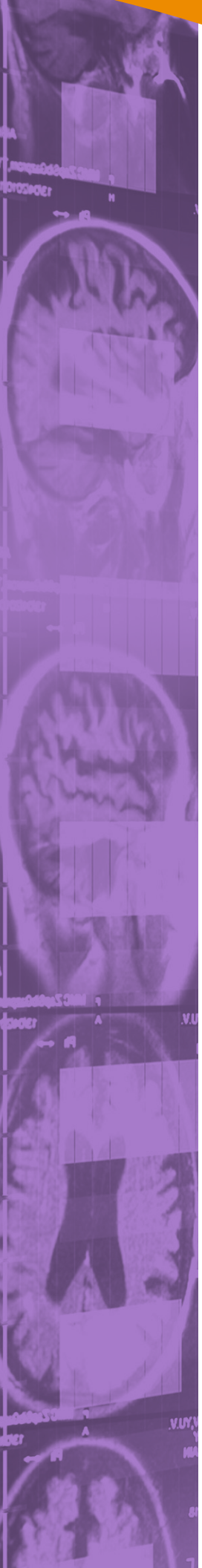

EPILEPSY, DEPRESSION & ANXIETY

WHAT DO WE KNOW?

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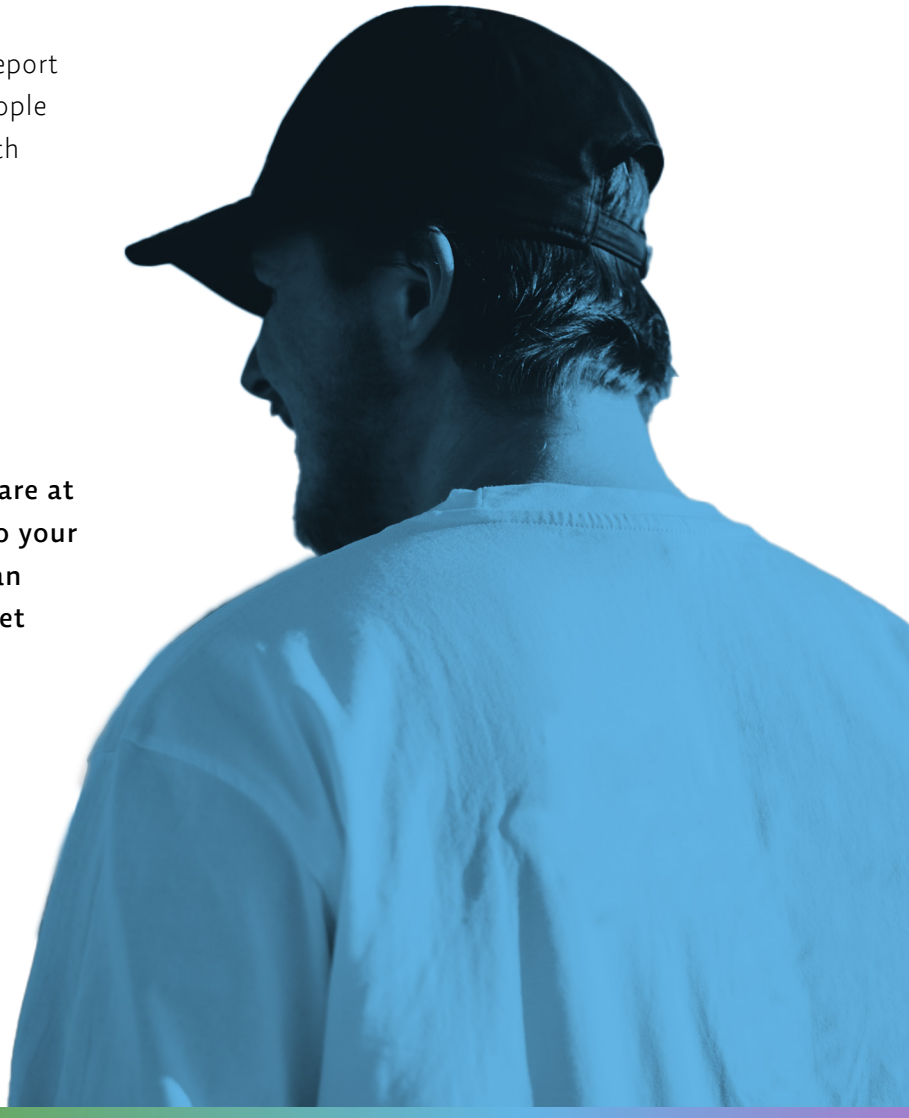
EPILEPSY, DEPRESSION & ANXIETY – WHAT DO WE KNOW?

