

**LIVING WITH LYMPHEDEMA:  
THE EMOTIONAL AND  
PSYCHOLOGICAL ASPECTS  
&  
STRATEGIES FOR SELF-CARE**

*Presented by:*

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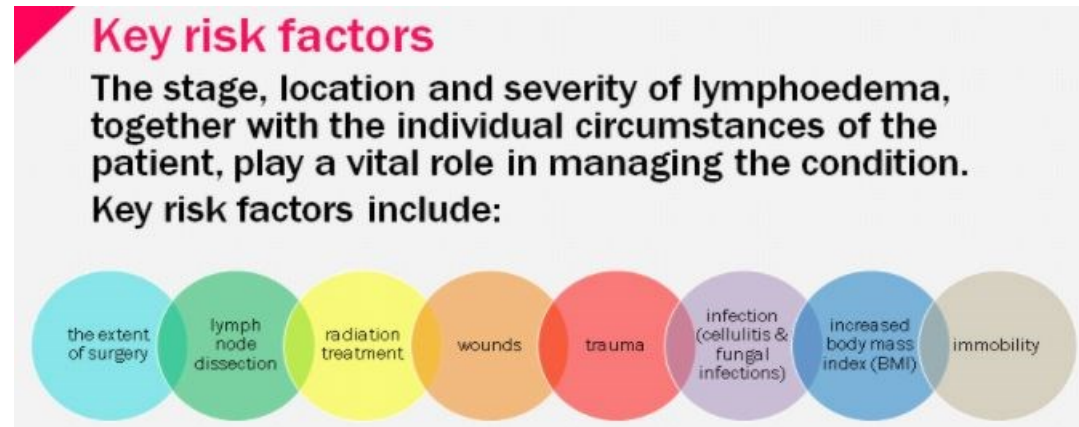
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# Who is at risk for developing Lymphedema?



## What happens next?

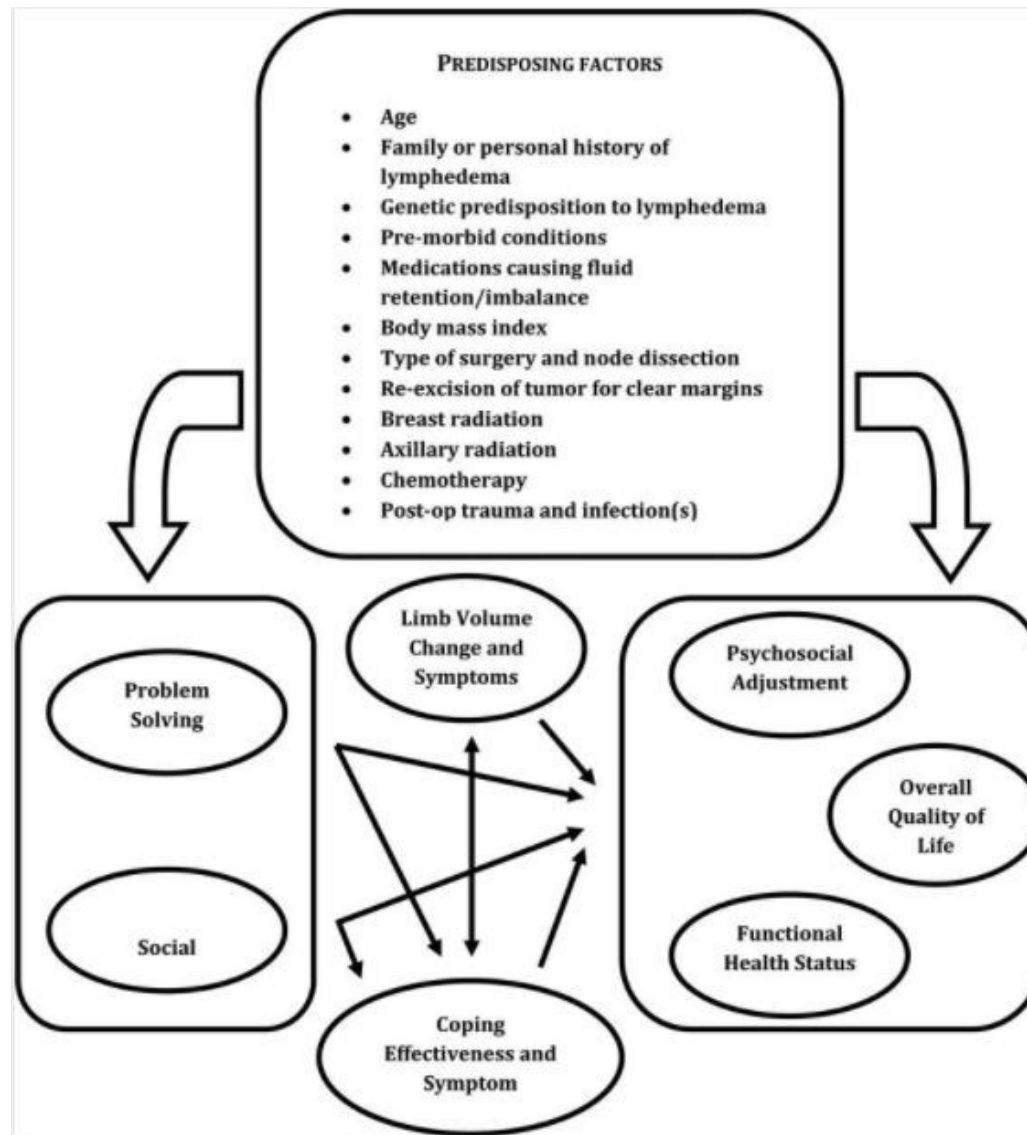
- Increased stress levels
- Dealing with the pain, swelling, discomfort and visible disability of enlarged limbs/body areas
- Searching for the right treatment options
- Affordability or financial stress, if no insurance coverage for treatment
- How to fit in time for new treatment, a more focused diet perhaps, an exercise plan
- Negative or disabling thoughts such as:
- “I thought I was fine after surgery, and/or chemo and radiation”, “I’ve just returned to work and life, how can I take more time off?”,
- “I don’t have time for this!”, “I don’t know if I can deal with anymore”, “what, now this, especially after everything I’ve been through!”

