

DEPRESSION AND ANXIETY IN SERIOUS CHRONIC ILLNESS 2023 PATIENT FAMILY GATHERING

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Depression and Anxiety in Serious Chronic Illness (SCI)

Experience with the ECD cohort and application
from the medical literature



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Erdheim-Chester Disease Patient and Family Gathering

Mayo Clinic

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Before we start– Don't fall asleep on me!

- Don't try to read every word, and don't scramble to write detailed notes
- The slides are available
- **Listen** to the ideas and **look** at the images. Let the information wash over you
- If something resonates with you, make a mental note
- The talk is meant to inform you, and not to diagnosis you

Objectives of the talk

- Learn about some causes of depression and anxiety in SCI like ECD
- Review some of the symptoms of depression and anxiety
- Develop awareness of the difference between an expected grief response and a depressive or anxiety disorder
- Learn about how depression and anxiety can negatively impact your treatment and physical health
- Review treatment options

Depression and Anxiety in Serious Chronic Illnesses (SCI)



- Decades of research confirm that feelings of depression and anxiety (D&A) are common with SCIs (cancer, neurological diseases, autoimmune diseases).
- These feelings are also common after diagnosis with a rare SCI about which little is known
- People worry about extent of disability, death, family, finances.
- Grief is normal reaction to an extraordinary situation (becoming seriously ill).
- These feelings do not mean you are weak or crazy, they affirm your humanity.

Causes of depression and anxiety in ECD

- Overwhelmed by so much change and loss.
The magnitude of change can easily overwhelm.

Examples of challenges faced by the ECD community:

- Loss of physical functioning: from neurological problems
Needing help with essential self-care.
- Career loss: Income and health insurance loss
creating financial instability and difficult decisions
- Loss of self-identity, self-worth, and self-esteem:
We often define ourselves and show our
worth through our work, earning money, the physical
things we do (home maintenance, leisure activities),



Causes of depression and anxiety in SCI

Marital discord or significant other:

Partner often the main caretaker and medical-legal advocate

- Partner may become the sole income source – in addition to a full-time caregiver.
- ***Relationship may change from an intimate relationship between equal partners, to a caretaker and a dependent.***

Other relationships:

- Children may become caregivers, and the parent a dependent, the opposite of what is culturally normal
- Loss of friendships and collegial work relationships



Causes of depression and anxiety in SCI/ECD

Exacerbation of pre-existing depression and anxiety:

- ECD associated with high life-time prevalence of depressive and anxiety disorders
- Un-addressed psychological issues can worsen when faced with SCI/ECD
- Depression and anxiety may present differently after onset of SCI

Tell your physician about pre-existing mental health issues

Causes of depression and anxiety in SCI

- Medical complications of ECD causing symptoms similar to psychiatric disorders. Mood and behavioral changes are caused by altered structure and function in certain organs

Examples of medical problems causing changes in behavior and mood in people with ECD

- **Pseudobulbar Affect (PBA):**
condition causing inappropriate laughter or crying episodes. Emotional expressions are uncontrolled, and may be opposite of what is expected (laughing at a sad scene in a movie or upon hearing bad news).
- **Dementia-related mood and behavior changes:**
Similar to mood and behavioral disturbances noted in Alzheimer's-type dementia, but can be seen in other forms of dementia.
- **Seizures** result in mood disorders or transient psychosis (schizophrenia like symptoms).

Causes of depression and anxiety in SCI

Endocrine disorders (hormonal imbalances):

- Hypothyroidism can cause depressive symptoms and behavioral changes
- Low testosterone levels in men can result in depression, mental slowing, apathy
- Severe adrenal insufficiency causing depressive-type symptoms
- Infertility

Medication-induced mood disturbances:

- Corticosteroids, alpha-interferon, and in some, opioid use

Poorly controlled pain:

- Bone pain- insomnia, irritability, fatigue, and mood disturbances
- Chronic inflammation associated with fatigue, weakness, low mood
- ***Some of these conditions can be treated with medications and by addressing the underlying medical issue (e.g., low testosterone)***

Signs and Symptoms of mood disturbances

Common symptoms include:

- Persistently **depressed mood** (sullen, withdrawn, or sad)
- **Anhedonia**- Loss of interest in enjoyable activities
- **Insomnia** not due to pain or other **obvious explanation**
- **Loss of appetite and weight loss**
- **Non-compliance with treatment regimen**
- Restlessness, or an inability to be calm and make decisions



Signs and symptoms of mood disturbances

- *Not everyone exhibits classical symptoms of anxiety and depression. Other behaviors and moods can predominate*
- Some Examples:
 - Uncharacteristic agitation/irritability and short temper vs. melancholy
 - Over eating (hyperphagia) and weight gain vs loss of appetite and wt loss
 - Sleeping too much (hypersomnia) vs insomnia
 - Leadens Paralysis- Persistent feelings of heaviness in limbs

When to Get Help

- Symptoms interfere with ability to function (e.g., make decisions, follow treatment regimen, concentrate, enjoy time with others)
- Persistent anxiety attacks
- Feelings that life is not worth living or “my family is better off without me”
- Overwhelmed by emotions and unable to organize yourself (self-care deficits)
- Acting impulsively, physically acting out, cannot control your anger



Katie Gerten | May 4, 2022 | Blog, Depression, Featured, Mental Health, Quotes

Help is Available: Treatment Options

Tell someone how you feel and get help:

- You are not weak or crazy because you feel depressed or anxious, you are human.
- Work with your provider to look for medical causes, especially if your moods are not improving with anti-depressants

Medication therapy:

- Anti-depressants can improve both depression and anxiety, but they take time to work, so get a treatment plan



<https://tenor.com/view/helping-hand-help-lets-go-come-here-come-with-me-gif-14788685>

Help is Available: Treatment options:

Talking therapy/counseling:

- Medical or health psychologist – a therapist trained in helping people with psychological issues related to SCI
- Educate yourself on the signs and symptoms of mood disturbances and learn coping strategies.
- Join a support group

Neuro-psychological testing:

- Formal examination of cognition, personality, and mood state
- Consider when mood changes occur with significant personality, cognitive, and physical changes



Help is Available: Treatment Options

Be proactive!!

- Learn self-care techniques (within safe limits):
 - Improves functioning, reduces complications, improves self-esteem and self-worth and reduces caregiver workload.

- Functional Therapies:
 - Commit to regular physical and occupational therapy
 - For those who can, vocational rehab/re-training because work can be therapeutic for patient and family.

Parting Thoughts

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It's OK to feel overwhelmed

Admit how you are feeling:

- Don't say everything is OK when it is not



You are not alone, so do not isolate yourself :

- Join ECDGA, other histiocytosis organizations
- Other support groups
- Learn what you can do (activities)

Gratitude is healing:

Thank your loved ones for their care and dedication



<https://tenor.com/view/thumbs-up-gif-18124999>

AND MOST IMPORTANTLY:



NO MATTER HOW MUCH IT
HURTS, HOW **DARK** IT GETS, OR
HOW HARD YOU **FALL**...
YOU ARE **NEVER** OUT OF THE
FIGHT.

-MARCUS LUTTRELL

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Patients, Caregivers and Families living with ECD

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Personal Challenges in ECD

Henderson's 14 Needs as Applied to Maslow's Hierarchy of Needs

<https://nurseslabs.com/nursing-theories/>

