

Telling your Illness Story: How to Use Your Brain to Influence Your Body:

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Goals of Talk

- Challenges of having IBD.
- Why how you experience having IBD is important.
- How telling your story about IBD can help you cope better.

What contributes to adaptive versus poor coping with IBD ?

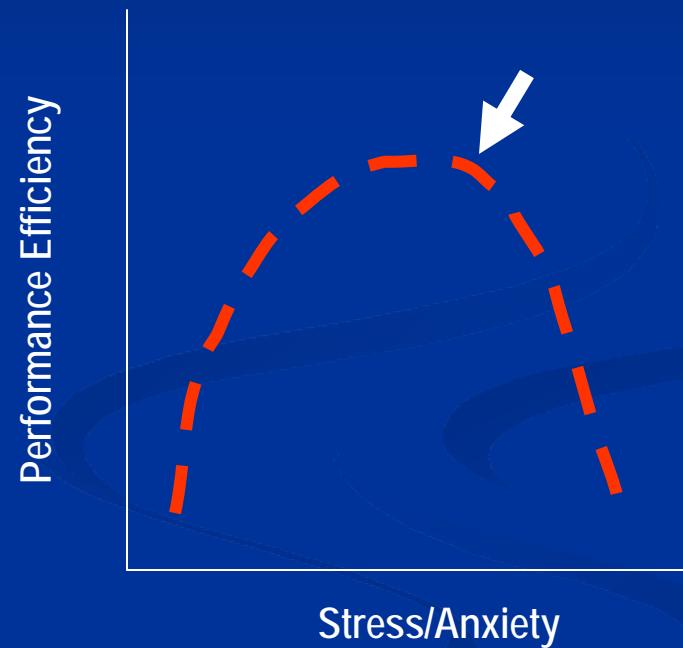
STRESS

What is **STRESS**?

- Stress results when something that happens to you exceeds the capacity of your mind to deal with the event effectively.
- The mental and physical effects of stress are due to the elevation of stress hormones that occurs when the stress related areas of the brain are activated
- Coping with stress means that you use thoughts and behaviors to keep stress reactive areas of the brain quiet.

Stress Can Exact A Toll On Body & Mind

- Can be useful in enhancing performance & efficiency
- Can be harmful & negative especially when it becomes chronic & excessive