# Where do my recommendations come from?

## Lymphedema



- Evidence-based research
- Based on the current standard of care
- An understanding of the emotional, mental and psychological effects of the body on the mind, and vice versa
- My own lived experience with breast cancer, mastectomy, lymph node dissection, chemotherapy, radiation and lymphedema
- Working one-on-one with clients who are cancer survivors and living daily with lymphedema & its effects



### Conceptual model of biopsychosocial factors influencing post-breast cancer lymphedema

Ref: Armer JM, Stewart BR, Wanchai A, et al. Rehabilitation concepts among aging survivors living with and at risk for lymphedema: A framework for assessment, enhancing strengths, and minimizing vulnerability. *Top Geriatr Rehabil.* 2012;28(4):260–8.

# The Emotional & Social Stigma of Having Lymphedema: What does the research say?

- Lymphedema and associated symptoms (e.g., swelling, heaviness, tightness, firmness, pain, numbness, stiffness, or impaired limb mobility) exert a negative impact on physical and functional well-being, resulting in diminished overall health-related quality of life (HR-QOL)
- Psychological distress, such as anxiety and depression from perceived abandonment by healthcare professionals
- Recent research reports that breast cancer survivors with lymphedema utilized more psychological counseling services than breast cancer survivors without lymphedema
- The sense of illness permanence and the chronicity of lymphedema elicited the negative emotions of fear, anger, sadness, loneliness, and frustration as well as psychological distress of depression, hopelessness, and helplessness
- Daily time-consuming self-care for lymphedema also caused frustration, depression, or anger
- Negative self-identity with associated reports of feeling 'ugly', 'old', 'unattractive', and 'disgusted' were ignited by the sense of body image disturbance with the visible appearance of lymphedema (the 'swollen arm' or 'puffy hand') as a 'a visible sign of disability
- A sense of body image disturbance and negative self-identity associated with losing the 'pre-lymphedema being' arose from the reality that lymphedema was a lifelong chronic health issue and could not be cured or hidden
- Reported negative emotions (frustration, anger, fear, self-blame, tiredness, and sadness) and psychological distress (depression, hopelessness, and helplessness)

