

THE DIAGNOSTIC JOURNEY IS COMPLICATED

The long road to a diagnosis presents one of the greatest challenges affecting the health and emotional wellbeing of people, and their families, affected by a rare disease.

This journey includes:

- SHOCK:** The initial paralysis of hearing the bad news
- DENIAL:** Trying to avoid the inevitable
- ANGER:** Questioning "Why Me"?
- DEPRESSION:** Frustration and outpouring of emotions
- ACCEPTANCE:** Final realization of the inevitable

Above all, learn to practice self-compassion and mindfulness.

YOUR FEELINGS

Feelings and emotions impact patients and their family

- Physical and mental health are closely linked
- Mental health issues can worsen a person's physical illness and contribute to physical ailments not previously present

EIGHT DIMENSIONS OF WELLNESS

Creates the overall wellbeing in a person's life. Having challenges in the physical dimension creates a "ripple" effect and may impact all other dimensions

- | | |
|----------------|-----------------|
| 1 Spiritual | 5 Environmental |
| 2 Emotional | 6 Financial |
| 3 Occupational | 7 Social |
| 4 Intellectual | 8 Physical |

Discovering Wellness

COPING AND ACCEPTING THE RARE DISEASE DIAGNOSTIC JOURNEY

CHANGING YOUR THOUGHT PATTERNS

Practicing calm acceptance will allow you to process your emotions and move forward

- Recognize the events that are causing challenging thoughts
- Pause the out-of-control train of thoughts by simply thinking "Stop"
- Rely on the present moment and what you are capable of managing, and your feelings will follow
 - Learn to observe your feelings as they come and go without being attached to them
 - Be aware of the factors that cause your thoughts to go in bad directions and deal with them when they occur
 - Remember, there are things you cannot control. Replace unpredictability with certainty

DISTRESS TOLERANCE

A person's ability to manage actual or perceived emotional distress

It also involves being able to make it through an emotional incident without making it worse.

Examples of Distress Tolerance Techniques include:

- DISTRACTION:** Take your mind off of your feelings of distress
- IMPROVING THE MOMENT:** Visualize a relaxing scene; look for the silver lining; take a break and do something pleasant
- PROS AND CONS:** Think about potential pros and cons of either tolerating the distress, or not tolerating it
- SELF-SOOTHING:** Use different sensory experiences that involve sight, sound, smell, taste, or touch
- RADICAL ACCEPTANCE:** Rather than focusing on things you cannot change, or that are out of your control, accept things as they are

A rare disease diagnosis can trigger a **stress response**, which can progress over time and trigger issues like depression and anxiety. **To cope with stress try:**

- POSITIVE BELIEF:** People believe they can successfully bring about desired consequences
- PROBLEM-SOLVING SKILLS:** Having specific knowledge or abilities related to specific problems
- SOCIAL SKILLS:** Ability to get other people to cooperate
- SOCIAL SUPPORT:** Feeling of being accepted and loved by others

Connect with resources to help guide you through this journey

1-833-PTC-HOPE
(1-833-782-4673)

In Spanish
1-833-PTC-VIDA
(1-833-782-8432)

patientengagement
@ptcbio.com