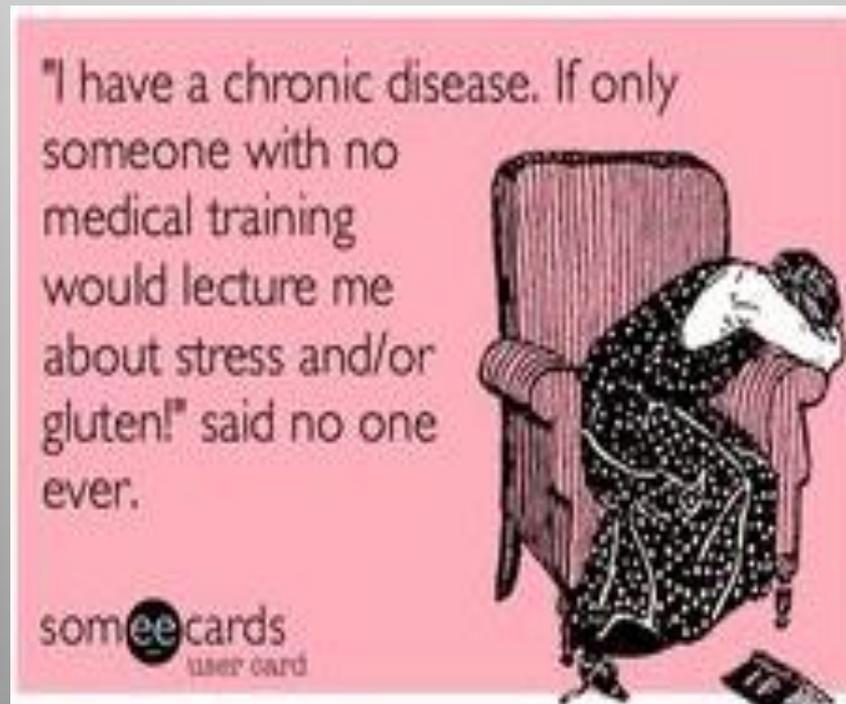


What we can learn from the Kubler-Ross grief stages about living well with Dysautonomia?

Morwenna Opie, PhD, DipClinPsych



Aims

- Shed some light on the emotional rollercoaster that is loss associated with chronic illness
- Suggest why particular strategies and interventions from CBT are especially relevant at different parts of that ride
- Make clear the importance of acceptance in living well



It will not...

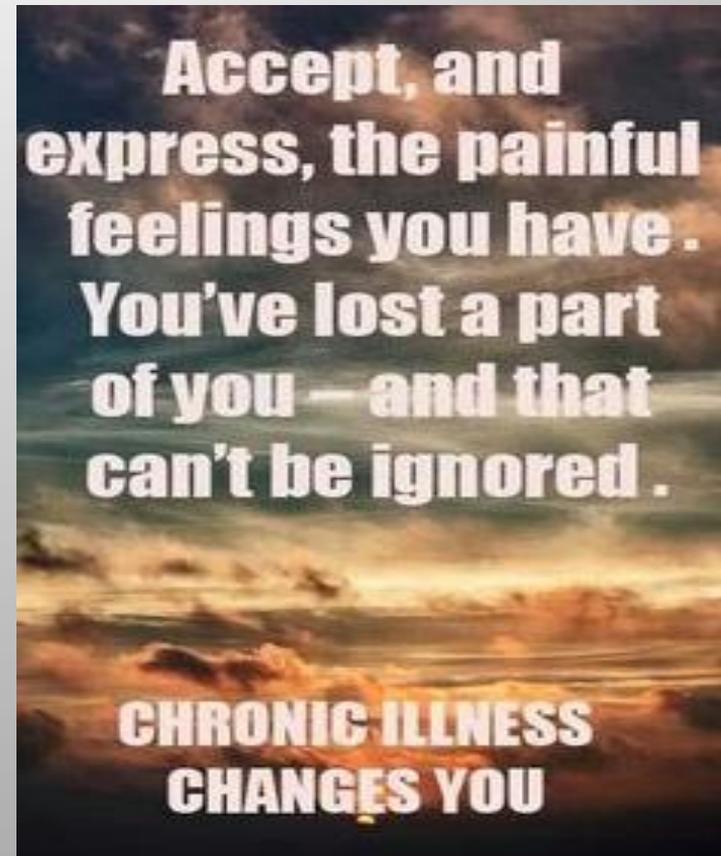
- Suggest psychological processes cause dysautonomia
- Suggest everyone responds to loss or ill health in the same way

People in mourning have to come to grips with death before they can live again. Mourning can go on for years and years. It doesn't end after a year: that's a false fantasy. It usually ends when people realize that they can live again, that they can concentrate their energies on their lives as a whole, and not on their hurt, and guilt, and pain.

