self-esteem. Writing a book that shows ways individuals can advocate from the smallest of actions to taking on grand platforms is helpful. I believe many of us think that we can't do anything, but all of us can find at least one golden nugget in this book, one action we can take and are comfortable with, to help the cause. When we start doing like things, it builds a sense of community and conversation. We create our own platforms then for individuals to connect, share experiences and support each other.

To Address Misconceptions

There are often misconceptions and stereotypes surrounding lipedema. A book can serve as a tool to

dispel myths, correct misinformation, and present accurate information about the condition.

To Provide a Source of Inspiration

By sharing my story, struggles, and achievements, maybe you'll be inspired to pursue your goals, seek appropriate medical care, and not let the condition define your life. Hopefully, gaining some insight into how you can advocate will give you purpose and a reality check that wherever you are, you can make a difference.

To Serve as a Catalyst for Policy and Research Advocacy

This book alone could serve as a catalyst for advocating and receiving more research funding, increased medical education about lipedema, and changes in healthcare policies to better support individuals with lipedema.

To Continue to Promote Body Positivity and Represent the Lipedema Patient Population

Lipedema often involves changes in body shape that are challenging for us to accept. And many people see us and immediately make stereotypes of our being lazy or ignorant or noncompliant, which simply isn't true in many cases.

Books being written by educated, well-spoken and skilled lipedema patients promote positivity and show that we are not taking this condition lying down and that we are not a stereotype. We are much more than our conditions. Patients need all the opportunities we can get to promote body and human positivity and self-love and encourage readers to embrace our bodies and recognize we are more than our bodies, so we can focus on overall well-being.

To Provide an Educational Resource

This book can serve as an educational resource for people with lipedema, providing information on coping strategies, available treatments, and resources for support. If this is the only book on lipedema you ever pick up, I want to be sure I gave you enough to get started on your treatment and self-care plan.

Overall, writing a book about lipedema advocacy and awareness helps me, as one person, to contribute to a broader conversation, promote understanding, and make a positive impact on the lives of those affected by the lipedema.

I hope you find my story to be relatable and to inspire you for action, and the key points in the book to be helpful in identifying ways you can fire up your own advocacy efforts and be a part of the bigger picture.