



Caregiving from a Distance: How to Support Someone Who Lives with Depression



Featuring
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Susan Weinstein, JD, *Co-Executive Director*
Families for Depression Awareness

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About FFDA

Families for Depression Awareness is a national nonprofit organization providing education, training, and support.

We help families recognize and cope with depression and bipolar disorder to **get people well and prevent suicides.**

We believe that mood disorders affect the whole family.



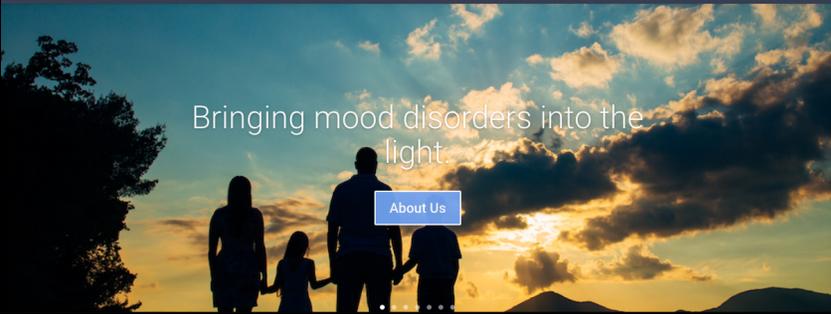
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Our Website: familyaware.org



Help Someone ▾ Mood Disorders ▾ Programs ▾ Support Us ▾ About ▾



Bringing mood disorders into the light.

About Us

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Stories and Interviews

Written and audio expert interviews such as

- Diagnosis and Treatment
- Managing Hard-to-Treat Depression
- Family Communication
- How to Find and Pay for Treatment
- Family History

plus **personal stories** about how families have addressed and managed depression and bipolar disorder



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Families for Depression Awareness Webinars for Caregivers



Understanding Teen Depression
with *Mary Fristad, PhD*



Coping with Stress and Depression in the Workplace
with *Marianne Clyde, LMFT*

Visit familyaware.org/trainings

Other teen mental health topics:

- Navigating Teen Depression and Substance Use as a Family
- Teen Self-Injury: Working Toward Healthy Coping Skills
- Recognizing and Managing Teen Anxiety



Bipolar Disorder: Beyond the Basics
with *Martha Tompson, PhD* and *Pata Suyemoto, PhD*

Also: Bipolar Disorder in Adults



More Than Mood: Depression Symptoms
with *Alice Medalia, PhD*

Some of our other webinars:

- How You Can Fit Mindfulness Into Your Busy Schedule
- Strategies for Families
- How Workplaces Can Support Mental Wellness and Prevent Suicides
- How to Choose and Use Health Insurance for Mental Health Care

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Families for Depression Awareness Videos that Educate and Inspire





Visit youtube.com/FFDA1

Our videos include

- Family Stories
- Expert Interviews
- "How To" videos for caregivers
- **COMING SOON:** Stages of Change series

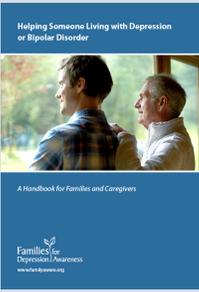






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Families for Depression Awareness Publications



Helping Someone Living with Depression or Bipolar Disorder
A Handbook for Families and Caregivers



Adult Bipolar Disorder Working Together Toward Wellness



Adult Depression Series of Families and Hope



Coping with Stress



Coping After a Suicide

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Families for Depression Awareness Free Online Tests

Bringing depression into the light

Home

The Depression and Bipolar Test

Also free webtools:

- Mental Health Family Tree for Bipolar
- Depression Wellness Analyzer



NEW: Caregiver Stress Test

Perceived Stress Scale (PSS)

Primary Reference: Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385-396.

Purpose: To assess the degree to which adults perceive their lives as overexacting. High levels of stress are associated with poor self-reported health, excessive alcohol use, depression, and susceptibility to illness.

Description: Individuals indicate how often they have found their lives unmanageable, uncontrollable, and overwhelming, and conducted in the last month.

Please check the box to confirm you have read our disclaimer and accept its terms.

Note: Depression and Bipolar Test is validated for 18+ only.

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Caregiving from a Distance

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Caregiving from a Distance

Approximately 11% of Americans who provide care for a family member who is older, ill, or has a chronic health condition **live an hour or more away** from their loved one.



*Caregiving in the U.S. May 2020 AARP/National Alliance for Caregiving. <https://www.caregiver.org/caregiver-statistics-demographics>

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Common Concerns



If your loved one lives away from you, you might have concerns about

- Their mental wellness
- How you can help
- What if you can't help?