Elisabeth Kubler-Ross, *On Death and Dying*

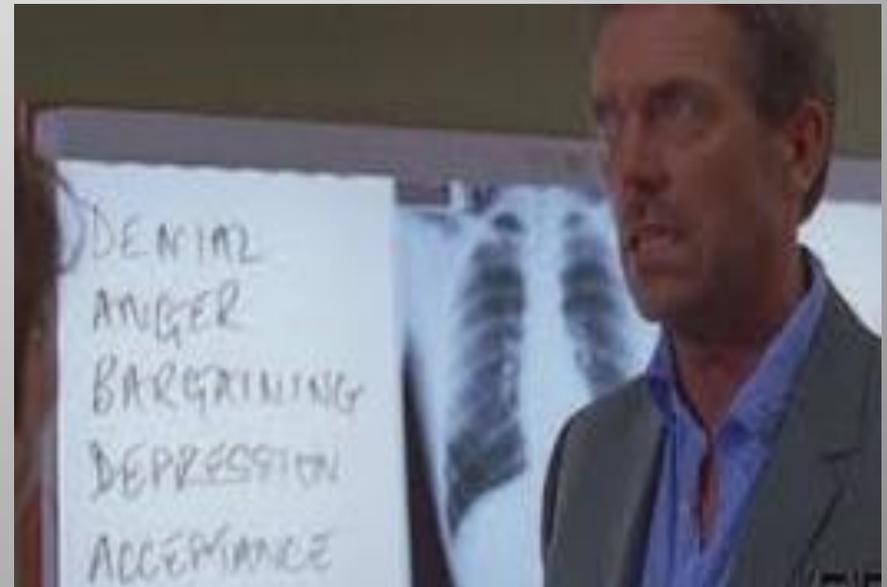
Why a grief model?

- **Illness is undoubtedly loss** – self, immortality, and envisioned future,
- Helps explain why psychological support is relevant
- Helps explain *what* might be relevant *when*
- Encourages self-compassion and understanding and hope
- Permission to grieve



Why a K-R grief model?

- Normalises a common but highly individual and challenging experience and associated complex emotions
- A reminder that loss and adjustment is not binary
- Has good face validity and is helpful for targeting intervention
- If it is good enough for House...



Examples of thoughts at each stage



DENIAL - “They are wrong” “This will pass” “I don’t need to change”

ANGER - “Why me” “Why not you” “It is all their fault” “I hate this and a world that did this to me”

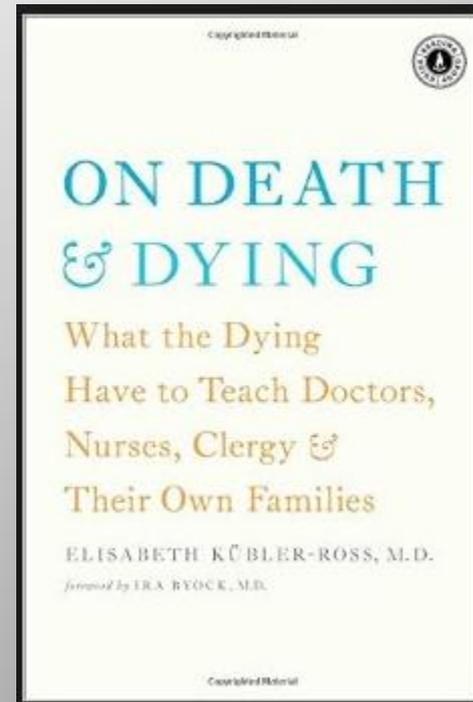
BARGAINING – “I will never say another mean word if I can just be better” “Just let me do this one more test/ try one more treatment and I will do anything”

DEPRESSION – “My situation and my future is bleak” “I don’t know who I am anymore”

ACCEPTANCE - “I don’t like this, but I can still live well and find meaning and joy in life.” “I can balance time dedicated to looking after and improving my health – with still living and loving life with it in the meantime.”