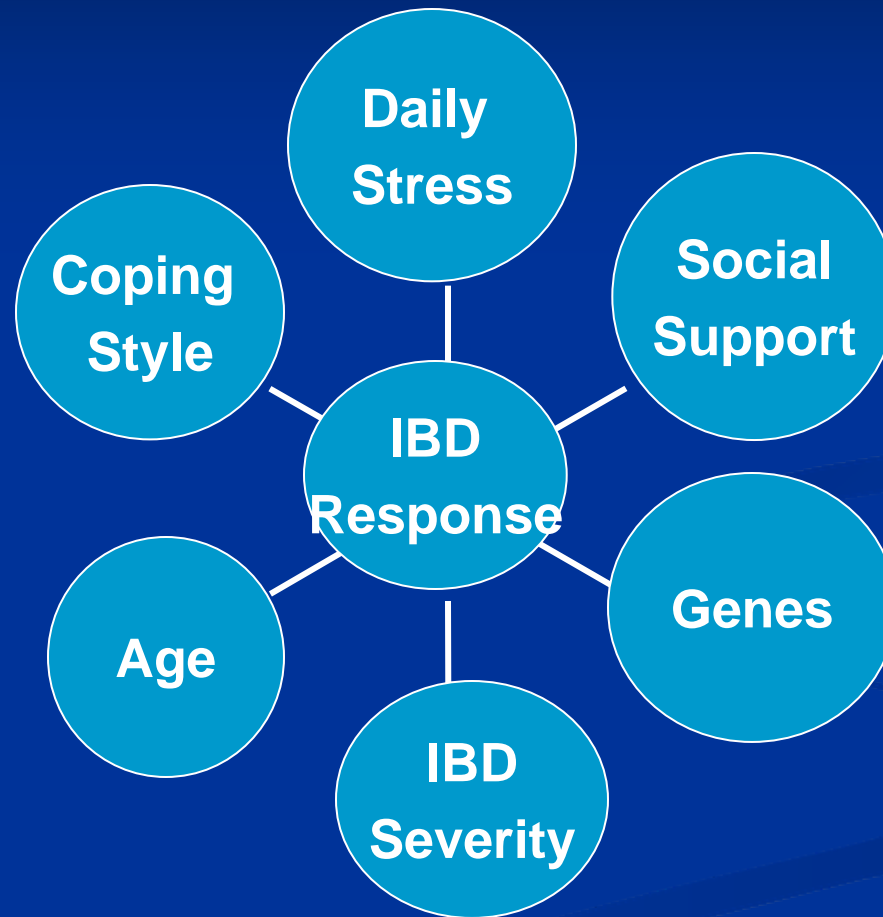
Effects of Stress on the Mind and Body

- Difficulty thinking clearly and focusing
- Depression, irritability or the “blues”
- Forgetfulness
- Fatigue
- Increased sensitivity to aches and pains
- Increased heart rate and breathing rate
- Increased muscle tension
- Increased blood glucose levels and insulin levels
- Immune system suppressed
- Decreased ability to fight infection

Consequences of Stress in Physically Ill Children

- Worse physical illness symptoms and course
- Decreased quality of life and functioning
- Medication non-adherence

Factors Contributing to IBD Response



Risk Factors for Impaired Coping with IBD

- Social isolation from peers
- Family conflict
- Excessive denial
- Anxiety and/or depression

Protective Factors in Coping with IBD

- Stable social support system
- Self-confidence/ self-efficacy
- Continued involvement in extracurricular activities
- Knowledge about health condition and belief that one can influence illness course
- Appropriate appraisal of stress and matching of coping strategy

What do we know about how to cope with stress?

Importance of Physical Illness Narrative

- Adjustment to illness is strongly associated with perceptions and experiences with illness
- Strong relationship between illness perceptions and coping, mood, functional adaptation, and medication adherence.
- Research indicates positive effects in patients who write or tell their stories about illness

How to tell your story...

What do you call your problem?

What do you think caused your problem?

Why do you think it started when it did?

What does your sickness do to you? How does it work?

How severe is it? How long do you think you will have it?

What do you fear most about your illness?

What are the chief problems your sickness has caused you?

Anyone else with the same problem?

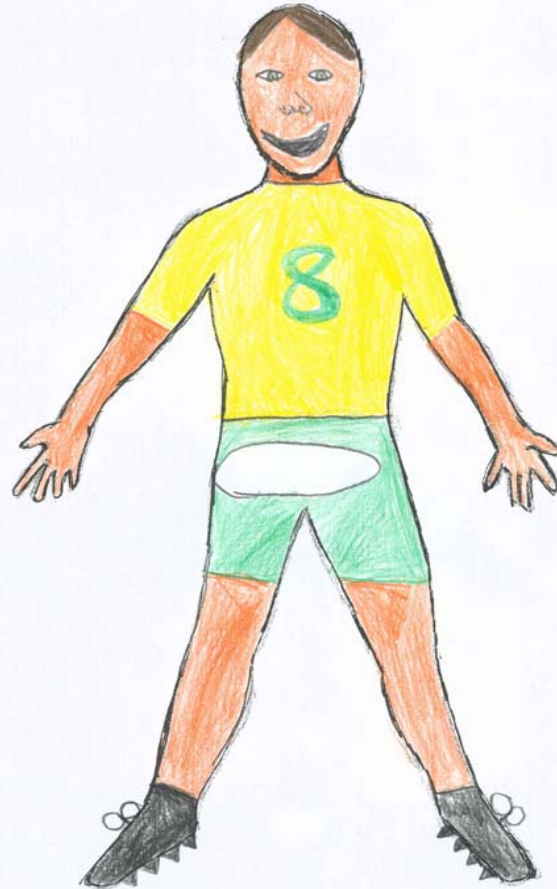
What have you done so far to treat your illness?:

Who else can help you?