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Agenda

- Caregiver Self-Care
- Caregiver's Role:
 - Identifying the Problem/ Recognizing Depression
 - Finding and Paying for Quality Care
- Communication
- Legal and Financial Issues
- Families for Depression Awareness Resources
- Questions and Answers



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Featured Presenters



Sandra Edmonds Crewe,
MSW, PhD, ACSW



JaNeen Cross, MSW, DSW,
MBA, LICSW, LCSW-C

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You Are Not an Afterthought: Practicing Caregiver Self-Care

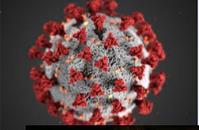
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Stress Affects Everyone

– and more so in 2020!

One study mid-year concluded that depression symptoms were **4 times as common** as the same time the year before



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Caregiving Is Stressful



Nearly 4 in 10 caregivers consider their caregiving situation to be highly stressful.
On average, caregivers of adults report emotional stress of 3.0 (out of 5).

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Factors Related to Higher Stress

Percent of caregivers reporting **high** level of stress

- 38% of caregivers age 18-64 versus 30% of older caregivers
- Among BIPOC, 44% of Asian American caregivers, 29% of African American caregivers, and 32% of Hispanic caregivers
- 42% of those who have provided care for 1 year or longer versus 38% for caregivers
- 40% of those living with the care recipient versus 34% of those not co-residing
- 48% of those with no choice about providing care (no viable alternative caregiver)
- 38% of those who are related to the one they provide care for versus 23% of those who do provide care for someone other than a relative

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Why Self-Care?

You can't pour from an empty cup



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Caring for Your Whole Self

Tend to your whole self: Dimensions of Wellness

- Emotional
- Personal
- Physical
- Professional
- Psychological
- Spiritual



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Manage Expectations

Learn about the **Stages of Change** to better understand your loved one's process for making changes, including being ready to get treatment for depression

Visit familyaware.org/stages-of-change



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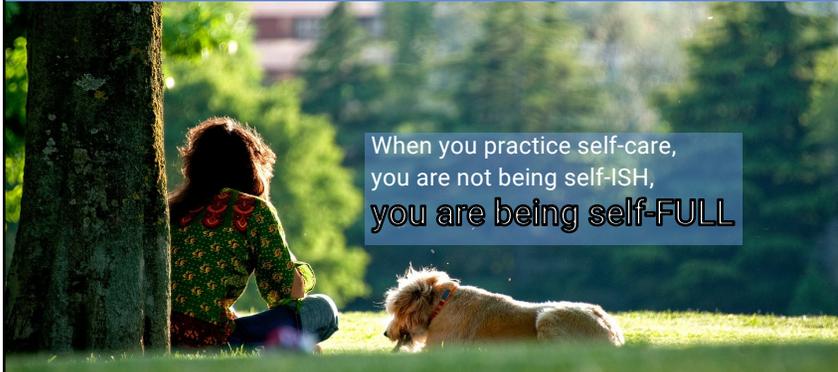
Families for Depression Awareness **Set Boundaries, Acknowledge Limits**

- Respect yourself
- You can't be all things to all people
- Communicate about what you are willing – and not willing – to do, then stick to it
- When you agree to do something, follow through without resentment (though you can discuss later why you don't want to do that again)



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Families for Depression Awareness **Reframe Negative Thoughts**



When you practice self-care, you are not being self-ISH, you are being self-FULL

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Families for Depression Awareness **You're Not Alone**

Nearly three-quarters (72%) of caregivers **who feel alone** report feeling high emotional stress, compared to just 24% of those who do *not* feel alone.

Take advantage of supports – social connections, support groups, faith communities, volunteer opportunities – that can reduce your sense of isolation.



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Rose on Recognizing Depression and Practicing Self-Care

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Caregiver Roles

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Caregiving for Depression



Caregivers can help people with depression to

- Recognize that there is a problem
- Get quality care and figure out how to pay for it
- Resolve legal or financial issues

One important skill: good communication. (We have tips!)

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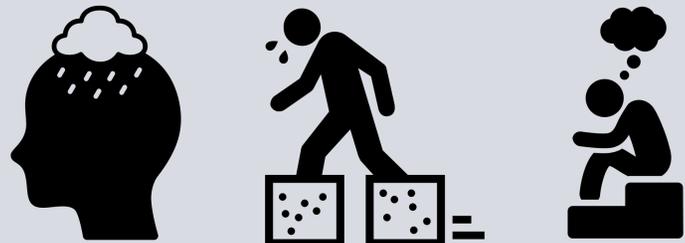
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Caregiver Roles: Help Them Recognize There Is a Problem

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What Is Depression Like?