The Model

- The 5 stages of grief by Swiss psychiatrist Kubler-Ross *On death and dying* (1969)– expanded to include other loss including rejection and chronic illness
- Not uncriticised. She herself first to acknowledge that the model not complete and individuals do not progress through stages
- Baxter Jennings, University of Kentucky, 2012 –inadequate consideration of the personal environment – social support and engagement in positive experiences as a very important mediating factor
- McDougall –maximise skills and knowledge and celebrate ongoing personal uniqueness
- **Legacy – discussing feelings candidly and courageously as beneficial to outcome**



Why CBT?

- CBT has a good empirical basis in helping navigate grief and also
- protecting against developing more serious mental-health difficulties

Complicated grief helped by cognitive restructuring and exposure therapy

November 12, 2007 | Written by *Cognitive Behavior Therapy News | Beck Institute Blog*

 2 Comments

The death of a loved one can precipitate the devastating clinical condition known as "complicated grief" (CG). In a [study](#) reported in *Journal of Consulting and Clinical Psychology*, maladaptive thinking and behaviors were described as significant contributors to CG. The effectiveness of cognitive-behavioral therapy (CBT) was compared with nonspecific supportive counseling (SC). In this study, CBT methods included cognitive restructuring and exposure.

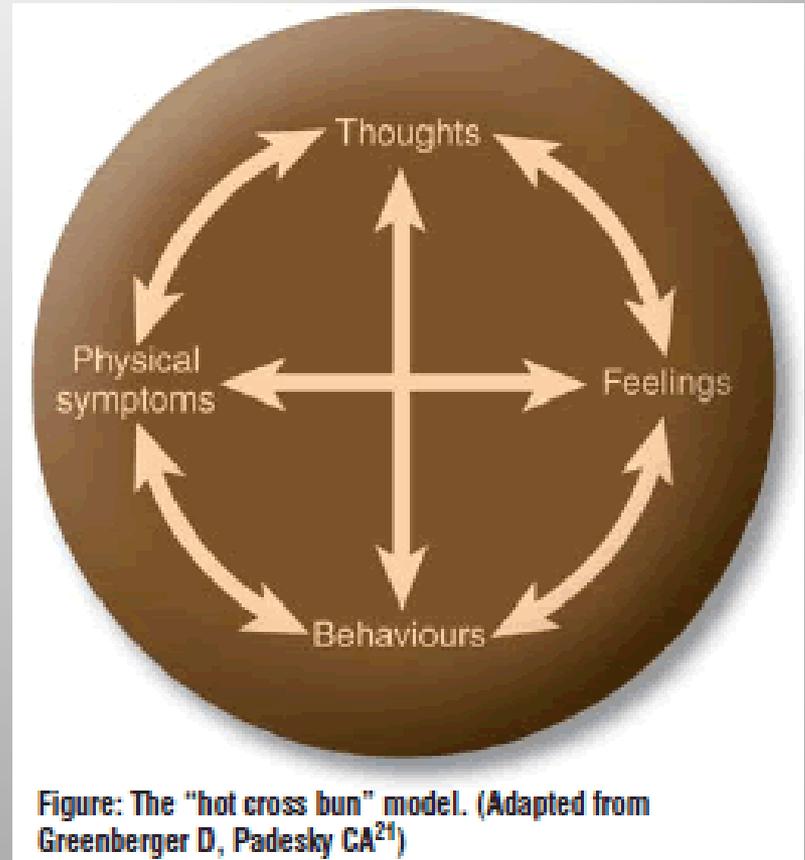
People suffering with CG often avoid reminders of the loss, which, the authors suggested, "is a key maintaining factor in CG." Recovery was aided when patients "gradually confront these reminders and elaborate on the implications of the loss." For example, patients were asked to recount the story of the loss, and therapists identified aspects that were particularly distressing. Homework assignments were aimed at gradually increasing exposure to the reality of the loss.