Ref: Fu MR, Ridner SH, Hu SH, Stewart BR, Cormier JN, Amer JM. Psychosocial impact of lymphedema: A systematic review of literature from 2004 to 2011. Jour Psycho-Oncology 2013; 22: 1466-1484. DOI: [10.1002/pon.3201](https://doi.org/10.1002/pon.3201)

# The Emotional & Social Stigma of Having Lymphedema: What does the research say?

- Explaining what lymphedema is to people is distressing
- Wearing a sleeve, glove, bandages, or other compression garments makes this disease more “visible”
- Social stigma at work, due to reduced abilities
- Public insensitivity & marginalization
- Diminished sexuality
- Social isolation
- Reduced activities
- Financial burden
- Lack of social supports
- Can lead to:
  - Anxiety and/or depression
  - Know the signs
  - Get help
  - Don't wait
- ***There is NO shame in asking for help***



Ref: [dynamicwellnesssolutions.org](http://dynamicwellnesssolutions.org)

# Risk factors for developing emotional or psychological distress



- Not everyone will suffer from emotional or psychological distress
- Previous experiences with anxiety, depression or chronic worrying, increasing the risk factors
- A genetic predisposition to anxiety, depression or mental health issues
- Inability to manage stress; ruminating thoughts
- Irrational thoughts and beliefs; reoccurring negative thoughts
- Inability to effectively regulate emotions and feelings
- Uncertainty about the future; job loss, career dissatisfaction
- Loneliness, lack of support, financial stress
- Low self-esteem; loss of independence; inability to enjoy
- Sleep dysfunction
- Relationship issues, such as sex and intimacy, negative body image, insecurity in the bedroom
- Anger, avoidance, minimizing, denial, fear, panic, guilt, sadness, blame, feelings of being hurt, carrying “baggage” from your past, unresolved family-of-origin issues

# Know the signs of emotional or psychological distress



- Irritability
- Quick to anger
- Getting defensive
- Avoiding
- Minimizing
- Denial (of feelings or actions)
- Sadness
- Blaming others for your illness
- Inability to let go
- Regret and guilt, self-blame
- Feelings of “why me”
- Feelings of being hurt by someone or something
- Carrying “baggage” from the past, such as previous relationships, romantic and other
- Unresolved family-of-origin issues



# Strategies for day-to-day living with lymphedema



- **Boost activities of wellbeing:**
  - journaling, yoga, walking, mindfulness, art therapy, breathing, relaxation exercises, meditation, visualizations
- **Mitigate stress:**
  - stay active, be social, laugh a lot, do things you enjoy, use positive affirmations, maintain a positive attitude, release old “baggage”
- **Find your joy:**
  - in your work, nature, pets, volunteering, children, singing, dancing, spirituality, set goals, cooking, baking, find a hobby
- **Change the narrative:**
  - redefine your life, live in the present

# The Importance of Emotional Self-Care

- Socrates said: “Know thyself” :
  - know your challenges,
  - know your symptoms,
  - know your mind,
  - know your body,
  - KNOW WHAT YOU NEED &
  - DON'T BE AFRAID TO SEEK IT OUT.
- Spread awareness on lymphedema and it's challenges
- As I say, “angels come in many forms”, so watch out for them!
- Thanks to folks like Wellspring, the Lymphedema Association of Ontario, and the Markham Lymphatic Centre, help is out there.



## Links to Articles and Handouts

- Link to my papers, relaxation techniques & cancer coaching:
- <http://nidhigupta.com/cancer-coaching/>
- [http://nidhigupta.com/wp-content/uploads/2016/02/capp\\_flyer.pdf](http://nidhigupta.com/wp-content/uploads/2016/02/capp_flyer.pdf)
- <http://nidhigupta.com/wp-content/uploads/2020/10/Cancer-Journaling.pdf>
- <http://nidhigupta.com/wp-content/uploads/2020/10/Relaxation-Mindfulness-Techniques.pdf>
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