Created by Victorlaur from Noun Project

Created by Luis Prado from Noun Project

Created by Adrian Coquet from Noun Project

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Depression Affects Thinking

People with depression often experience cognitive challenges, that is, difficulties with thinking.

FFDA adopted the “ROAM” acronym as shorthand for the kinds of functions affected by depression.

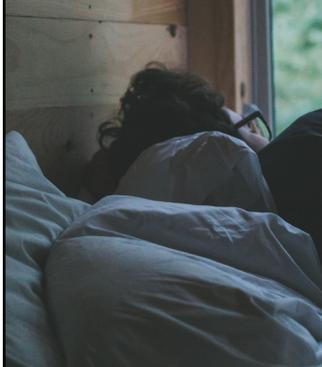
Learn more at familyaware.org/more-than-mood



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Depression Affects Motivation



When a person doesn't believe they can escape their emotional pain or that people would be better off without having to worry about them, they may need support

- finding a provider
- sharing medical and family history
- getting an accurate diagnosis
- evaluating treatment options
- ascertaining positive and negative effects of treatments
- sticking to their treatment plan.

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Depression Symptoms

Depression causes significant impairment or loss of function

For at least 2 weeks, feeling miserable, depressed, sad, empty, or irritable most of the day, nearly every day OR losing interest or pleasure in most activities



Other indicators include **changes in**

- sleep patterns or eating habits (too much or too little)
- energy levels and activity (unrest or fatigue)
- sense of self-worth (or feeling guilty)
- ability to concentrate or make decisions
- physical health, e.g., unexplained or nonspecific aches and pains
- recurrent thoughts of death or suicide; suicide plan; suicide attempt

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Make Observations



What do your observations and your knowledge of your loved one – and of depression symptoms – tell you about their current condition?

- Appearance: physical signs
- Demeanor
- Content
- Behavior
- Executive functions
- Changes from before this current period

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Get Input from Others

Who else can you ask what they have noticed?

- Roommates
- Friends
- Coworkers
- Partner



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When Harm to Self or Others Is a Concern

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Addressing Safety Concerns



- Check in with their provider(s)
- Ask if they are planning to take their own life
- If needed and safe to do so, contact their local police and request a wellness check-in
- If no immediate danger, discuss next steps and how you can support

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Check in with Their Provider(s)

You can report things like

- a concerning behavior you observed
- changes in activity level and mood
- frequency and/or severity of symptoms
- family history of mental health conditions.

The provider may not be able to talk with you, but they can listen.



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Ask the Question

“Are you thinking of killing yourself?”

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Wellness Check-In

The local police can check in on your loved one in a wellness (or wellbeing or welfare) visit.

This is an option that is good to talk about ahead of time, as a possible action you'd take if you were concerned.

Also, be sensitive to concerns about police interactions.



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What Support Would Help?



What can I do that would make you feel supported?

Would it be helpful for me to come to you?

Would you like to come home?

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Caregiver Tips

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Families for Depression Awareness **Let Your Loved One Lead**

If no immediate safety threat, work to make decisions **WITH** your loved one rather than **FOR** them

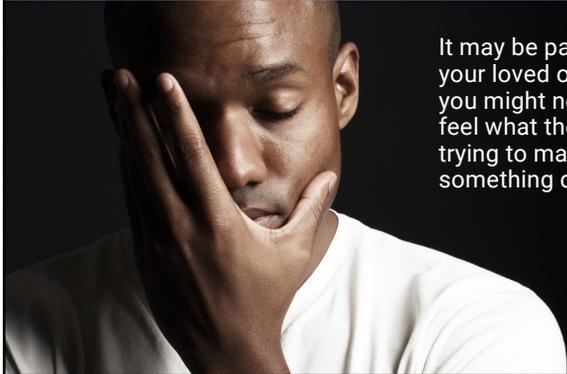
Focus on

- what they say they need, not what you think they need
- listening, not problem-solving
- providing support, not making demands



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Families for Depression Awareness **Validate Their Experience**



It may be painful for you to see your loved one struggling, but you might need to let them just feel what they feel, without you trying to make them feel something different.

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Families for Depression Awareness **Meet Them Where They Are**

Ask yourself:

- What kind of conversation would be appropriate at this point?
- What would be supportive?
- What would be constructive?
- What would be productive?