The study results showed CBT to be more effective than SC and the authors concluded that helping patients to confront and work through the loss is important in treating CG.

Study authors: P. A. Boelen, J. de Keijser, M. A. van den Hout, J. van den Bout

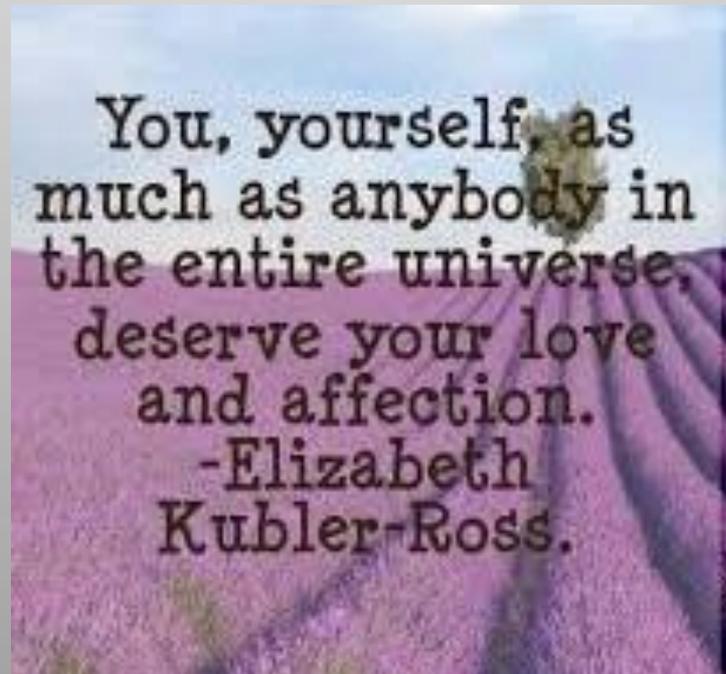
Put simply, CBT is...

- The way we feel isn't directly determined by what life throws at us, but is mediated by our environment, our physiological responses, and also how we think about/evaluate it (*our cognitions*) and what we do as a result (*our behaviours*)
- If we can gain some control over the latter two, we can ultimately have some choice about how we feel.



Put even more simply, CBT is...

- CBT is about how to be as good a friend to ourselves as we generally are to others

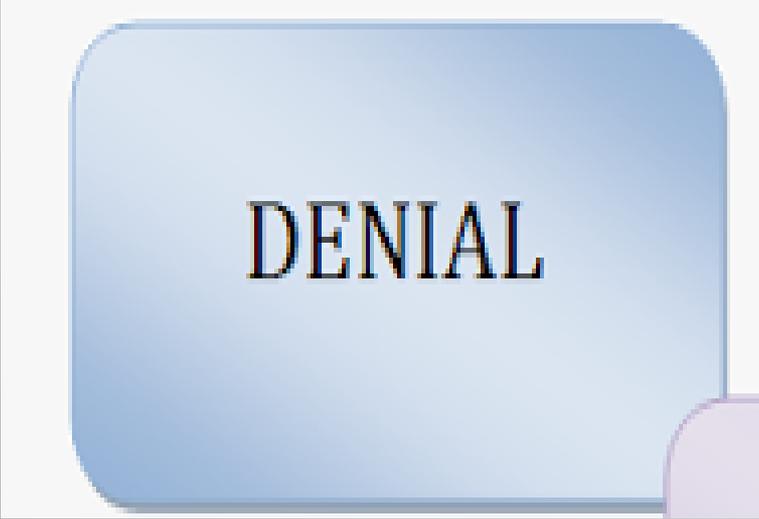


Flags and signposting

- Examine each of the 5 stages of loss in the K-R model
- Consider the psychological processes involved
- Consider ways to support yourself or a loved one at each phase (and perhaps what not to attempt)
- NB **All emotions are legitimate** and understandable (or else we tell ourselves we are somehow unacceptable with consequences for self-esteem and self-trust) – but we can consider them a flag to consider rather than an emotional/behavioural inevitability



1). Shock and Denial



DENIAL

- “They are wrong” “This will pass” “I don’t need to change”
- Reckless or uncharacteristic behaviours
- Emotions numbed

1). Shock and/or denial

- Process of emotional protection, numbing, which can allow time to process manageably
- **Problematic when:** Important lifestyle advice and health-related behaviours are ignored e.g. failing to pace, medicate or to self-soothe, & withdrawal.
- **Useful strategies for shock/denial:** 5 senses soothing, memory box, getting informed, company, establishing simple routines, TIME, rest

I have never met a person
whose greatest need was
anything other than real,
unconditional love.