C.J. is a 28-year-old male who was diagnosed with epilepsy two years ago. He previously worked as an accountant, but the anti-seizure drugs he's taking make it difficult to concentrate. He left his job and is currently looking for employment. Although his epilepsy is well-controlled, he has occasional breakthrough seizures that prevent him from having a drivers' license. Since his diagnosis, he has become more isolated and is anxious about having a seizure in public. C.J. lives with his parents and on some days, he doesn't have much energy and is unable to get out of bed. He would like to get married one day and have a family, but he worries that his seizures will get worse and that he will pass his epilepsy onto his children. His girlfriend has noticed his changes in mood, lower energy levels and increased social isolation and is encouraging him to get support for his mental health.

Stories like CJ's are very common. This report is intended to provide information to people with epilepsy who are also struggling with depression or anxiety and encourage them to seek appropriate treatment and support. If you are struggling with your mental health, please talk to your health care providers and see the list of resources at the end of this document.

If you are thinking about suicide, and are at immediate risk, please call 911 or go to your nearest emergency department. You can also connect to a crisis responder to get help. Call 1-833-456-4566 (toll free and available 24/7) or text 45645 (available 4pm – midnight EST) to connect to talksuicide.ca



SECTION 1:
BACKGROUND

WHAT IS EPILEPSY?

Epilepsy is a brain disorder where individuals experience recurrent seizures during their lifetime. Seizures occur when there is a sudden burst of brain activity, sometimes resulting in convulsions and loss of consciousness. There are many different types of seizures (e.g., tonic clonic, focal impaired awareness, etc.) and they can affect one or both sides of the body.

WHAT IS DEPRESSION?

Depression is a mood disorder in which an individual experiences five depressive symptoms daily for at least two weeks, causing severe difficulty in daily functioning (e.g., missing an important work meeting). These symptoms vary from person to person and depression does not affect everyone the same way. Symptoms may include:

- Poor concentration or decisiveness
- Excessive crying
- Feeling angry all the time
- Feelings of worthlessness, guilt, or self-blame
- Change in appetite
- Loss of interest or pleasure in activities
- Poor or excessive sleep
- Suicidal thoughts

WHAT IS ANXIETY?

Anxiety is a mood disorder associated with feelings of excessive uneasiness, worry, and nervousness. Types of anxiety disorders include:

- Generalized anxiety disorder (disabling and persistent worry that is present for at least 6 months)
- Phobias (fear of specific situations or objects)
- Panic disorder (sudden and severe waves of fear and anxiety)
- Obsessive–compulsive disorder (recurrent, intrusive, or unpleasant thoughts and/or compulsive behaviours)

HOW COMMON ARE DEPRESSION AND ANXIETY IN PEOPLE LIVING WITH EPILEPSY?

Compared to the general population, both adults and children living with epilepsy are at a higher risk of developing mood disorders (e.g., depression and anxiety), with a prevalence rate of around 25–50%. Around 30% of people with epilepsy (and up to 55% of people with drug–resistant epilepsy) will experience depression, and women with epilepsy have a higher likelihood than men of having a depressive episode. Increased anxiety also frequently co–occurs with epilepsy.

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SECTION 2:

WHAT IS THE LINK BETWEEN EPILEPSY, DEPRESSION AND ANXIETY?

There is no single reason why mood disorders are more common in people with epilepsy. Depression and anxiety may be linked to seizures themselves, to treatments such as anti-seizure drugs, or there may be a common cause for both conditions. Learn more about each of these reasons below.

1. IT MAY BE BIOLOGY

It has been shown that the relationship between epilepsy and depression goes both ways, meaning that someone with depression is more likely to develop epilepsy, and someone with epilepsy is more likely to develop depression. This suggests that certain brain changes can lead to both conditions, and this idea is supported in current research. For example, reduced levels of a chemical called serotonin are often seen in both people with epilepsy and people with depression. Similarly, inflammation, which occurs when the brain's immune response is activated, is linked to both seizures and depression.

Brain injuries, illnesses, or high levels of prolonged stress can change the structure and function of brain cells. This can create an imbalance in brain activity or brain chemistry that can trigger seizure activity and also lead to mood disorders. In some cases, these changes are determined by our genes and may be present from birth.

