You Should Totally Meditate!
Realistic, Effective Strategies to Cope with Day-to-Day Life with HPEN

Presented to: Oley Patient Webinar
Presented on: September 10, 2019
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Research Assistant Professor, Division of Gastroenterology
Disclosures

- Speaker, Abbvie (Physician Education)
- Owner, Oak Park Behavioral Medicine LLC
Who Am I?

• Licensed clinical psychologist with specialized training in chronic medical illness
• Private practice owner working with patients living with digestive diseases, including those using HPEN
• Research Assistant Professor studying the social and emotional impacts of digestive disease
• Crohn’s disease patient since 2002, EoE patient since 2016
Today’s Topics

• Quick overview of psychological impacts of HPEN
• What is clinical health psychology?
• What are some treatments health psychologists use?
• How can you implement some of these strategies on your own?
The Potential Impacts are Many

- Anxiety
- Depression
- Quality of life
- Intimacy
- Stigma
- Food anxieties
- Disordered eating

- Insomnia & fatigue
- PTSD
- Body Image
- Sexuality
- Uncertainty
- Social life
- Relationships
And We’ve Known This is an Issue For a While

“If, in addition to being a life-sustaining procedure, TPN is to restore the psychological stability of patients, all team members must be aware of the psychosocial factors involved.”
- Price & Levine, JPEN, 1979
It’s More Than Mood or Worry

“The importance of food and feeding in reliance upon nutrition support incorporates more than the biological value of nutritive food.”

**Neuro-Cognitive Impacts**
- Attention
- “Executive” Function
- Memory
- Learning
- Language Skills
- Motor Skills

**HRQOL Impacts**
- Loss of autonomy
- Role limitations
- Self-Esteem
- Social challenges
- Increased sense of vulnerability

**Eating Impacts**
- Missing favorite foods
- Food takes on new meaning
- Preoccupation with cravings
- Embarrassment
- Not having options

Some Statistics

- 70% of HPN patients have “reasonably good” QOL
- 10% to 80% have depression – from mild to severe
- 41% have frequent anxiety
- 35% to 42% report social impacts
- 27% to 60% report sexual concerns
- 32% to 53% report difficulty traveling
- 23% to 54% report substantial fatigue
- 11% to 26% report concentration difficulties

Huisman-de Waal et al., 2007. The impact of home parenteral nutrition on daily life- A review. *Clinical Nutrition*
Health Related Quality of Life (HRQOL)

- Physical health
- Mental health
- Functional status
- Social support
- Finances
- Resources
- Measures the burden of a chronic illness
What Helps?

• The passage of time
• Maintaining job, family, & financial stability
• Being younger at diagnosis/need for HPEN
• Send supplies ahead when traveling
• Positive social support
• Being connected to a patient organization
What is Clinical Health Psychology?

“The interdisciplinary field concerned with the development and integration of behavioral, psychosocial, and biomedical science knowledge and techniques relevant to the understanding of health and illness, and the application of this knowledge and these techniques to prevention, diagnosis, treatment and rehabilitation.”
Bio-Psycho-Social Model

BIOPSYCHOSOCIAL APPROACH TO UNDERSTANDING HEALTH

Gender
Physical illness
Disability
Genetic vulnerability
Immune function
Neurochemistry
Stress reactivity
Medication effects

Learning/memory
Attitudes/beliefs
Personality
Behaviours
Emotions
Coping skills
Past trauma

Social supports
Family background
Cultural traditions
Social/economic status
Education

Northwestern
Feinberg School of Medicine
Stress-Symptom Cycle

- Worsening GI Symptoms
- Initial GI Discomfort (nausea, abdominal pain, diarrhea)
- Unhelpful Thoughts (“Oh no, here we go again…”)
- Emotions (anxious, embarrassed, angry)
- Sympathetic Arousal (HR, respiration, GI distress)
So We Develop Habits

- Plan my day and my eating around the disease
- Scared to eat in the morning if I know I have to go anyplace for fear of urgency, pain, or having to use bathroom at inopportune time.
- Wait until end of day to eat so I am in control of where I am when symptoms are triggered
- Not eating at all so that you don’t experience pain or other symptoms
- Constantly researching information on the Internet to see how specific foods react to others even though it isn’t reliable….most everyone has a different experience
- When you get home you automatically go into the bathroom after you've been out to eat even if you don't have to go.
Get “gutsy” and eat a food you desperately crave but know it will hurt later....but you eat it anyway!
Can’t Just enjoy a meal

Fear of trying new foods

Constant vigilance to urgency or pain

Bored with eating the same things

Can’t eat fresh fruits & veggies

Can't Just enjoy a meal
What Do Psychologists Do with HPEN Patients?

