

Discovering Wellness

COPING AND ACCEPTING THE RARE DISEASE DIAGNOSTIC JOURNEY

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 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 |

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

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

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