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Help Them Find Quality Care and Figure Out How to Pay for It

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Families for Depression Awareness **Local* Supports and Treatment Team**

Research and identify

- mental health clinics or providers who take their insurance
- resources at their job or school (e.g., how to contact EAP or counseling services)
- tele-mental health providers
- support groups
- nearby hospitals with a psychiatry unit
- crisis intervention units or mobile crisis teams (if available in their community)
- possibly spiritual communities
- outlets for socializing and engagement
- relatives or family friends (or even college alumni/ae) nearby



*(Local to them)

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Families for Depression Awareness **Ways You Can Help**

Depression symptoms can make it hard for your loved one to arrange and advocate for their own treatment. You can offer support.

- Share your observations with them in a nonjudgmental way
- Talk with them about their vision of wellness
- Help them feel equipped and confident in advocating for themselves
- Research treatment options
- Provide support around medication
- Encourage productive use of therapy
- Help with logistics
- Offer to help with care coordination



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Families for Depression Awareness **Paying for Care with Insurance**

Look for a provider in your loved one's insurance network. If there is not an appropriate provider available, you can advocate for out-of-network coverage with the insurance company.

Many insurance companies limit access to prescription medications or treatments. You can appeal these decisions.

Visit www.familyaware.org/healthinsurance for information about getting the most out of your health insurance for mental health care.



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Families for Depression Awareness **Getting Care without Insurance**

- Ask providers if they offer an income-based sliding scale, if they will accept a lower payment, or if they offer a payment plan
- Utilize community mental health clinics where available
- Universities may offer low-cost services so their graduate students can gain experience
- Look for providers at findtreatment.samhsa.gov
- For medications, tell your prescriber that cost is a consideration; also, check for income-based support through www.rxassist.org



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Communication

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Communication Technology

Use whichever options are available and acceptable to you and your loved one.

- Access to computer, smart phone, etc.
- Internet service availability
- Comfort with different programs
- Access to private space to talk
- Time zones
- Work/school schedules



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Communication Techniques



- Use active listening
- Be nonjudgmental and compassionate
- Discuss difficult issues before they arise
- Ask in what ways they would like your help and involvement
- Only offer or agree to do what you can and will do to build trust and confidence
- Remind them that you care about/love them, even if they don't want to engage at the time
- Know your audience and tailor comments accordingly

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They Might Want to Talk to Someone Else

You might have to accept that – for some issues and situations – you might not be the person that your loved one wants to turn to for support. That's okay, as long as they are getting the help and support they need.



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Legal and Financial Issues

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Legal Issues Overview*

What kinds of legal issues might arise?

- Working within privacy and confidentiality laws
- Insurance denials, inadequate network, surprise billing
- Incapacity to make decisions
- Accessing government benefits
- Disability/leave or discharge from employment/loss of income



Download the legal issues fact sheet from the Webinar Handouts section!

*This is not legal advice. For help with your particular situation, consult with a qualified attorney with experience in that area.

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Helpful Documents



- HIPAA waiver/authorization
- Authorization/waiver of health and educational privacy
- Psychiatric Advance Directive (<https://www.nrc-pad.org/>)
- Health Care Proxy
- Durable Power of Attorney

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Financial Support

- Consider your willingness and ability to contribute toward their living and treatment expenses, and under what conditions
- Never express resentment about any money that you spend for their care



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Your Next Steps

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Practice self-care!

Stay hopeful!

Essential Takeaways	Essential Takeaways
Work on communication techniques, especially active listening	Gather contact information for your loved one's provider(s). With their agreement, report changes in behavior and affect
Identify resources local to your loved one	Help to address insurance issues
Make calls to identify appropriate, available providers	Keep learning!

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Families for Depression Awareness Resources and Information

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FFDA Website Resources

<http://familyaware.org>

- Caregiver Stress Test: /stress-test
- Stress Management: /resources-for-coping-with-stress/
- Depression and Bipolar Disorder Test: /moodtest
- Insurance: /healthinsurance
- Family Action Plan Template: /actionplan
- How to Help (general): /help-someone/
- Role of the Family Caregiver (general): /caregiver-role
- Stages of Change Videos: /stages-of-change/



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Families for Depression Awareness **Thank You to Our Advisors**

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Families for Depression Awareness **And Thank You!**

Thank you for spending this time with us!

Please consider supporting the work we do by making a tax-deductible donation to Families for Depression Awareness at <http://familyaware.org/donate>.



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Rose's Takeaways

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Questions and Answers

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Wrap Up



- Please fill out the evaluation at <https://www.surveymonkey.com/r/FFDACAREGIVING2020>
- Take the Caregiver Stress Test at familyaware.org/stress-test
- Commit to practice self-care: you're worth it!
- Keep learning at familyaware.org and by subscribing to our newsletter
- Stay hopeful!

Stay safe and be well.

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