Elisabeth Kubler-Ross

- Example of a memory/hope box



2). Anger



- “Why me” “Why not you”
“It is all their fault” “I hate this and a world that did this to me”
- Aggressive behaviours
- Externalised emotional expression

2). Anger

- Primary emotions often emerge before more complex emotions surface. Expression can be cathartic and allow more complex cognitive processes to follow and be worked through
- **Problematic when:**
 - a). misdirected and causes further loss as a result (friends, loved ones, medics)
 - b). anger is arousal, fight/flight, an inflammatory process counter to healing and which can exacerbate symptoms of dysautonomia
- **Useful strategies for anger**
 - To recognise it is justified is not the same as feeling it must be fuelled
 - Discreet safe cathartic activities (smashing things, noise etc) and exercise
 - Self-soothing - 5 senses, breathing, relaxation

All-senses soothing strategy for strong emotions including anger

- SELF-SOOTHING has to do with comforting, nurturing and being kind to yourself. One way to think of this is to think of ways of putting together an activity plan/package which soothes each of your five senses:
- **VISION:**
Look at the nature around you. Go to a museum with beautiful art. Buy a flower and put it where you can see it. Sit in a garden. Watch the snowflakes decorate the trees during a snowfall. Light a candle and watch the flame. Look at a book with beautiful scenery or beautiful art. Watch a travel movie or video.
- **HEARING:**
Listen to beautiful or soothing music, or to tapes of the ocean or other sounds of nature. Listen to a baby gurgling or a small animal. Sit by a waterfall. Listen to someone chopping wood. When you are listening, be mindful, letting the sounds come and go.
- **SMELL:**
Smell breakfast being cooked at home or in a restaurant. Notice all the different smells around you. Walk in a garden or in the woods, maybe just after a rain, and breathe in the smells of nature. Light a scented candle or incense. Bake some bread or a cake, and take in all the smells.
- **TASTE:**
Have a special treat, and eat it slowly, savouring each bite. Cook a favourite meal. Drink a soothing drink like herbal tea or hot chocolate. Let the taste run over your tongue and slowly down your throat. Go to a potluck, and eat a little bit of each dish, mindfully tasting each new thing.
- **TOUCH:**
Take a bubble bath. Pet your dog or cat or cuddle a baby. Put on a silk shirt or blouse, and feel its softness and smoothness, or a favourite persons sweater. Sink into a really comfortable bed. Float or swim in a pool, play with playdough

Humour, the great anger diffuser



We have all been here...



3). Bargaining



- “I will never say another mean word if I can just be better” “Just let me do this one more test/ try one more treatment and I will do/give anything”
- Can be prone to desperate acts and illogical behaviours
- Emotions can be chaotically directed

3). Bargaining

- Attempt to gain some control over the situation (i.e. get rid of all pain and symptoms and distress)
- **Problematic when:** magical thinking becomes obsessive or obstructive to positive planning and adaptation
- **Useful strategies for bargaining**
- Use this energy to begin engaging in healthy choices and becoming responsible TO (not for) the illness
- Hope
- Meditation to step back to notice and defuse magical thoughts and increase psychological flexibility
- e.g. replace buts with ands & tolerating not running from pain and difficulty

Meditation

- **Meditation** - benefits wide ranging in health, including bp, cancer progression, even blood-sugar regulation in diabetes)

Cancer



Original Article

Mindfulness-Based Cancer Recovery and Supportive-Expressive Therapy Maintain Telomere Length Relative to Controls in Distressed Breast Cancer Survivors

Linda E. Carlson, PhD^{1,2,4}; Tara L. Beattie, PhD^{1,3,4}; Janine Giese-Davis, PhD^{1,2,4}; Peter Faris, PhD²; Rie Tamagawa, PhD^{1,2}; Laura J. Fick, PhD^{3,4}; Erin S. Degelman, MSc^{3,4}; and Michael Speca, PsyD^{1,2}

