

Finding a Balance: Adults Coping with Mental Health and EB

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Mental health difficulties can happen to anyone regardless of who they are, where they live, how much money they have, what they do for a living, or whether or not they or a loved one has a chronic illness. However, some mental health issues such as depression and anxiety occur more often in people who have a family member with the same condition. Having a mental health disorder does not mean that a person is weak, “crazy,” or has a flaw in their character, but rather that they have an illness that may require treatment, just like any other condition such as diabetes, heart disease, or EB. People with mental health concerns often feel very ashamed or guilty and may not seek help on their own. They might not know how. Treat them with care and compassion and help them to get the treatments they need. These treatments can vary from individual, family, or group therapy and can involve art, music, movement, talking, learning skills, medications and everything in between and in almost any possible combination. Expecting someone with a mental health disorder to simply “Snap out of it,” “Pull themselves up by their bootstraps,” “Get over it,” or “Just think happy thoughts” is no more easily done than expecting a person living with EB to “Grow better skin.” Because of the stressors unique to EB, it is very important that people living with EB, their families, and their caregivers be given extensive, long-term support that begins as early as possible to help them cope in the best way possible. If you feel that you or a loved one might be in crisis or have a mental health condition, seek help right away.

Look for these signs and symptoms of when it might be time to seek professional help:

Common Symptoms	
Depression	Anxiety
<ul style="list-style-type: none"> • Feeling sad, down, blue or “empty” most of the time • Loss of interest/pleasure in almost all activities, including sex • Difficulties concentrating • Decreased energy/Fatigue • Overeating or weight loss • Restlessness • Moving or talking more slowly • Feelings of guilt, worthlessness, and helplessness • Sleeping too much or too little • Increased aches, pains, stomachaches, headaches, digestive issues • Suicidal thoughts or suicide attempts 	<ul style="list-style-type: none"> • Feeling restless, nervous, or tense • Sense of impending danger or doom • Breathing fast (hyperventilating); Fast heartbeat • Sweating • Racing thoughts • Heightened alertness • Trembling/Shaking • Avoiding anxiety triggers • Difficulties concentrating or thinking • Problems sleeping • The worry is hard to control • Worry gets in the way of work, life, relationships, etc. • Stomachaches/Headaches

Risk Factors for Suicide	Warning Signs of Suicide
<ul style="list-style-type: none"> • Depression • Bipolar disorder • Difficulties with drugs or alcohol • Prolonged stress like bullying, domestic violence, unemployment, relationship problems • Access to lethal means such as drugs and firearms • Previous suicide attempt • Family history of suicide • History of abuse or trauma 	<ul style="list-style-type: none"> • If a person <u>talks about</u> killing themselves or wanting to be dead, having great shame/guilt, unbearable pain, hopelessness, having no reason to live, being a burden • <u>Behavior changes</u> such as withdrawal/isolation, giving away important possessions/making a will, saying goodbye, increase in drug/alcohol use, sleeping more/less, researching ways to die • <u>Mood</u> issues such as anxiety, depression, shame, anger, rage, loss of interest in fun activities, extreme mood swings

A sudden or unexpected improvement in signs and symptoms above might mean that the person has developed a plan, obtained the means to do it, made the final preparations to die, and is only waiting the “right” time.

If this happens, seek help immediately!

Finding Mental Health Services in the United States

- Contact your insurance provider.
- Talk with your EB Team, they may have a list of providers with whom they work who are familiar with EB.
- Ask your PCP if they know of a provider with whom they work.
- If you have a Case Manager assigned to you through your insurance or another agency, they may be able to help you to find mental health providers in your area.
- Talk to trusted friends/colleagues about mental health providers that they know about.
- Go onto your state's Psychology and Psychiatry licensing boards website or your state's Psychological Association. Many of these sites have a searchable database that can help you find a provider.
- Go to www.psychologytoday.com. It is a searchable database that has many (but not all) providers in your area.

Important Phone Numbers – Suicide/Crisis/Abuse/Assault/Violence Helplines/Hotlines

United States

- Call 911
 - National Suicide Prevention Hotline (open 24/7/365): 988 (after 07/16/2022) or at 1-800-273-TALK (8255) for English and 1-888-628-9454 for Spanish
 - Crisis Text Line: Text SIGNS to 741741 for 24/7, anonymous, free crisis counseling
 - National Domestic Violence Hotline: 1-800-799-7233 or text LOVEIS to 22522
 - National Child Abuse Hotline: 1-800-4AChild (1-800-422-4453) or text 1-800-422-4453
 - National Sexual Assault Hotline: 1-800-656-HOPE (4673)
- LGBTQ+**
- Trans Lifeline: 1-877-565-8860 (para español presiona el 2)
 - The Trevor Project's TrevorLifeline: 1-866-488-7386

Canada

- Call 911
- National Suicide Prevention Hotline (open 24/7/365) at 1-833-456-4566
 - For residents of Quebec, call 1 866 APPELLE (1.866.277.3553)
 - Pour les résidents du Québec, composez le 1 866 APPELLE (1.866.277.3553)
 - Text 45645 4PM-Midnight ET (French text support is currently unavailable)
- For more chat and text resources go to <https://www.crisisservicescanada.ca/en/>
- A list of numbers to call to report child abuse can be found at <https://cwrp.ca/provincial-and-territorial-assistance>

United Kingdom

- Call 999 (or the pan-European emergency response service 112)
- National Suicide Helpline UK (open 24/7/365) at Tel: 0800 689 5652
- Samaritans UK & Ireland (24-hour emotional support to anyone in distress Tel: 116123)
- Child Abuse Reporting call 0808 800 5000

Other Countries

- Call your local emergency response number if available