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Presentation to Lymphoedema Ireland Open Day – March 2018

Living with a Chronic Condition: Coping and Self-caring with Lymphoedema

What is self-care?

“1. The practice of taking action to preserve or improve one's own health”. “1.1 The practice of taking an active role in protecting one's own well-being and happiness, in particular during periods of stress” (<https://en.oxforddictionaries.com/definition/self-care>).

Psycho-social impact of Lymphoedema:

The psycho-social impact of being diagnosed with a chronic condition, and with lymphoedema in particular, cannot be underestimated. How it affects people in many aspects of their personal and social life and how this in turn impacts on individual thoughts, emotions and behaviours is now well documented. What follows is a non-exhaustive list:

- Loss of control
 - Loss of confidence in the body, poor body image, body image disturbance, particularly in younger women
 - Psychological distress (anger, sadness, depressive symptoms, feeling unheard, undesirable lifestyle changes).
 - Social anxiety and avoidance
 - Sleep difficulties
 - Physical inactivity
 - Overeating
 - Lack of self-confidence in social activities, recreational activities, and in performing self-care
 - Sexuality concerns for both the person with lymphoedema, but also for the partner
 - Loss of role: not being able to work in the same capacity, not being able to contribute to family life in the same capacity
 - Economic concerns as treatment is costly
 - Issue of time management as patients must make time for burdensome self-care activities
 - Not attending GP because of perception/experience that s/he doesn't understand the condition
 - Vigilance regarding acute episodes and the risk of infection
- (Adapted from Ridner, 2009 – Alcorso & Sherman, 2016)

From grieving to coping:

Many of the issues listed above are categorised as losses (loss of control; physical loss; loss of role). Grief is a natural reaction to loss. It is a difficult but tangible process, leading to adjustment. So

difficult in fact, that it can be likened to walking on a tightrope: a delicate balance needs to be found between allowing time and space to feel the emotions, and (re)engaging. It is indeed important and part of the grieving process to experience and to let out sadness, distress, frustration, anger in healthy ways, allowing yourself to cry, hitting pillows, etc., putting the energy of anger into anything that can act like a release for it without causing harm to other parties. Support groups or buddy systems can be a safe place to let out difficult emotions and thus be heard by people who can really understand.

Adjustment. Adjustment does happen. Research has focused on people becoming handicapped following an accident. It shows that on average, they are back to their baseline happiness level two years after the traumatic event (Lenoir, 2013, p.13).

Becoming more aware of coping strategies can help you not only find that balance but move forward faster.

Coping styles or “emotional karate”:

The growing field of positive psychology is particularly relevant here given most of the strategies that help people become happier also help them cope with life’s challenges.

There are two main ways of coping when facing adversity: problem-focused coping and emotion-focused coping. On average men rely more on the earlier and women on the latter, but when dealing with a chronic condition, both are required. It is important to identify which tends to be your habitual coping style, as you will benefit most from learning from the other style (Lyubomirsky, 2014, pp.154-7). They add up to form what could be called your “emotional karate” or self-defence.

1. Problem-focused coping:

Here are a few examples of problem-focused coping strategies:

- I concentrate my efforts on doing something about the issue
 - I do what has to be done step by step
 - I make a plan of action
 - I seek advice from someone about what to do
 - I talk to someone who can do something concrete about it
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- You are using problem-focused coping by educating yourself as to what you can do, what help is out there and/or building up your motivation to bring Lymphoedema under control and maintain the condition.
 - You are also tapping onto this coping strategy by adhering to the steps of treatment protocols including drainage exercises, skin and nail care, etc. According to Ridner: “if people perceive they are doing something that is helping to reduce or maintain arm size, they feel more in control of their life.” They “show improved physical and emotional health”; they are also doing more and feel more energetic. (Ridner, 2009).
 - Ridner also encourages pushing for social change, advocating better health cover “for maintenance lymphedema treatment or early treatment” and training of healthcare providers (Ridner, 2009).

2. Emotion-focused coping: is also tremendously important, especially in instances where all or part of a situation is not in our control. This is further divided into two sub-categories, the first one focusing on the **mind**, the second on **behaviours**.

2. Strategies for the mind (Cognitive emotion-focused strategies):

This is not about shortcutting grief. These strategies focus on acceptance, which in fact is part of the grief process and takes time as people become adjusted to new circumstances; learning to live with the reality of what has happened; trying to learn from the experience.