BACKGROUND: Group psychosocial interventions including mindfulness-based cancer recovery (MBCR) and supportive-expressive group therapy (SET) can help breast cancer survivors decrease distress and influence cortisol levels. Although telomere length (TL) has been associated with breast cancer prognosis, the impact of these two interventions on TL has not been studied to date. **METHODS:** The objective of the current study was to compare the effects of MBCR and SET with a minimal intervention control condition (a 1-day stress management seminar) on TL in distressed breast cancer survivors in a randomized controlled trial. MBCR focused on training in mindfulness meditation and gentle Hatha yoga whereas SET focused on emotional expression and group support. The primary outcome measure was relative TL, the telomere/single-copy gene ratio, assessed before and after each intervention. Secondary outcomes were self-reported mood and stress symptoms. **RESULTS:** Eighty-eight distressed breast cancer survivors with a diagnosis of stage I to III cancer (using the American Joint Committee on Cancer (AJCC) TNM staging system) who had completed treatment at least 3 months prior participated. Using analyses of covariance on a per-protocol sample, there were no differences noted between the MBCR and SET groups with regard to the telomere/single-copy gene ratio, but a trend effect was observed between the combined intervention group and controls ($F [1,84], 3.82; P = .054; \eta^2 = .043$); TL in the intervention group was maintained whereas it was found to decrease for control participants. There were no associations noted between changes in TL and changes in mood or stress scores over time. **CONCLUSIONS:** Psychosocial interventions providing stress reduction and emotional support resulted in trends toward TL maintenance in distressed breast cancer survivors, compared with decreases in usual care. *Cancer* 2015;121:476-84. © 2014 The Authors. *Cancer* published by Wiley Periodicals, Inc. on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

KEYWORDS: psychosocial interventions, mindfulness-based stress reduction, supportive-expressive therapy, telomere length, clinical trial.

Meditation cont.



Mindfulness-Based Stress Reduction Decreases Fasting Glucose in Overweight and Obese Women

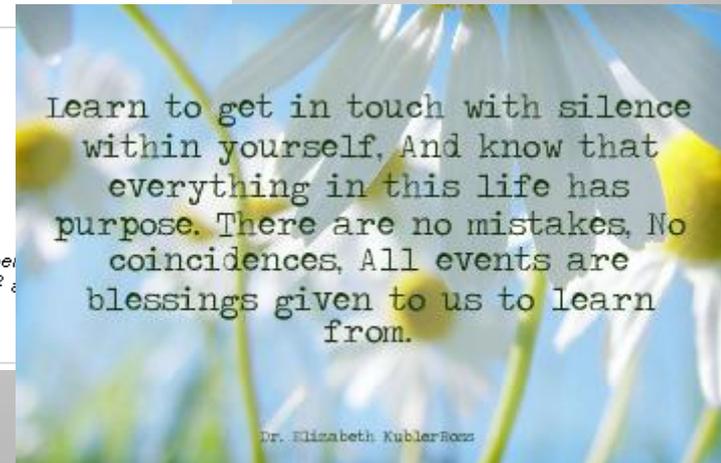
Program: Abstracts - Orals, Poster Previews, and Posters
Session: FRI 542-551-Obesity - Clinical Trials II
Clinical

Friday, March 6, 2015: 1:00 PM-3:00 PM
Hall D-F, Obesity (San Diego Convention Center)