Show us where in your body IBD affects you?

Show us where in your body IBD affects you?

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Importance of Physical Illness Narrative

- Individual adjustment to illness strongly associated with perceptions and experiences with illness
- Relationship between cognitive illness perceptions and coping, mood, functional adaptation, and medication adherence.
- Patients cluster ideas about illness into 5 components (illness narrative; Leventhal 1998):
 - Identity
 - Cause
 - Time-line
 - Consequences
 - Cure-control

Analysis of Illness Narratives

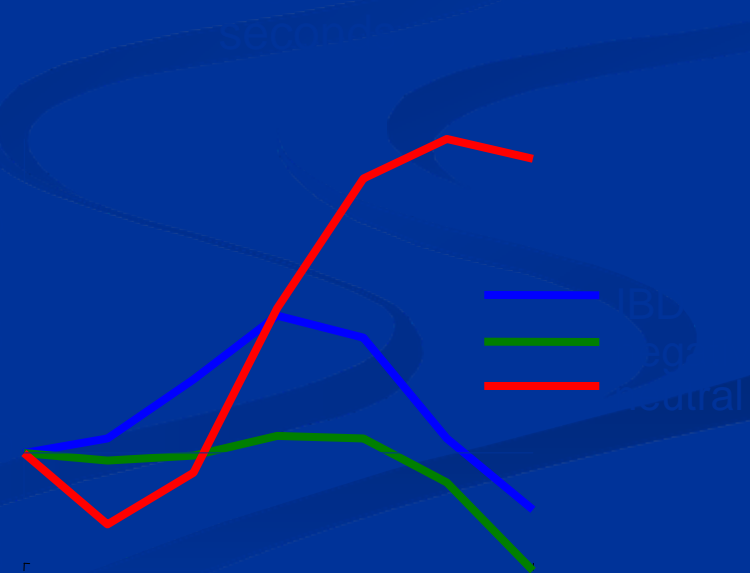
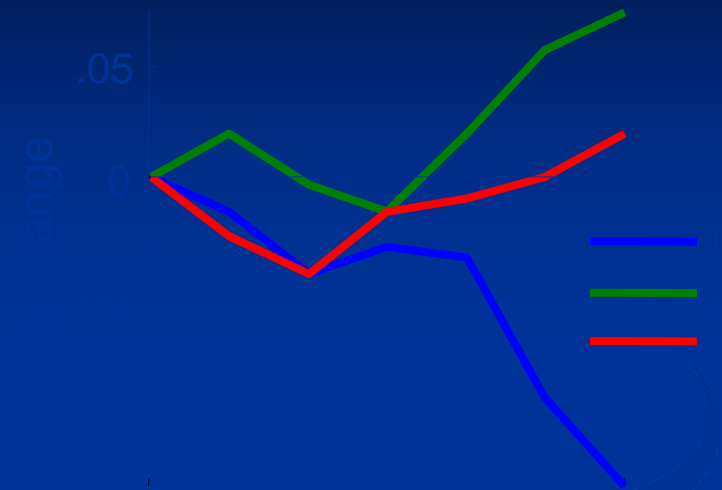
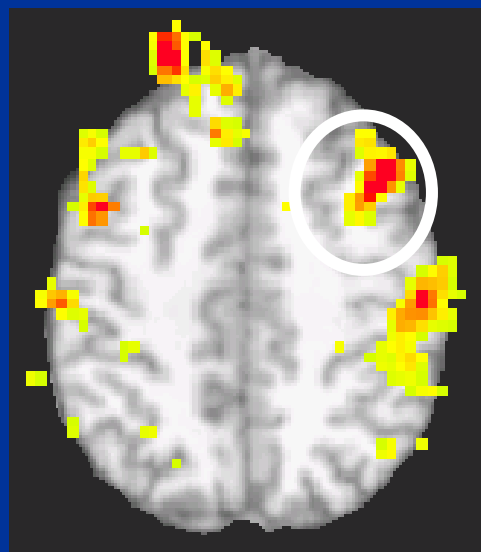
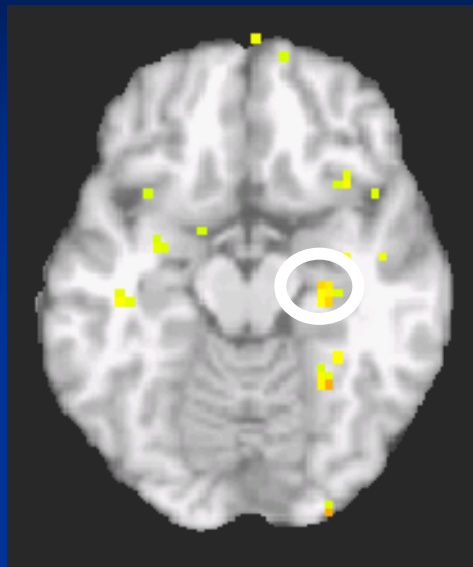
- 20 adolescents with IBD and depression
- NVivo qualitative narrative analysis coding for themes from transcribed illness narrative interviews.
- Most common themes:
 - Damaged Self
 - Negative Contingency
 - Pessimism
 - Preoccupation with food
 - Preoccupation with bathroom access
 - Parent/child conflict over IBD management