Such strategies are about easing the process by creating more awareness of the fact our thoughts affect our emotions; it thus makes sense to practice **“Thought management”**, that is catch rumination of negative thoughts.

ABCD disputation technique:

An example of a technique that can be used is the ABCD disputation technique:

You are being asked to focus on **A**dverse experiences

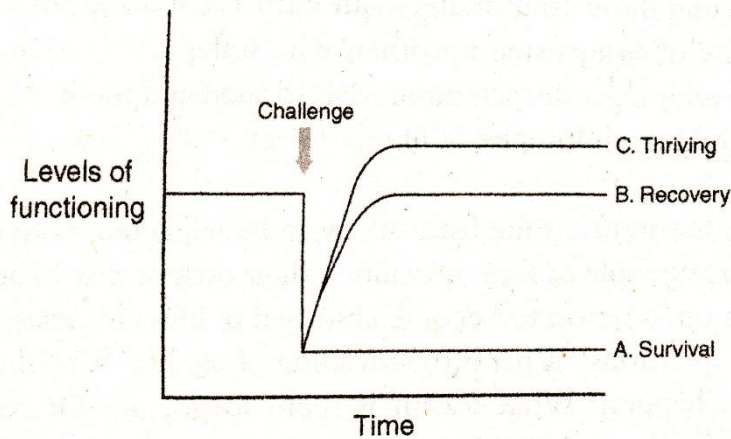
Next, write down your negative **B**eliefs about the adverse events and the **C**onsequences of these beliefs.

Then vigorously **D**ispute your current beliefs.

A dverse experience
B eliefs about the adverse event
C onsequences of these beliefs
D ispute current beliefs

If you find it difficult to dispute the thoughts on your own, turning to a friend or a loved one for help in finding the disputation may be helpful. “What is the evidence for the belief?” and “What alternative ways can I look at this situation?”. When you identify a pessimistic belief that is warranted, you might then ask yourself “What does this negative event really mean”? or ask yourself “How useful is it for me to dwell on this negative event or belief?” (Seligman, 2002).

From coping to thriving. Up to now, the focus has been on adjustment, yet people do better than adjust and cope. It can be extremely difficult to reinterpret a situation positively when faced with major challenges and trauma. Yet it is key to one astonishing finding: we can do more than survive, cope or return to our baseline happiness: we can thrive and flourish despite adversity.



(Tennen & Affleck, 1999)

Many studies depict what is also called “traumatic growth”: people typically talk about “a wake up call, prompting them to reorder their priorities and to realize what [is] truly important in life (a common one [is] family over work), of deciding to devote more time to their most significant relationships and to spend less time on things like housework”. (Lyubomirsky, 2014, p.158). “Some people claim that their relationships have benefited, that they are more profound, significant and meaningful ...”, “... others assert that they have grown enormously as a result of their traumatic experience, discovering a maturity and strength of character that they didn’t know they had ...” “a renewed appreciation of the preciousness of life and a sense that one must live more fully in the present” (Lyubomirsky, 2014, p.159).

3. Behavioural strategies (Behavioural emotion-focused strategies):

These involve adopting the behaviours that enhance your mood the most. They include feeling connected to significant others, getting understanding and sympathy from a loved one; “positive distractions”, that is to say hobbies and activities you enjoy; a physical activity which lifts your spirits.

Feeling connected to significant others, whether a partner, family, friends, is crucial, as healthy relationships enhance our sense of well-being. Servan-Schreiber relates how our hearts reach a state called “heart coherence”, when in the presence of a loved one. He gives the example of a young boy and his pet Labrador who were inseparable. They were found to be in that state of heart coherence when they were together, but not when apart (Servan-Schreiber, 2004, p.46). Here are other markers of the physiology of well-being: Lower blood pressure, and cortisol levels, higher DHEA levels, improved immune function (Servan-Schreiber, 2004, pp.59-60). This is why nurturing and healing relationships is so important. While allowances need to be made for different personalities, three friends seems to be the “magic number” (according to Stanford Professor Laura Carstensen).

Getting together (creating rituals with friends that enable you to do so regularly), and communicating effectively are simply crucial.