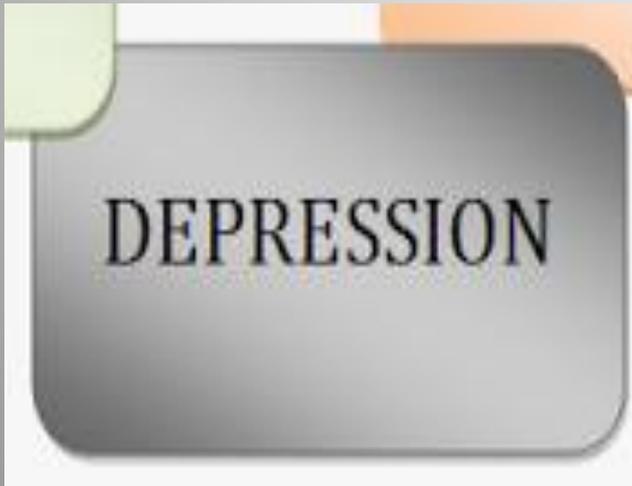
Poster Board FRI-550

Nazia Raja-Khan, M.D.¹, Katrina Agito, M.D.¹, Julie Shah, M.D.¹, Christy M. Stetter, B.S.¹, Thea M.S., R.D.¹, Holly Socolow, M.H.S., C.E.A.P.¹, Allen R Kunselman, M.A.¹, Diane K Reibel, Ph.D.² & MD¹

¹Penn State Univ Coll of Med, Hershey, PA, ²Thomas Jefferson University, Philadelphia, PA



4). Depression

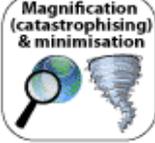


- “My situation and my future is bleak” “I don’t know who I am anymore”
- Withdrawal, lack of self-care
- Internalised emotion

4). Reactive depression

- Very present and deep grief and sadness in reaction to loss. Not indicative of mental illness, but an appropriate response to loss and concern for the future. Associated with anxiety/disinterest in future
- **Problematic when** incapacitating, hope disappears, isolation
- **Useful strategies for reactive depression**
- Paced behavioural activation
- Cognitive work restoring more balanced thinking
- Typical thinking errors from those experiencing loss – grey glasses including

Unhelpful Thinking Styles

 <p>All or nothing thinking</p>	<p>Sometimes called 'black and white thinking'</p> <p><i>If I'm not perfect I have failed</i></p> <p><i>Either I do it right or not at all</i></p>	 <p>Over-generalising</p>	<p>Seeing a pattern based upon a single event, or being overly broad in the conclusions we draw</p>
 <p>Mental filter</p>	<p>Only paying attention to certain types of evidence.</p> <p><i>Noticing our failures but not seeing our successes</i></p>	 <p>Disqualifying the positive</p>	<p>Discounting the good things that have happened or that you have done for some reason or another</p> <p><i>That doesn't count</i></p>
 <p>Jumping to conclusions</p>	<p>There are two key types of jumping to conclusions:</p> <ul style="list-style-type: none">• Mind reading (imagining we know what others are thinking)• Fortune telling (predicting the future)	 <p>Magnification (catastrophising) & minimisation</p>	<p>Blowing things out of proportion (catastrophising), or inappropriately shrinking something to make it seem less important</p>
 <p>Emotional reasoning</p>	<p>Assuming that because we feel a certain way what we think must be true.</p> <p><i>I feel embarrassed so I must be an idiot</i></p>	 <p>should must</p>	<p>Using critical words like 'should', 'must', or 'ought' can make us feel guilty, or like we have already failed</p> <p>If we apply 'shoulds' to other people the result is often frustration</p>
 <p>Labelling</p>	<p>Assigning labels to ourselves or other people</p> <p><i>I'm a loser</i></p> <p><i>I'm completely useless</i></p> <p><i>They're such an idiot</i></p>	 <p>"this is my fault"</p>	<p>Blaming yourself or taking responsibility for something that wasn't completely your fault. Conversely, blaming other people for something that was your fault.</p>

Reactive depression

Thought Record Sheet - Depression

Situation	Unhelpful Thoughts / Images	Feelings: • Emotion/s rate 0 – 100% • Physical sensations	Alternative response / healthier more balanced perspective	What I did / What helped? Action plan / Defusion technique What's the best thing to do?	Re-rate emotion 0 – 100%
<p>What happened? Where? When? (Day & time) Who with?</p>	<p>What went through my mind? What disturbed me? What did those thoughts/images/memories mean to me, or say about me or the situation? What am I responding to? What 'button' is this pressing for me? What would be the worst thing about that, or that could happen?</p>	<p>What emotion did I feel at that time? What else? How intense was it? What did I feel in my body?</p>	<p>Am I looking at things through those 'gloomy specs'? How would things look without those 'gloomy specs'? Am I filtering out and dismissing any alternative perspective? What would someone else say about this situation? Is there another way of seeing it? What's the bigger picture? What advice would I give someone else? Is my reaction in proportion to the actual event? Is this fact or opinion?</p>	<p>What could I do differently? What would be more effective? Do something! What will be most helpful for me or the situation? What will the consequences be of doing or not doing...?</p>	

