



# **Coping with Chronic Illness**

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# A Little Bit of Background

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- I'm a family therapist and a researcher
  - I have been working for the past 15 years at National Jewish Health
  - There are many therapists who work in medical settings. We focus not just on treating mental health problems. Our work is much broader—helping people cope with chronic illness.
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# Main Topics

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- Coping Skills
  - Social Support
  - Psychological Distress
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# Coping Skills

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- What do I mean by “coping skills”?
    - Anything that you do to help yourself shift gears, de-stress, or relax
  - No one is starting at zero; everyone already has coping skills
  - Which coping skills work well for you?
    - Now or in the past
    - Remember to be intentional about using your coping skills
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# Coping Skills

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- Make the most of your existing coping skills
  - Consider whether you need to develop additional coping skills
  - Start exploring—and keep an open mind
    - Breathing techniques
    - Journaling
    - Hobbies/art
    - Yoga
    - Progressive muscle relaxation
    - Guided imagery
    - Taking a long bath
    - Prayer
    - Etc.
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# Coping Skills

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- It is handy to have some coping skills that you can use in short bursts (5 minutes or less) and in any location
    - For example: breathing techniques
  - Coping skills include:
    - Activities that you do
    - Ways of thinking about stressful situations
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# Coping Skills

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- Focus on the present; don't spend too much time thinking about the future
    - Making concrete plans for the future is helpful
    - General worrying about the future is not helpful
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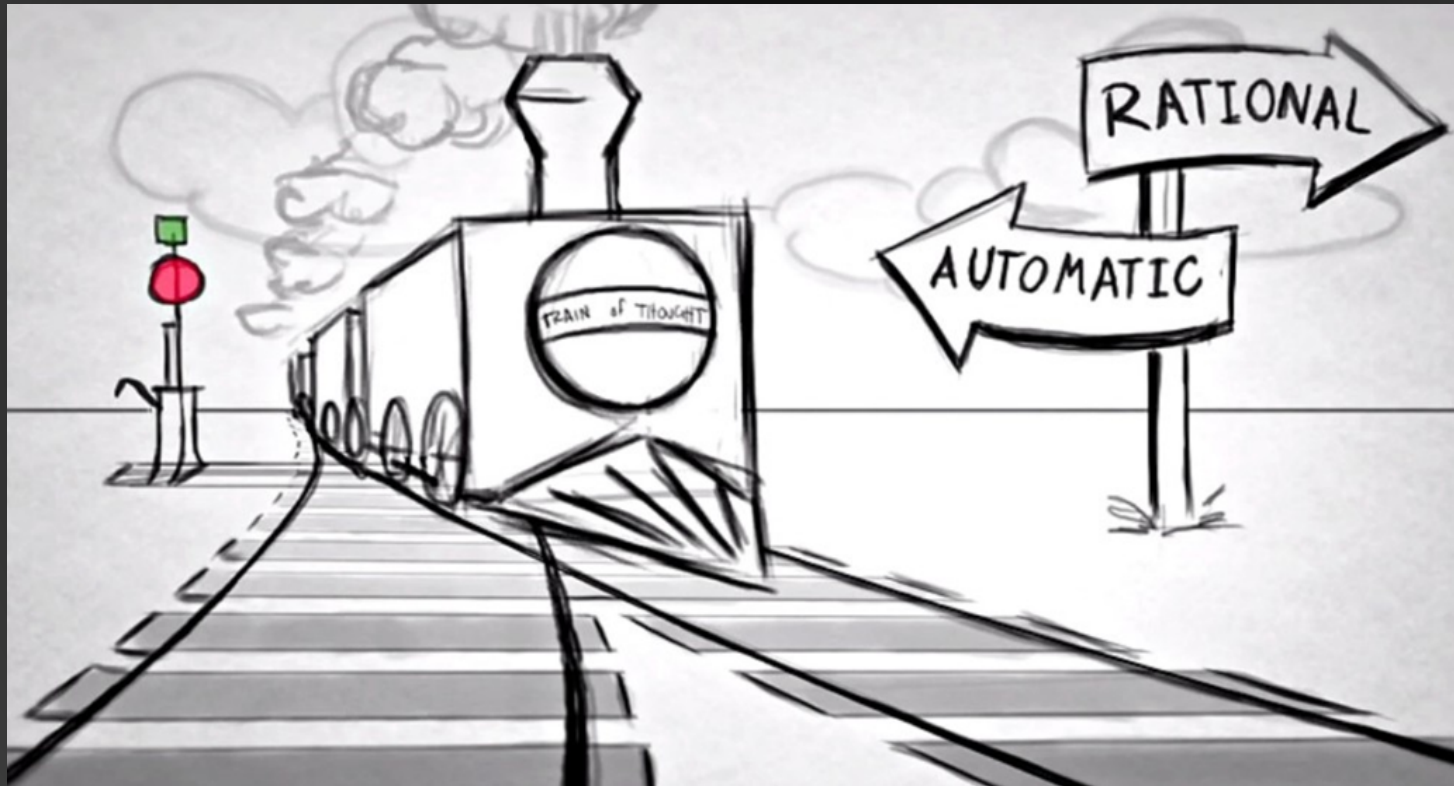
# Coping Skills

