

FIVE SIGNS OF EMOTIONAL SUFFERING

Often our friends, neighbors, co-workers, and family members are suffering emotionally and don't recognize the symptoms or won't ask for help. If you recognize that you or someone else needs help, reach out, show compassion and a willingness to find a solution when the person may not have the will or drive to do it alone.

Here are five signs that may mean someone is in emotional pain and might need help:



PERSONALITY CHANGES.

You may notice sudden or gradual changes in the way that someone typically behaves. People in this situation may behave in ways that don't seem to fit their values, or the person may just seem different.



UNCHARACTERISTICALLY ANGRY, ANXIOUS, AGITATED, OR MOODY.

You may notice the person has more frequent problems controlling his or her temper and seems irritable or unable to calm down. People in more extreme situations of this kind may be unable to sleep or may explode in anger at a minor problem.



WITHDRAWAL OR ISOLATION FROM OTHER PEOPLE.

Someone who used to be socially engaged may pull away from family and friends and stop taking part in activities that used to be enjoyable. In more severe cases the person may start failing to make it to work or school. Not to be confused with the behavior of someone who is more introverted, this sign is marked by a change in a person's typical sociability, as when someone pulls away from the social support typically available.



MAY NEGLECT SELF-CARE AND ENGAGE IN RISKY BEHAVIOR.

You may notice a change in the person's level of personal care or an act of poor judgment. For instance, someone may let personal hygiene deteriorate, or the person may start abusing alcohol or illicit substances or engaging in other self-destructive behavior that may alienate loved ones.




OVERCOME WITH HOPELESSNESS AND OVERWHELMED BY CIRCUMSTANCES.

Have you noticed someone who used to be optimistic and now can't find anything to be hopeful about? That person may be suffering from extreme or prolonged grief, or feelings of worthlessness or guilt. People in this situation may say that the world would be better off without them, suggesting suicidal thinking.

Weekly Emotions Tracker

Keeping It Real

Rare caregivers report twice the amount of emotional stress than general caregivers (NAC 2018). To help track how you're feeling as you stay busying caring for others, make a check  mark if you felt any of the below. Most of these are normal emotions. However if you've had these feelings more than two weeks, stop and take action to get the help you need.

I am feeling...

1

2

3

4

5

6

7

8

9

10

11

12

13

14

"Off"

I FEEL

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Moody

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Angry and
agitated

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

That I want to be
alone all the time

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Like I want a drink
alcohol in order to
cope/relax

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Like I don't
care if I'm clean

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Overwhelmed

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Hopeless

☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

*this is not a diagnostic tool. The goal is to become aware of your emotions so that you can track your emotional baseline and recognize when you need to reach out for help.

TAKING CARE WHEN YOU ARE A CAREGIVER: TIPS FOR ACCESSING MENTAL HEALTH CARE

WHY SEEK CARE

The daily impact of rare caregiving extends to each aspect of life. The emotional roller coaster that comes along with rare disease makes it even more important to keep your mental health and emotional wellbeing in shape. Think of mental health care as a gym that will give you exercise techniques you need to get through it all. Asking for help can feel vulnerable and bring up many feelings. Seeking therapy is positive. Therapists listen and help you make connections. They may offer guidance or recommendations when you feel lost. There is no single, correct approach in finding care. As a rare caregiver, you probably know all too well that connecting with the right provider may take some time. Prioritize YOU just like you do for the one you care for, and with patience & perseverance, these tips will help you find your provider.



WHEN TO SEEK CARE

- Anytime! Maintenance is essential to your mental health
- You feel like you can't do normal daily activities you previously were able to accomplish
- Thinking about or coping with an issue is taking more than one hour of your day
- You have a major life event
- You've developed habits to cope with your emotional health that are impacting you physically in a negative way

WHO TO CHOOSE

- If you have a mental health condition that may benefit from medication, consult a mental health doctor, such as a psychiatrist or mental health nurse practitioner who has experience treating your condition (MD, DO, PMHNP, APN)
- If you're seeking help with emotions, behaviors, and patterns, consult with a therapist, counselor, or psychologist. Like medical doctors, these professionals have specialties, so find one who knows about your specific issue (credentials include LCSW, LPC, LMFT, PhD)

Remember You Cannot Care for Others if You're Not Healthy Yourself



Finding a Therapist

Finding a therapist can be daunting, every therapist has different training, experience, insights, and character to bring to the table. How can you find a therapist who is right for your needs?

HOW TO FIND CARE

Common places to find mental health providers:

- Ask the doctor who cares for your child if they have a relationship with a mental health professional who can support you
- Ask your insurance company for a list of in-network providers or your company's employee assistance program (EAP)
- Ask trusted family or friends or other caregivers for recommendations
- Search nonprofit, government or mental health organization websites that have lists of providers
- Contact local or national mental health organizations
- Consider consulting your physician. Some physical health issues may cause symptoms similar to mental health illnesses. A physician can navigate this concern.

WHAT TO ASK PROVIDERS

Before the first session:

- Do you have experience working with caregivers?
- Do you accept my insurance? If I don't have insurance, do you have a sliding scale for payments?
- What kinds of therapy do you offer?
- Do you have a regular opening that fits my schedule?

After the first session:

- Do you think we are a good fit?
- What will my treatment plan or our sessions look like?
- How often do you think I should come?
- Will we make goals together? How will we measure success?
- How do I reach you in an emergency?