Do depressed teens with IBD process illness specific negative words differently than non-depressed IBD teens?

Words Used in the KVID Task

- ┌ **Negative Words-** angry, bad, cry, die, scared
- ┌
- ┌ **Illness Words-** diarrhea, toilet, pain, surgery
- ┌
- ┌ **Neutral Words-** bird, computer, pencil, tree

Regions that differentially responded to negative, illness and neutral words (n=4; p<.005)



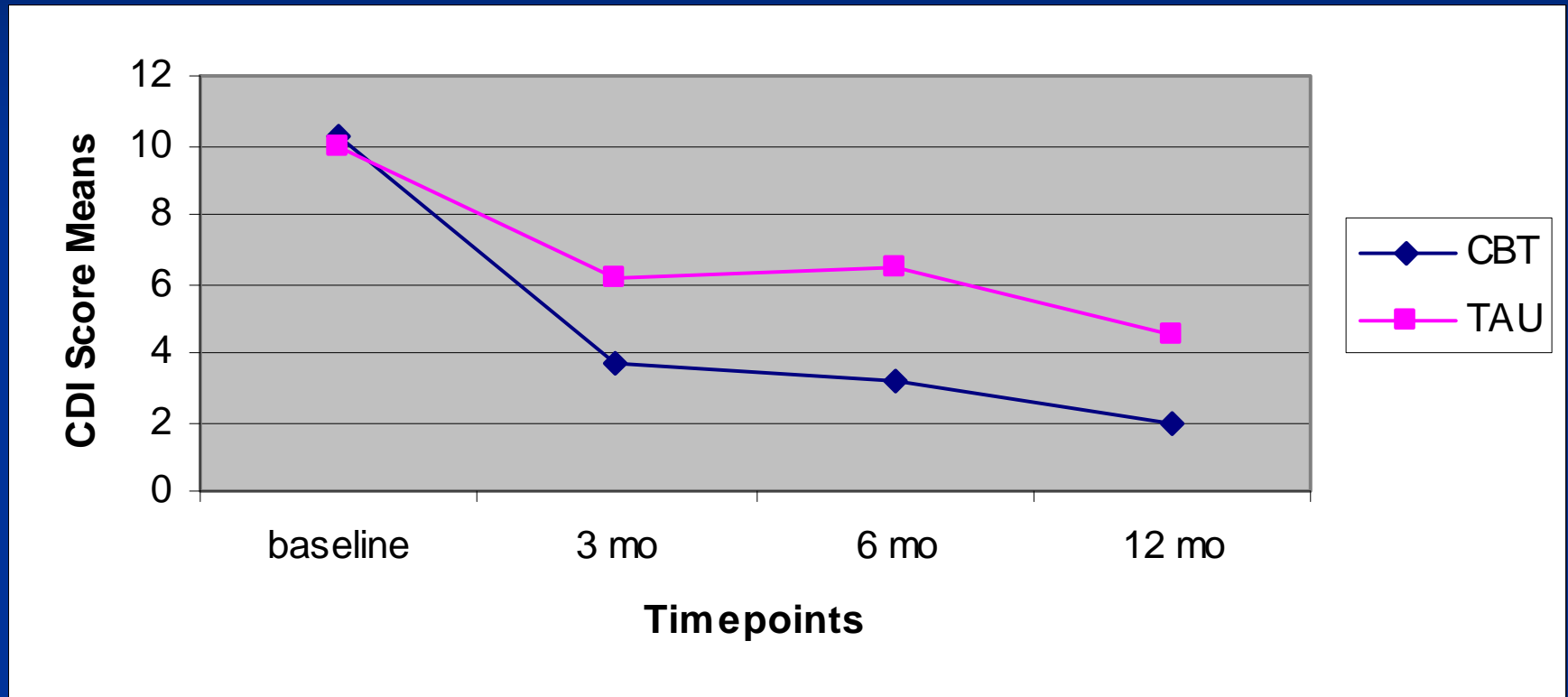
These preliminary data show that youth with IBD differentially process general negative words versus IBD-related negative words.

Children with IBD may be suppressing or trying to forget illness-related words.

ACT & THINK CHART

- **A** Activities
- **C** Calm & Confident
- **T** Talents
- **T** Think Positive
- **H** Help from a Friend
- **I** Identify the Silver Lining
- **N** No Replaying Bad Thoughts
- **K** Keep Thinking- Don't Give Up

Significant Reduction in Depressive Severity in Cognitive Behavioral Therapy group compared to Treatment as Usual over 12-months in Youth with IBD



There was also a significant improvement in global functioning and IBD severity in the CBT group.

Personal Stress Management- things you can do.....

- Taking daily time outs – yoga, exercise, hobby, meditation
- Social Support
- Relaxation Techniques
- Laughing Place
- Journaling



The Art of Positive Thinking....Reversing
BLUE thoughts....

- **B**laming yourself
- **L**ooking for the negative
- **U**nhappy guessing
- **E**xaggeration

Physical Illness Narratives

Subject	Pre-CBT Physical Illness Narrative	CBT Skills for IBD-related problems	Post-CBT Physical Illness Narrative
<p>15 year old female</p>	<p>“I know it’s genetic but I still blame myself.</p> <p>I hate the pain in my stomach when I have a flare-up and having to use the bathroom a lot.</p> <p>There is nothing good and everything bad about having IBD.”</p>	<ul style="list-style-type: none"> * Reinforcing knowledge about causes of IBD * Problem-solving about using public bathrooms * Relaxation for Pain * Cognitive reframing of negatives 	<p>“Finding things you can enjoy doing might help to cope when you are not feeling well.</p> <p>It is important to let your closest friends know about your illness so they can support you when you are feeling sick.</p> <p>It could be worse- I could need surgery.”</p>

www.experiencejournal.com

Example from 15 year old: “My Advice”

“Finally, as a seasoned IBD patient, I have the following advice to offer:

Don't focus on what you can't do because of your disease but instead busy yourself with what you can do.