• Cognitive-Behavioral Therapy (CBT)
  – Behavioral Self Management
• Gut-Directed Hypnotherapy (GDH)
• Mindfulness Based Therapy (MBT)
• Acceptance & Commitment Therapy (ACT)
Psychogastroenterology treatments offer a direct, non-drug strategy to reduce the impact of stress, whether it’s daily hassles or major life events, on bodily functions.

**Pros:** Effective, no side effects

**Cons:** Takes practice, motivation, lack of trained GI psychologists
Barriers to Seeking Mental Health Care

- IBD Provider Discounts Therapy: 7%
- Therapy for IBD is Ineffective: 9%
- Implication that Symptoms Aren’t Real: 10%
- Implication of Mental Illness: 20%
- Excessive Travel Required: 20%
- Stigma Associated with Therapy: 24%
- Scheduling Conflicts/Time Commitment: 36%
- Inadequate Insurance Coverage: 44%
- Lack of Therapists who Understand IBD: 50%
- High Therapy Costs: 55%

Taft et al., How Well is Mental Health Integrated into Inflammatory Bowel Disease Patient Care in the United States: Insights from a Patient Survey, In Press, 2018
Contrary to what Dr. Phil implies, making meaningful change takes a lot of time and practice. But most people can do it on their own with the proper tools.
3 Things to Evaluate
How is My Social Network?

• Have I told anyone that I use HPEN or about my disease?
  – Research shows that disclosing an illness is the better option
• Who are the people in my social network?
  – Who can I count on?
  – Who might not be the most helpful?
• What online resources do I use?
  – Are they helpful?
  – How do I feel after I use them?
• How is my relationship with my doctor?
<table>
<thead>
<tr>
<th>CHRONIC ILLNESS BINGO</th>
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</thead>
<tbody>
<tr>
<td>You need to get out more</td>
<td>Are you getting enough sleep?</td>
<td>You sleep too much</td>
<td>You don't look sick</td>
</tr>
<tr>
<td>My friend was cured by...</td>
<td>Yesterday you ___? Why can't you today?</td>
<td>Have you tried ___?</td>
<td>You need to exercise</td>
</tr>
<tr>
<td>You should try this diet</td>
<td>Oh, I get that too</td>
<td>Are you trying hard enough?</td>
<td>Dr. Oz says...</td>
</tr>
<tr>
<td>I wish I didn't have to work</td>
<td>It could be worse</td>
<td>Just push through it</td>
<td>It's made up by big pharma</td>
</tr>
<tr>
<td>Are you better yet?</td>
<td>You're just stressed</td>
<td>I haven't heard of that</td>
<td>Is it real?</td>
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Am I Taking Basic Care of Myself?

- What do I do to de-stress?
  - Does it work?
- If I don’t exercise regularly, what is keeping me from doing so?
- How’s my diet?
- How’s my sleep?
- How much “down-time” do I allow myself every day?
Tools for Self-Care

- What have you tried?
- What works?
- What doesn’t work?
Mind Reading

Fortune Telling

Discounting Positives

Catastrophic Thinking

Should Ought To Must

Negative Filter

What Ifs?

Dichotomous Thinking

Personalizing

Over-Generalizing

Unfair Comparisons

@DrTiffTaft
Start with Diaphragmatic Breathing

Primary Targets
- Nervous System Arousal
- Hypersensitivity in the Gut

Secondary Targets
- Worry About Symptoms
- Hypervigilance
- Low Mood
Practice twice a day
For at least 2 weeks before
Assessing how well this
Works for you.

It may feel weird at first
Especially if you are mostly
A chest breather

DON’T only practice this
During peak stress. Like
Bringing a fire extinguisher
To a 5 alarm fire
Yes, You Should Try Meditation

Benefits of Meditation

- Reduces pain and enhances the immune system
- Increases blood flow & helps reverse heart disease
- Helps control negative thinking
- Stress reducing
- Provides a sense of calm, peace & balance
Practice 3-4 times a week For at least 2 weeks before Assessing how well this Works for you.

It may feel weird at first Especially if you have a lot Of thoughts or don’t sit still easily

DON’T only practice this During peak stress. Like Bringing a fire extinguisher To a 5 alarm fire
What Else Ya Got, Doc?

Cognitive Behavioral Therapy
Think of Your Brain Like a Cell Phone
Think of Your Brain Like a Cell Phone
Start Here

Tell yourself “STOP”

Take some breaths

Notice what you are thinking and feeling
First, Write it Down

What will help and be best for me, others and this situation right now?

Get a journal and keep it with you so you can jot things down as soon as possible after.