REMEMBER: YOU ARE IN CONTROL OF YOUR THERAPY RELATIONSHIP. ADVOCATE FOR YOURSELF AND SEEK ANOTHER CARE PROVIDER IF YOU DO NOT FEEL LIKE IT IS A GOOD THERAPUTIC FIT. ONE SIZE DOESN'T FIT ALL!

****If you, or someone you love, is in immediate danger, call 911 or go to your nearest emergency room right away****

SELF-CARE FOR RARE CAREGIVERS:

ESTABLISHING HEALTHY HABITS OUTSIDE OF CAREGIVING

Prioritizing self-care can be a challenge when providing rare caregiving to others. Self-care is essential to prevent burnout as the healthier you are, the more energy you will have to care for others. Self-care does not look the same for every rare caregiver. Try incorporating one of these tips each month and with practice, taking care of yourself will become second nature.



Learn & practice
stress reducing techniques



Attend to your own
healthcare needs



Get adequate rest
and nutrition



Exercise regularly
even if only for a short time



Take time off without guilt



Participate in
enjoyable activities,
like reading a book



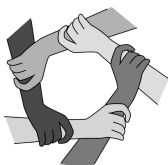
Seek and accept the
help of others



Seek counseling
when needed



Practice mindfulness:
identify and acknowledge
your thoughts, emotions,
feelings, and challenges



Practice common humanity:
through shared experiences,
i.e. peer support, online
support groups



Set obtainable goals



Practice self-kindness



Practice the Healthy Habits
of Emotional Wellbeing



HEALTHY HABITS OF EMOTIONAL WELLBEING

It is important to recognize when someone is in emotional pain. It is equally important to learn basic habits that keep up emotionally healthy.

What are the Healthy Habits of Emotional Wellbeing? They are habits that everyone can learn, habits that allow each of us to identify and practice that works for us.



Take Care of You

Eat, sleep, and be active. We don't often think about how important these basic activities are for our mental health -- but they are critical.



Check in and get checkups

We get check-ups for our physical health. We see our dentist to take care of our teeth. It's time to take responsibility and get check-ups for our emotional wellbeing. Talk with your doctor, a counselor, a faith-based leader....and your family and friends to make sure you, and those you love, are doing well emotionally.



Engage and connect wisely

Pay attention to your relationships. We can't be healthy if our relationships are not.



Relax

Learn ways to reduce the stress that we all face -- and practice what works for you: meditate, run, knit, dance, sing, write, love...



Know the Five Signs of Emotional Suffering

The Five Signs are change in personality, agitation, withdrawal, decline in personal care, and hopelessness. Someone may exhibit one or more signs. Many conditions can result in emotional pain. If you see them in someone you love, reach out, connect and offer to help.

If everyone is more open and honest about mental health,
just like we are with our physical health, we can prevent pain and suffering,
and those in need will get the help they deserve.

CREATING SUPPORT SYSTEMS

Rare Caregivers often feel isolated and find it challenging to connect. 51% report difficulty in maintaining friendships and 53% report feeling alone*. Since the rare care journey is often emotional and difficult, it is important to prioritize support. Research has shown that supportive relationships have many benefits. These include reducing stress, depression and anxiety; living longer; having higher levels of well-being; and acquiring better coping skills. So how do you build strong support systems? Figure out what kind of support you need then work on building and sustaining them. Yes it takes energy, but you will get so much in return.

Type of Support Needed

Different relationships check particular boxes. When you have limited time and energy, be intentional about the relationships you build & the people you surround yourself with.



Tangible

A service or a favor; reinforces that it's healthy to ask for help when needed and accept the help



Emotional

Acceptance, understanding, reliable encouragement and empathy; reminder that we are not alone



Affirmational

Feelings that build your motivation and respect your efforts



Informational

Receiving positive, supportive information or new knowledge; provides support without an emotional connection



Belonging

Belonging to a community or peer group that understands your beliefs and/or situation

Support Systems Build You UP!

Tips to Sustain Support Systems

- Respect boundaries
- Accept help
- Be available
- Be honest
- Be patient...it takes time to develop
- Stay in touch
- Reciprocate: support their successes and share appreciation
- Engage when it's healthy

Counselors, Therapists & Psychologists, *Oh my!*

Who to Choose

Choosing to seek mental health services is the first step to working on mental health and emotional wellness. The next step is choosing a mental health professional, so how to choose?

The Right Fit!

Understanding the differences between licenses can help you feel more comfortable reaching out to a professional. The license reflects the professional training received by the professional to treat mental health conditions and help people achieve their personal growth goals.

It's more important to find a therapist who uses methods that suit your needs. Seeking a provider who has experience working with clients like you is more important than what license they hold.

Types of Providers

A counselor is someone who usually offers short term care and helps you figure out how to deal with situations that are in the future.

A therapist is someone who usually offers long term care and care can be more focused on working through past experiences.

A psychiatrist is someone who can prescribe medications and administer tests to help determine a mental illness. They are a medical doctor.

A psychologist is someone who can also diagnose and treat a mental illness, but with behavioral intervention instead of medication.

A social worker is someone who helps you identify your needs and goals. They are trained to connect you with the services available in your community who can get you the help you need to meet your needs/goals.

Decoding Degrees

- Licensed professional counselors (LPCs)
- Licensed mental health counselors (LMHCs)
- Licensed marriage and family therapists (LMFTs)
- Licensed clinical social workers (LCSWs)
- Psychologists (PhDs or PsyDs)
- Psychiatrists (MDs or DOs)