"The reality is you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same again. Nor should you be the same, nor should you want to."
-Elizabeth Kubler-Ross

5). Acceptance



- “I don’t like this, but I can still live well and find meaning and joy in life.”
- Healthy balanced behaviours (challenges and recuperation)
- Emotions channelled productively

5). ACTIVE Acceptance

- A starting point to make plans, adaptations and alterations to a new reality
- **Problematic when:** stops values-based living and seeking to make life as fulfilling as possible
- **Useful strategies for ACTIVE acceptance**
- Values-based living (still meet values on a 'bad' day, short and long-term plans etc)
- In focusing on what we can do, and tolerating what we can't, we can get a new appreciation for life and what truly is precious and live better, even if wounded, going forward.



“The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.”

~ Elisabeth Kübler-Ross



Acceptance – values can be met multiple ways

Me:

- Somewhat unconventional/qwerky
- A new project on the go
- Reciprocal valuing and generous interactions
- Silliness
- Family – safe-base to explore
- Community/contribution
- Art

• Achievement	• Fast-paced work	• Pleasure
• Advancement and promotion	• Financial gain	• Power and authority
• Adventure	• Freedom	• Privacy
• Arts	• Friendships	• Public service
• Autonomy	• Having a family	• Recognition
• Challenge	• Health	• Relationships
• Change and variety	• Helping other people	• Religion
• Community	• Honesty	• Reputation
• Compassion	• Independence	• Security
• Competence	• Influencing others	• Self-respect
• Competition	• Inner harmony	• Serenity
• Cooperation	• Integrity	• Sophistication
• Creativity	• Intellectual status	• Spirituality
• Decisiveness	• Leadership	• Stability
• Democracy	• Location	• Status
• Economic security	• Love	• Time away from work
• Environmental stewardship	• Loyalty	• Trust
• Effectiveness	• Meaningful work	• Truth
• Efficiency	• Money	• Volunteering
• Ethical living	• Nature	• Wealth
• Excellence	• Openness and honesty	• Wisdom
• Expertise	• Order (tranquility/stability)	• Work quality
• Fame	• Peace	• Work under pressure
• Fast living	• Personal development/learning	• Other: _____

Values-based living template

For each of these domains write a quick summary of your values, for example "to live a healthy life and take care of my body" (physical wellbeing), or "to be a good friend to people who need me, and to enjoy my time with the people I love" (friendships). Rate each domain for how important it is to you from 0-10 (0=not important)

Physical wellbeing

Family relations

Marriage / couple /
intimate relations

Citizenship /
community

Parenting

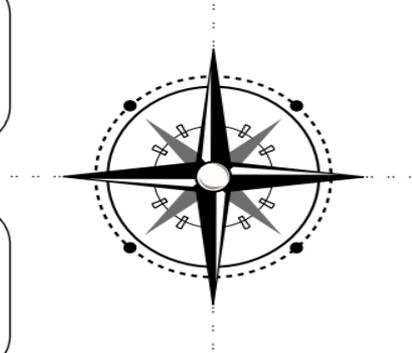
Spirituality

Friendships / social
relationships

Recreation

Education / training /
personal growth

Employment



Take home messages

- Rationale for seeking good emotional and psychological support (to deal with acute distress, prevent long-term deterioration and help to maximise the future)
- Find own ways to switch off fight/flight and have self compassion respond to different ways we react in different times
- Communicate your needs to others



Final thoughts

- Our capacity to heal is affected by our stress (and associated inflammatory processes) and this is affected by our relationships, our behaviours and beliefs – we have a responsibility to do all we can to influence this process positively. Helping ourselves and seeking help through the grief process is one of many important factors in maximising our health.
- Dr Kubler-Ross had very powerful messages about **self-compassion**, **silence within**, **sharing our experiences**, and the **inner-beauty** that can emerge as people find their way through loss