Keep your journal next to your bed to review or write down other things.

Give this at least 2 weeks of practice.
Dial Up Your Relaxation Skills

What will help and be best for me, others and this situation right now?

Imagery is considered to be more effective when we are feeling relaxed, so when using these imagery techniques for self help, start by:

- getting comfortable in a quiet place where you won't be disturbed
- focus on your breathing for a few in and out breaths
- close your eyes
- become aware of any tension in your body
- let that tension go with each out-breath
Dial Up Your Relaxation Skills

All imagery can be strengthened by ensuring you engage all your senses in building the picture in your mind's eye - it is more than just "seeing"!

If you notice any negative links or images entering your positive imagery (or positives entering negative imagery), then abort that image and think of something else.

Finish each visualization by taking a few moments to bring yourself back into the room where you are

- open your eyes
- sit up
- look around and notice what you see in the place where you are right now
Modifying Your Thinking

• Stop, take a deep breath or 2
• Write down your thoughts
• Evaluate each one
  – How useful is it?
  – What’s the evidence to support it?
  – What are some alternative explanations?
• How much control do I really have?
• Is this a solvable problem?
• Am I underestimating my ability to cope?
• What would I tell a friend?
# Replace Negative with Positive

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Negative Self-Talk</th>
<th>Positive Self-Talk</th>
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<tbody>
<tr>
<td>Meeting someone new</td>
<td>&quot;They won’t like me. &quot;</td>
<td></td>
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<tr>
<td>Trying something that seems hard</td>
<td>&quot;I can’t do it. ”</td>
<td></td>
</tr>
<tr>
<td>Tasting something you have never tried</td>
<td>&quot;I won’t like it. ”</td>
<td></td>
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<tr>
<td>Joining a group conversation</td>
<td>&quot;I have nothing to say. ”</td>
<td></td>
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<tr>
<td>Doing something you have never done before</td>
<td>&quot;I am scared. &quot;</td>
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What do you want to write about? Name it.

Review or reflect on it – close your eyes, take deep breaths, and focus.

Investigate your thoughts & feelings. Just start writing and keep writing.

Time yourself – write for 5 to 15 minutes straight.

Exit “smart” by re-reading what you’ve written & reflecting on it with 1 or 2 sentences.
It’s OK to write only a few words. It’s OK to write pages. Simply write at your pace.

Don’t worry about how well you write. Write down what makes sense and what comes naturally to you.

Write as if no one will read it. This allows you to write authentically.
We Need To Have Some Degree of Acceptance

"Acceptance doesn't mean resignation. It means understanding that something is what it is and there's got to be a way through it"

- Michael J. Fox
How Do I “Accept” Life with HPEN / My Disease?

- Being Present: Focus on the here and now
- Acceptance: Be willing to experience difficult thoughts
- Defusion: Observe your thoughts without being ruled by them
- Values: Discover what is truly important to you
- Commitment: Take action to pursue the important things in your life
- Self as Context: See yourself as unchanged by time and experience

Northwestern Medicine
Northwestern School of Medicine
@DrTiffTaft
First: What Are My Values?

A value is a life direction, an internal compass which guides us throughout life. Values are different to goals which have an end-point. Values are often life-long. Perhaps what we would like to be remembered for, or written as our epitaph, our headstone inscription.

Values give life meaning and purpose.

To identify our values, we can think about what it is in life that is \textbf{REALLY} important to us, the most important, what gives our life meaning and purpose.
Is it our relationships, e.g. to be a good parent? Is it our careers, connecting with nature, healthy living, community service or making a difference? Consider what legacy you want to pass on.

Having identified our values, we know where we want to go in life, the direction we want to progress towards. We might set goals along the way.

Knowing our values will help us decide how to react to stress and distress. In spite of how we feel, we can still move in the direction and service of our values.
<table>
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<tr>
<th>STRUGGLE &amp; SUFFERING</th>
<th>RICH &amp; MEANINGFUL LIFE</th>
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<tbody>
<tr>
<td><strong>Problematic Thoughts And Feelings:</strong> What memories, worries, fears, self-criticisms, or other thoughts do you get “caught up” in? What emotions, feelings, urges, or sensations do you struggle with?</td>
<td><strong>Problematic Actions:</strong> What are you doing that makes your life worse in the long run: that keeps you stuck; wastes your time or money; drains your energy; impacts negatively on your health or your relationships; or leads to you “missing out” on life?</td>
</tr>
<tr>
<td><strong>Values:</strong> What matters to you in the “big picture”? What do you want to stand for? What personal qualities and strengths do you want to develop? How do you want to enrich or improve your relationships? How would you like to “grow” or develop, through addressing your issue(s) or problem(s)?</td>
<td><strong>Goals &amp; Actions:</strong> What are you currently doing that improves your life in the long run? What do you want to start or do more of? What life-enriching goals do you want to achieve? What life-enhancing actions do you want to take? What life-improving skills would you like to develop?</td>
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Second: Get Present (Looks Familiar, Right?)