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- Be aware of your automatic thoughts
    - Example: You get a voicemail message from your doctor, asking you to call back
      - Is your automatic thought: “Something is wrong!”
      - If so, challenge yourself to think differently: “I don’t know if there is something wrong. I will reserve my conclusions until we talk.”
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# Coping Skills



# Illness-Specific Coping Skills

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- Can you lighten your load/simplify your life?
    - What is most important to you?
    - What is most meaningful in your life?
    - Are you spending your precious time and energy on things that are not worth it?
    - How comfortable are you saying “no”?
    - How comfortable are you with prioritizing your own self-care?
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# Illness-Specific Coping Skills

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- Can you simplify your life? (continued)
    - This isn't just about scheduling/time management; it goes a lot deeper than that
      - What is most important to you?
      - Are you able to make yourself a priority?
    - Taking care of yourself needs to be a priority
    - Give yourself permission to let some things go (at least temporarily)
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# Illness-Specific Coping Skills

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- Are you being too hard on yourself?
  - If it was a friend who had NTM, what would you say to your friend?
  - Give yourself credit, not guilt
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# Illness-Specific Coping Skills

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- Gather information/learn as much as you can
    - Consider the source of the information
      - Excellent source: [www.ntminfo.org](http://www.ntminfo.org)
    - Type of information:
      - factual
      - other patients' experiences
    - Use a “filter” when reviewing information
    - Don't overwhelm yourself with too much information; set limits if you need to
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# Illness-Specific Coping Skills

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Whenever possible, focus on controllable rather than uncontrollable aspects of the situation

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# Illness-Specific Coping Skills

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- What aspects of having a chronic health condition are under your control?
    - Meeting with your medical team
    - Following through with medical recommendations
    - Utilizing your coping skills
  - Give yourself credit for managing the controllable aspects of your health condition
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# Illness-Specific Coping Skills