Tell as many people as you can about your situation. I know it's really hard to tell your friends and you're not sure how they'll react, but as I got older I found that I could tell more of my friends, and when I did they were completely understanding and supportive.

Listen to your doctors! Despite what you may think, they DO know more than you do and probably put you on a medication for good reason, so try really hard not to miss doses.

Don't give up; just keep fighting. I'm constantly on the lookout for new studies and drugs and will hopefully find one that works well and has few side effects.”

Experience Journal Specific Impacts

	<u>Mean (SD)</u>
Sense others facing the same issues	6.4 (0.9)
Helpful to read about others experiences	6.1 (1.4)
Decreased the extent to which you felt alone	5.8 (1.5)
Increased your sense of hope	5.4 (1.4)
Increased your understanding of experience	5.4 (1.4)

Note: 7-point scale anchored at one end by "1 = not at all" and at the other end by "7 = a great deal" or "extremely satisfied."

Web Statistics

September 2001 – May 2007

- 298,237 Total visitors to date
- 4,386* Mean visitors per month
- 4,315,240 Total hits
- 4.2 Mean minutes per visit

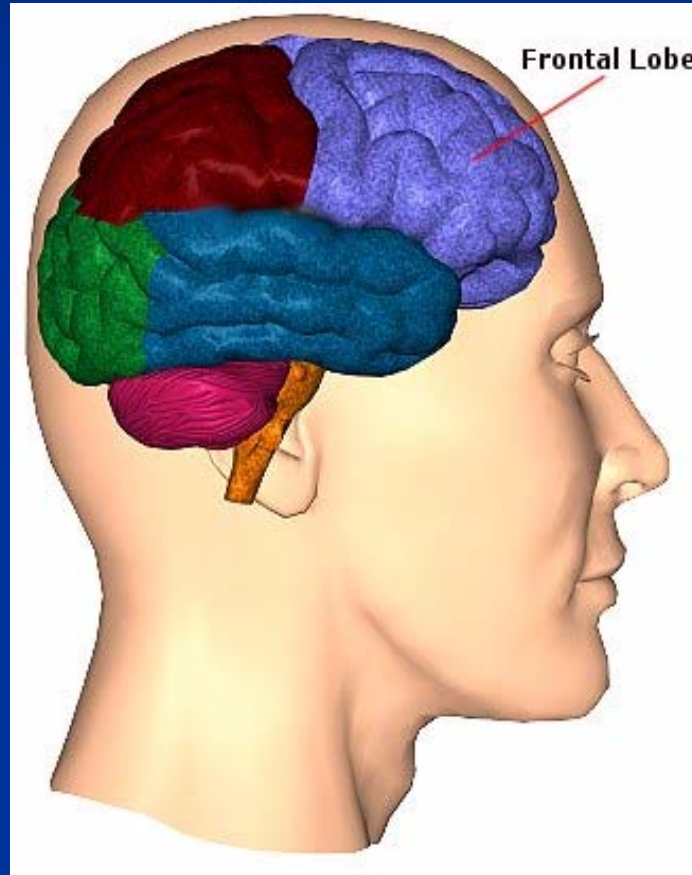
GIRLS CONNECT

Effects of a support group for teenage girls with inflammatory bowel disease and their mothers



- 1) Provided a forum for mothers and daughters to discuss day-to-day issues they face living with IBD; 2) helped and encouraged this group to learn all that they could about coping with IBD; and 3) provided valuable social support with other girls and mothers struggling to manage IBD.
- Both daughters and their mothers described the Girls Connect program as very helpful and very satisfying and improved self-reported quality of life.