Compassionate listening technique: feeling heard and understood. We can all name the good listeners around us without any hesitation. Many people do this naturally. They have good eye contact, give us the space. They may also convey that they are hearing, by mirroring some of what they heard. It is not so difficult: Servan-Schreiber reports a study on passive and attentive listening where people were set up in pairs with one person assigned to talk about a trauma or difficult event in their lives and the other one to simply nod and say "Hmm . . . hmm . . ." or "tell me more". The "talkers" reported feeling heard and feeling lighter. (Servan-Schreiber, 2004, p.194)

You also know what the opposite of this is: people interrupting to draw parallels to something that happened to them (which brings the focus back on them), or who are prone to giving unsolicited advice. It is important to spend more time with people who are making you feel heard and understood or teach people listening skills. Reciprocity is key and we can all become better listeners. Again support groups or buddy systems can be a great way to form such connections and open days, such as ones organised by Lymphoedema Ireland are a great opportunity to create new ties.

Communicating. We can grow in emotional intelligence throughout our life. And in addition to listening skills, it is important to communicate effectively to help bolster relationships. Lyubomirsky recommends spending five minutes a day expressing appreciation or gratitude for a particular behaviour, expressing admiration, affection, rejoicing in the good fortune of a loved one (Lyubomirsky, 2014, pp.142-50). Self-disclosure of intimate thoughts and feelings can be difficult for some people, but helps nurture friendships, it is critical to female friendships (Lyubomirsky, 2014, p.149).

Self-care is also learning to ask for help. Practical help and emotional support from family and friends, and sometimes added help from a professional.

The ability to manage conflict with emotional intelligence also helps safeguard relationships. One technique The STABEN is based on Rosenberg's Nonviolent communication technique. This technique purports to maximise the chances of being heard by addressing an issue without it being perceived as an attack. STABEN is a six-point technique used for handling conflict with nonviolent assertiveness and thus minimise negative communication and its consequences, to preserve emotional connections.

SIX-POINT CUE CARD FOR HANDLING CONFLICT

S is for SOURCE

T is for TIME

A is for AMICABLE APPROACH

B is for OBJECTIVE BEHAVIOR

E is for EMOTION

N is for NEED

Practising kindness. It may sound paradoxical for some people living with a chronic condition but also being at the "giving end", practising kindness, offering help, can satisfy that same basic human need for connecting with others. It earns you gratitude, appreciation and sometimes valued friendships. There is also the sense they will reciprocate in our time of need (Lyubomirsky, 2014, pp.130-1). Research on volunteering shows that it is associated with diminished depressive symptoms and enhanced feelings of happiness, self-worth, mastery and personal control (Piliavin, 2003, pp.227-47). It is important to find the right balance for you.

Touch is another way we connect to others and that is now demonstrated to enhance well-being. This applies to a simple hug: A group of students was instructed to give a minimum of 5 hugs a day (in a non-sexual way) over the course of a four-week study. Compared with the control group they reported becoming much happier. Hugs also relieve stress, make you feel closer to someone and even diminish pain (Lyubomirsky, 2014, p.150-1 – Doehring, 1989, 32-3). Similarly, there is a growing body of evidence regarding the benefits of massage. What follows are findings of a meta-analysis: “Reductions of trait anxiety and depression following a course of treatment were MT’s [massage treatment] largest effects. The average MT-participant experienced a reduction of trait anxiety that was greater than 77% of comparison group participants, and a reduction of depression that was greater than 73% of comparison group participants.” (Moyer & al., 2004, p.14). Several clinical studies are also underway at the Mayo clinic.

Beside connection to others behavioural strategies also encompass other mood enhancing behaviours categorised as “positive distractions” by positive psychology. These are namely any activities or hobbies you enjoy, including physical activity.

Exercise. Lymphoedema brings the importance of exercising to the forefront with the need to exercise to simply maintain the condition, maintain mobility and help if indicated with weight loss or maintenance of a healthy Body Mass Index. It also helps build up energy levels and enhance the mood.

Recommendations for the general population are 20 to 30 min 5 times a week. Dr Noel McCaffrey, who is the Medical Director for the MedEx Wellness Programmes in DCU, stresses the importance of being out of breath. According to him if you are “sweating and puffing a bit”, your heart is doing exactly what it needs to be doing. If you were not physically active before, this is about building up fitness gradually. From a psychological point of view “tricking the brain” can be effective, for instance establish “minimal contracts” with yourself: if you have decided to start walking, for the first week you can tell yourself you have fulfilled your contract by only getting out the door. Chances are you will do more. Then build it up gradually, a couple of minutes at a time.

It is also obviously easier to stick to something you like: Yoga, Pilates, dance classes, kickboxing, Nordic walking, swimming, hydroaerobics, running, etc.