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- What to do about uncontrollable aspects of the situation?
    - Really, the goal here is to manage the emotions that are evoked by the situation
    - This is easier said than done, but look for ways to:
      - Accept/Make peace with...
      - Distract yourself with activities that make you feel better
      - Talk with other people (express those emotions)
      - Allow yourself to worry ON A LIMITED BASIS
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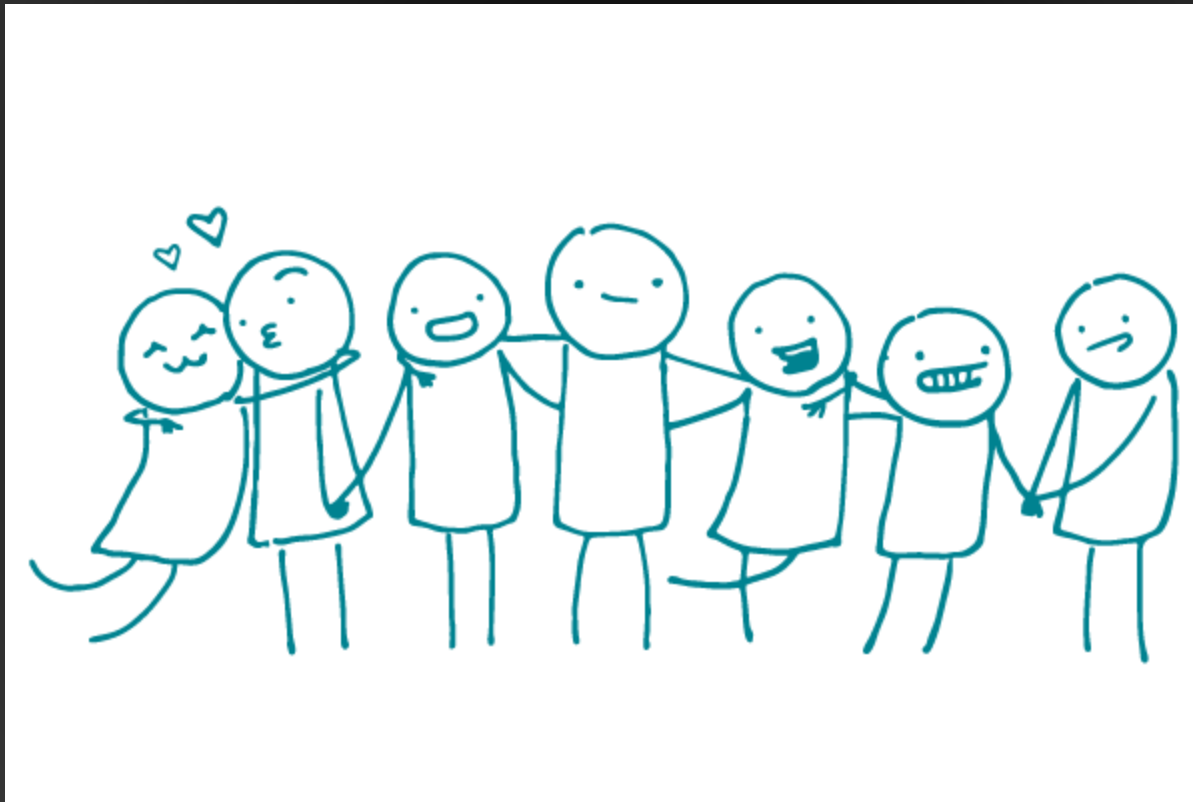


# Some Final Thoughts on Coping Skills

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- Start with what already works for you; you are NOT starting at zero
  - Coping skills are not one-size-fits-all, and how useful a given coping skill is may change over time
  - If you need to develop additional coping skills:
    - Experiment; keep an open mind
    - Consider working with a therapist
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# Social Support



# Social Support

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- Do you have enough people in your life?
    - Do you have people to have fun with?
    - Do you have people to be sad with?
  - Do you allow other people to support you?
  - Do you feel isolated? Or do you feel connected?
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# Social Support

- Being diagnosed with a chronic illness is like being sent to live in a foreign country



# Social Support

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- “Educating Visitors”
    - Who will you invite to visit you?
    - You are in control
    - You will likely be lonely without visitors
    - It is worth investing the energy to invite/educate key people in your life
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# Social Support

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- Relationships are a two-way street
  - Friends & family genuinely want to help
    - Are you willing to receive help?
    - Are you comfortable asking for what you want and need?
    - Friends and family members often don't know the best way to help
    - You can help others help you by having honest conversations about what would be most helpful to you personally
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# Social Support