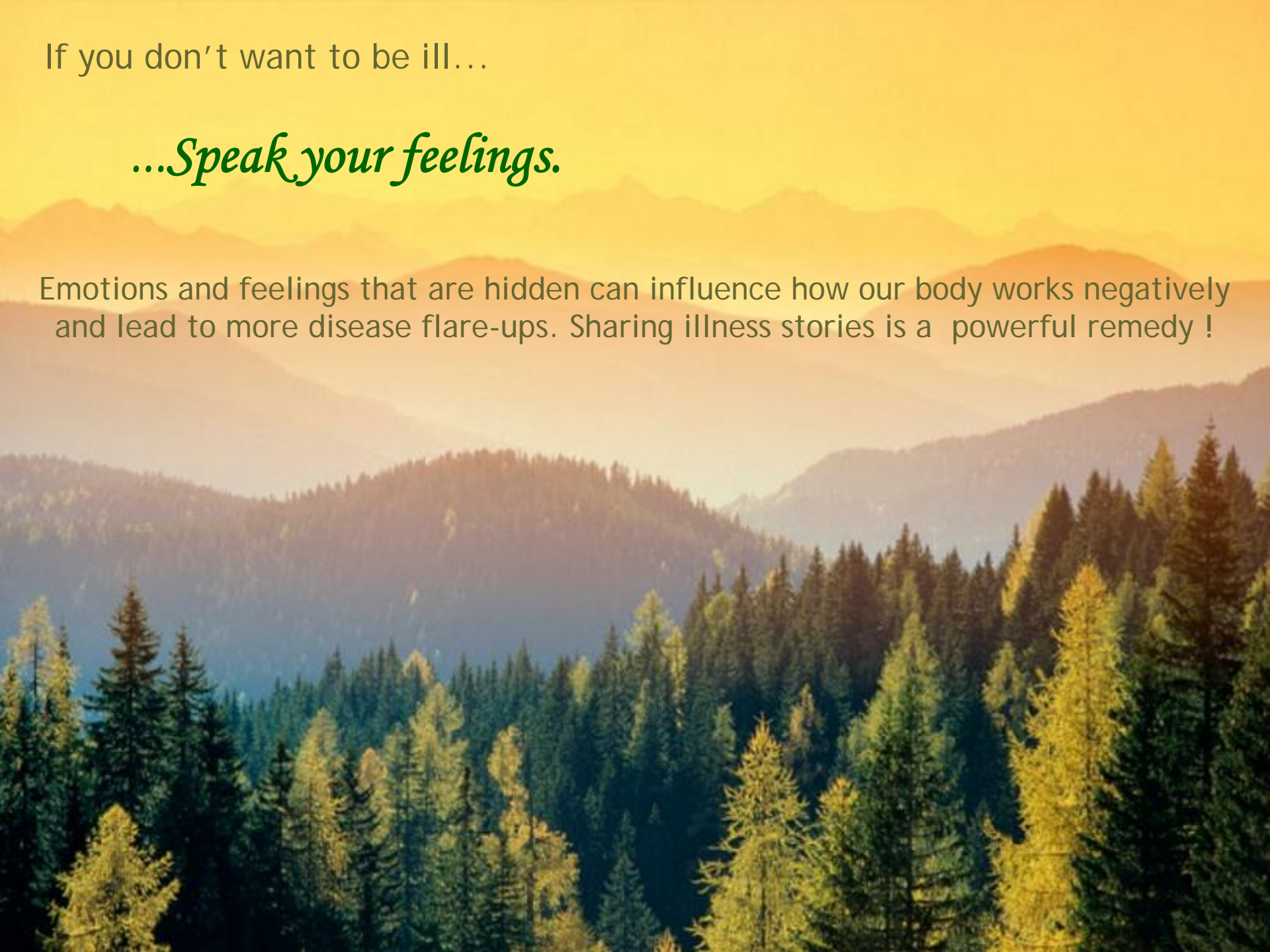
Telling your story, active coping and positive thinking alter the effects of stress on the brain



If you don't want to be ill...

...Speak your feelings.

Emotions and feelings that are hidden can influence how our body works negatively and lead to more disease flare-ups. Sharing illness stories is a powerful remedy !



I have IBD but IBD does not have me!