Notice Five Things
This is yet another simple exercise to center yourself and engage with your environment. Practice it throughout the day, especially any time you find yourself getting caught up in your thoughts and feelings.

1. Pause for a moment
2. Look around and notice five things that you can see.
3. Listen carefully and notice five things that you can hear.
4. Notice five things that you can feel in contact with your body (for example, your watch against your wrist, your trousers against your legs, the air on your face, your feet upon the floor, your back against the chair).
5. Finally, do all of the above simultaneously
3. Mindfulness of Pleasant Activities

Pick an activity you enjoy such as cuddling with a loved one, eating lunch, stroking the cat, playing with the dog, walking in the park, listening to music, having a soothing hot bath, and so on. Do this activity mindfully: engage in it fully, using all five of your senses, and savor every moment. If and when your attention wanders, as soon as you realize it, note what distracted you, and re-engage in whatever you’re doing.
Acceptance Resources

The Bus Technique: https://www.theemotionmachine.com/the-mindbus-technique/


The Struggle Switch: https://www.youtube.com/watch?v=rCp1l16GCXI

The Sushi Tray: https://youtu.be/tzUoXJVI0wo

Many other short exercises to try: http://eightfoldcounseling.com/act-metaphors/
Another Buzzword: Resilience

Resilience is very different than being numb. Resilience means you experience, you feel, you fail, you hurt. You fall. But, you keep going.

Yasmin Mogahed
What the Heck Is Resilience?

- **Natural resilience**: What you’re born with, your human nature and drive to survive.
- **Adaptive resilience**: ”Trial by Fire” or how we learn to change and adapt after challenges.
- **Restored resilience**: Aka “learned”. Strategies to help tap into your natural resilience.
### Strategies

**The 4-factor Approach**

1. Stating the facts.
2. Placing blame where it belongs.
3. Reframing.
4. Giving yourself time.

**Scenario:** Need to have my catheter replaced again.

<table>
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<tr>
<th>Step</th>
<th>Example Things to Say or Do</th>
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<tbody>
<tr>
<td>Talk about problem without magnifying it</td>
<td>“My catheter needs to be replaced and that’s annoying, but I caught it before I got an infection.”</td>
</tr>
<tr>
<td>Take ownership but don’t beat yourself up</td>
<td>“Ok, my catheter is bad. It happens. I took really good care of it and did my best. I’m OK.”</td>
</tr>
<tr>
<td>Re-frame and Re-evaluate</td>
<td>“Things could have been worse. I could have gotten an infection. I’ve only had to have my catheter replaced one other time many years ago.”</td>
</tr>
<tr>
<td>Take time to heal and adjust</td>
<td>Make time for solitude. Cultivate humor. Do a relaxation exercise.</td>
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Gratitude Apps

ThinkUp

SMILING MIND

shine

happify
Resilience Resources

- https://positivepsychologyprogram.com/resilience-activities-worksheets/
- https://www.mindful.org/how-to-cultivate-the-resources-for-resilience/
Seeking Help

• If you’re struggling on your own, consider therapy
• Most insurance covers mental health visits without limits
• Ask any potential therapist about their experience working with people who have chronic illnesses
• What does successful therapy mean? A good fit
Questions to Ask a Potential Therapist

✓ What is your approach to treatment?
✓ How many clients have you seen with [my illness/on HPEN]?
✓ Do you have any specialty training in chronic illness?
✓ How long does your typical client work with you?
✓ What strategies do you use most often with your clients?
✓ Do you accept insurance?
✓ How will you work with my physician?
✓ What are you fees?
Important Takeaways

1. Emotional impacts are consistent over the entire course of HPEN use and can be independent of remission status of underlying disease
2. Intervention BEFORE emotional impacts become overwhelming lead to best outcomes
3. Most people are able to implement self-help strategies but enough time is needed before giving up
4. Practice anything for at least 2 weeks
5. Use the technology
6. Reach out to a professional if you continue to struggle
Thank You!

THE LAST OF HUMAN FREEDOMS

THE ABILITY TO CHOOSE ONE’S ATTITUDE IN ANY GIVEN SET OF CIRCUMSTANCES,

THE ABILITY TO CHOOSE ONE’S OWN WAY.

VIKTOR FRANKL