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- Role Changes in the Family
    - Have roles within the family changed due to NTM? (or do you anticipate future changes?)
    - Communication: discuss the best way for you to manage role changes
    - Allow yourself to grieve; also focus on the roles that you still fill
    - Recognize that it is not necessarily negative for other family members to take on new roles
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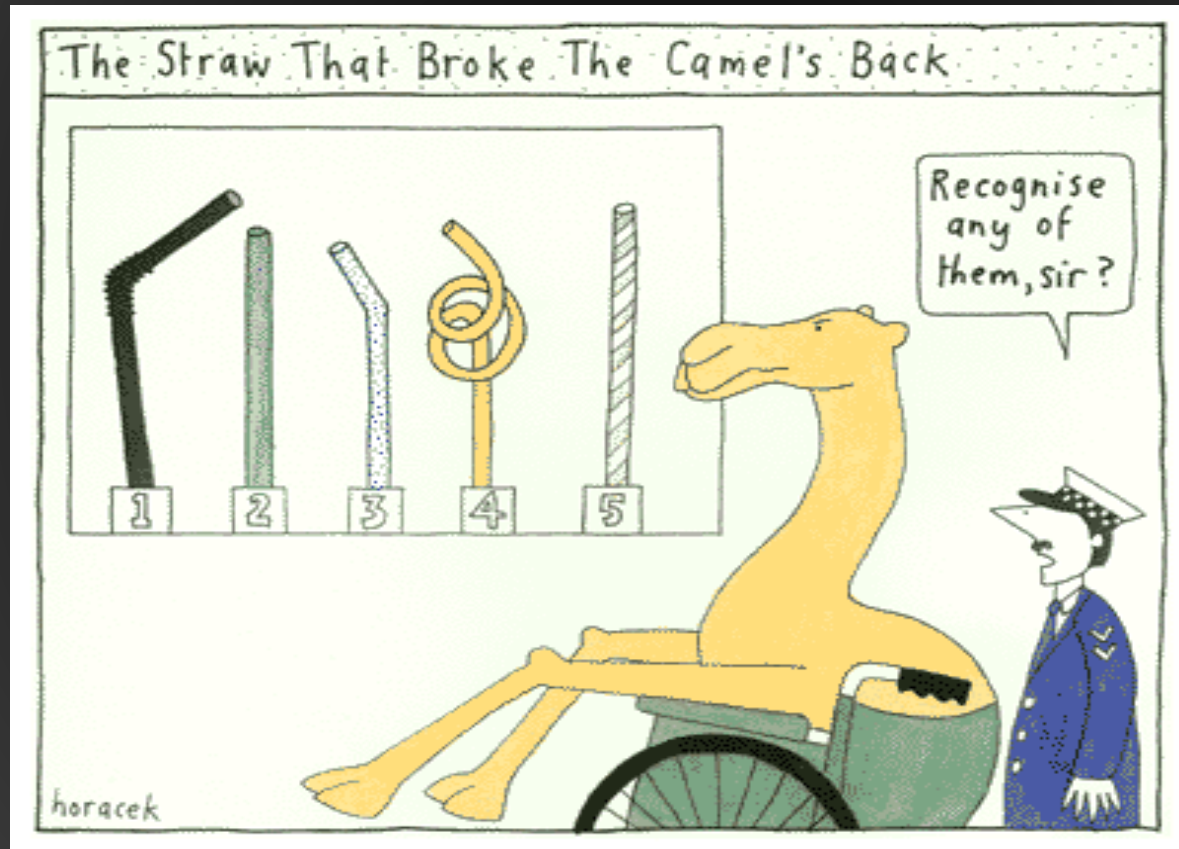
# Social Support

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- Role Changes (continued)
    - Roles tie into identity and self-worth
      - I keep our house clean; therefore I am a valuable person
    - Has your identity changed?
      - Make sure you still can identify positive aspects of yourself
      - Remember that there are many important ways to contribute to your family and to society
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# Psychological Distress



