

DEPRESSION AND ANXIETY IN  
SERIOUS CHRONIC ILLNESS  
2023 PATIENT FAMILY GATHERING

KEVIN O'BRIEN, MD  
GENOME RESEARCH OF THE NATIONAL INSTITUTE OF HEALTH



# National Human Genome Research Institute



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# Depression and Anxiety in Serious Chronic Illness (SCI)

Experience with the ECD cohort and application  
from the medical literature



**Kevin O'Brien, RN, MS-CRNP**

OCD/NHGRI /NIH



Erdheim-Chester Disease Patient and Family Gathering

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

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- 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

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- 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

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## 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

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- 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

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## 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
  - Leaden 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/>