In terms on emotional well-being, the payoff increases if you exercise in nature: research has shown, through cortisol levels measurements, that the same exercise practised in nature will lower your stress levels further than if practised indoors. Many activities also require sustained attention which takes people away from their worries. This can create a state of flow, hence the label of positive distraction.

How could you get started?

Meditative Practices. Meditation and other forms of relaxation could also be considered part of these strategies, as regular meditation makes our brain more resilient to difficult emotions.

There are many different types of meditation. Mindfulness Meditation, which is secular, may be the best known. With the progress of neuro-imagery, much research is being devoted to the effects of meditation: in the same way different forms of physical activity will reinforce different muscle

groups, it now appears that different forms of meditative practices (and prayer for religious individuals) impact positively on different parts of the brain (See Servan-Schreiber, 2014).

Matthieu Ricard, a French Buddhist monk and scientist who holds a Ph.D in molecular biology, explains that: “Two months of daily mindfulness meditation sessions lasting 20 to 30 minutes each were found to lower significantly anxiety, susceptibility to anger and depression”. According to his work with neuroscientists, the most powerful form of meditation, namely the one which triggers most gamma waves in the brain, is compassion (or altruistic love) meditation (See Wolf Singer, 2017).

Instant effects:

- Better tolerance of pain: Meditators feel between 21 and 24% less pain (Zeidan 2015).
- Stress and anxiety management: It lowers negative thoughts which can be a source of insomnia and inflammation (Hofmann 2010)

Medium term:

- It reinforces immunity (Davidson 2003)

Long term:

- It makes people more resilient to depression (Segal 2003)
- It improves people’s cardio-vascular system, lowering blood pressure (Hughes 2013)

How to start meditation? At home: meditation apps, guided meditations on YouTube: for instance “The Honest Guys”, CDs, meditation music. Trying different types of guided meditation: mindfulness, body scan, compassion, open heart, heart coherence... It is usually easier to start with a voice (guided meditation), to cut through the racing mind, and to help bring back your mind when it wanders off. You could also find a course in Dublin as group meditation can be quite supportive.

Yoga is a form of meditative practice. It has similar benefits with regards to stress and anxiety, immunity, depression and heart health. There has also been research on benefits in relation to back and neck pain (West Virginia University, 2019), improved cognition (University of Illinois, 2013) and on stabilising weight (Fred Hutchinson Research Centre, Seattle, 2005).

Arts, crafts and hobbies. The University of Gloucestershire carried out research on a programme called “Arts on prescription” run by a charity called Artlift. Under that programme “Health professionals refer patients with a wide range of conditions – from depression and anxiety to chronic pain to stroke – to take part in an eight-week course of two-hour sessions, led by a professional artist working in poetry, ceramics, drawing, mosaic or painting. Participants are encouraged to pursue their own creativity in a studio-like, rather than medical, environment”. “This found a significant improvement in well-being, improved mood and enjoyment of creative activity” (*Creative Health: The Arts for Health and Wellbeing*, 2017, p.73)ⁱ

You may want to start brainstorming. What do you enjoy doing, or what did you use to enjoy as a child? Singing, playing a musical instrument? Drawing, painting, model building or clay modelling? Knitting, sawing, wood-turning, writing? Are you a DIY enthusiast, or a keen gardener? Is there anything you have always wanted to do but keep pushing back? How about deciding the time is now, trying it and observing how it feels. Chances are you will get to a state of flow (or “zone”, or heart coherence), by focusing on something you enjoy, and feel happier as a result of engaging in a positive

distraction. The need for fun is a basic need and is also reinforced by learning something new, so this could be an opportunity to learn a new language, a craft, a musical instrument you have always wanted to learn.

And of course Arts can be enjoyed in a more contemplative way, by going to exhibitions, the cinema, theatre, reading, spending time in a place of beauty, listening to music you love...

Conclusion. A well-balanced life:

This presentation endeavoured to increase your awareness of coping techniques, and of the importance of building them up to improve well-being. From Problem-focused (solution-focused) coping to emotion-based interventions including cognitive and behavioural strategies.

To conclude, Jeffers' "Balanced life table" below is a simple way to illustrate and bring home some of the emotion-focused strategies that help us cope, regain balance and even thrive when faced with life's challenges.

How well are you keeping balance between the different boxes? Where are you now, and where do you want to be?

Career	Family	Hobby
Relationship	Me time	Learning and development
Friends	Exercise	Spirituality/ Contribution

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ⁱ It also showed that GP consultation rates dropped by 37 percent and hospital admissions by 27 percent.