# Symptoms of Depression

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- Depressed mood most of the day, nearly every day
  - Diminished interest or pleasure in activities
  - Fatigue or energy loss
  - Diminished ability to think or concentrate
  - Feelings of worthlessness or guilt
  - Weight loss/gain or appetite loss/gain
  - Insomnia or hypersomnia
  - Psychomotor agitation or retardation
  - Suicidal ideation
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# Symptoms of Anxiety

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- Excessive anxiety and worry about a variety of events and situations, more days than not, for at least 6 months
  - Difficulty controlling the anxiety
  - Additional symptoms
    - Wound-up, tense, restless
    - Easily fatigued or worn out
    - Difficulty concentrating
    - Irritability
    - Muscle tension
    - Difficulty with sleep
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# Symptoms of Depression and Anxiety

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- These symptoms do not “count” if you are experiencing them due to:
    - your medical condition
    - the medications you are taking to treat your medical condition
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# Symptoms of Depression and Anxiety: “Normal” vs “Clinical Problem”

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- Being sad or worried is normal
  - You can go there, just don't park there



# Symptoms of Depression and Anxiety: “Normal” vs “Clinical Problem”

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- How do you know when symptoms are beyond what is normal?
    - Do you feel stuck?
    - Do symptoms interfere with work, activities, relationships, or sleep?
  - If symptoms are interfering with your life, it's time to seek help
  - When in doubt, seek evaluation/treatment
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# Treatment is Always an Option



# Treating Depression and Anxiety

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- For mild to moderate depression and anxiety
    - Medications very effective
    - Psychotherapy very effective
    - Medications and psychotherapy equally effective
  - For severe depression and anxiety, medication is more effective than psychotherapy
  - Most effective approach is medication and psychotherapy together
  - Medication usually has quicker results; psychotherapy is more effective than medication at preventing relapse
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# Treatment Resources

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- Association for Behavioral and Cognitive Therapies
    - [www.abct.org](http://www.abct.org)
    - 212-647-1890
  - American Psychological Association
    - [www.apa.org](http://www.apa.org)
    - 800-374-2721
  - American Association for Marriage and Family Therapy
    - [www.aamft.org](http://www.aamft.org)
    - 703-838-9808
  - American Psychiatric Association
    - [www.psychiatry.org/](http://www.psychiatry.org/)
    - 202-559-3900
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# Finding a Therapist

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- Don't get stuck on exact credentials, but you probably DO want someone who is licensed
  - Ideally, you want someone with experience working with individuals and families re: chronic health conditions
  - Do you feel comfortable with this person?
    - Not every therapist is a great fit for you
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# Not All Therapy is the Same

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- Couple/family Therapy
    - May be ideal for concerns such as:
      - Changes in relationship dynamics due to illness
      - Fear of burdening family
  - Cognitive Behavioral Therapy (CBT)
    - Time-limited
    - Structured
    - Excellent for treating symptoms of depression and anxiety
    - Individually-based
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# Self-Help Books Based on Cognitive Behavior Therapy

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- The Cognitive Behavioral Workbook for Depression (Knaus)
  - The Cognitive Behavioral Workbook for Anxiety (Knaus)
  - The Relaxation and Stress Reduction Workbook (Davis, Eshelman, & McKay)
  - Mastering Stress 2001: A Lifestyle Approach (Barlow, Rapee, & Reisner)
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# Some Final Thoughts

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- Coping skills
    - Make the most of your existing coping skills
    - When developing additional coping skills, experiment and keep an open mind
  - Social support
    - It may take energy to “educate” people about your experience with NTM, but it is worth it
    - The goal is to feel connected rather than isolated
  - Symptoms of depression and anxiety
    - Medications are useful and talk therapy is useful
    - Talk therapy can also address coping skills and social support
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Questions?