Areas of the brain where seizures commonly start, such as the temporal lobes, are also involved with regulating emotions. Certain brain structures located in the temporal lobes, such as the hippocampus and amygdala, play important roles in both epilepsy and anxiety, and any damage to these regions can make it more likely that both anxiety and epilepsy will occur. As with depression, the relationship goes both ways – seizures may trigger anxiety, and anxiety may trigger seizures through the release of stress hormones.

In some cases, seizures themselves can lead to depression or anxiety. Seizure activity may disrupt the levels of certain chemicals in the brain, leading to changes in mood.

Our genetics also play a role: a person with a family history of anxiety or depression is at greater risk of experiencing mood disorders regardless of whether or not they have epilepsy. The combination of our genes and our environment determine our risk of inheriting specific disorders.

2. ANTI-SEIZURE DRUGS

In some people, certain anti-seizure drugs may contribute to feelings of anxiety or depression. These drugs help to control seizures but can also affect the mood centres in the brain. Depression and suicidal thoughts are possible side effects of many different anti-seizure drugs, such as pheonobarbital, primidone, levetiracetam, perampanel, vigabatrin and topiramate.

Anxiety is a less common side effect of anti-seizure drugs but is sometimes seen with levetiracetam and brivaracetam. There is conflicting evidence about the link between suicide and anti-seizure drugs, and the exact risk is currently unknown.

3. PSYCHOLOGICAL AND SOCIAL IMPACT OF EPILEPSY

Having epilepsy can affect a person's life in many ways. Some people might feel shocked and sad after receiving a diagnosis. Restrictions such as not being permitted to drive, increased social isolation, or difficulties remembering or concentrating can contribute to a depressed mood.

Factors such as stigma, a lack of freedom, worrying about further seizures or side effects, a lack of social or family support, or past traumas can all lead to depression. Some people may also have struggled with mood prior to having epilepsy. Individual differences in how we respond to stress, such as our coping strategies, emotional responses or negative thought patterns also play a role.

Similarly, anxiety can be a reaction to the fear and unpredictability of seizures. Someone with epilepsy might worry about their health or prognosis, their relationships, their employment, or how they might be perceived if they disclose their diagnosis. Many people may feel a loss of control over their lives, leading to anxiety.

If you have depression or anxiety, any or all of the above reasons may contribute. In some cases, your mood changes may be unrelated to your epilepsy. It's important to discuss your mental health with your health care providers at every appointment so they are aware of any changes. Keeping a record of your mood and your symptoms can also help to identify any triggers. If treatment is needed, your health care providers will work with you to find the best option.

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SECTION 3:

IF I HAVE EPILEPSY AND DEPRESSION OR ANXIETY, WHAT ARE MY TREATMENT OPTIONS?

The first step to treating mental health conditions is a correct diagnosis. Ontario's epilepsy guidelines recommend that all people with epilepsy be regularly screened for changes in mental health. Once diagnosed, depression and anxiety are typically treated the same way in people with epilepsy as in those without epilepsy, but other considerations, such as lifestyle factors or drug interactions, need to be taken into account.

Treatment may involve one or more of the following options:

1. COUNSELLING OR PSYCHOTHERAPY

In people with epilepsy and mild depression, or epilepsy and anxiety disorders, it is often best to begin first with psychotherapy, which is useful for many aspects of depression and also psychological issues related to epilepsy. These psychological or "talk" therapies involve discussions with a trained professional to help you better understand your own thoughts and behaviours. Cognitive behavioural therapy (CBT) is a type of treatment that aims to change thinking patterns through recognizing negative thoughts, promoting understanding and acceptance, and providing behaviour change strategies. This type of therapy is currently recommended in the epilepsy population. While other types of therapies may also be effective, they have not been well-studied specifically in people with epilepsy. Counselling provides an opportunity for people to express their thoughts, feelings and fears. Through conversation, a counsellor can guide a person toward finding their own strategies and solutions.

Some people find that mindfulness training helps them to manage negative thoughts and feelings. For those with anxiety, training in cognitive strategies can also help to restore a sense of control over seizures. In general, there is a lack of research on the most effective treatments for people who have both anxiety and depression.

In Ontario, a distance-delivery group intervention called "Using Practice and Learning to Increase Favourable Thoughts" (UPLIFT) is offered through community epilepsy agencies. UPLIFT is a mindfulness-based CBT program that improves depression, anxiety, and overall psychological quality of life. This virtual program is led by trained facilitators and provides strategies to improve mental health in a group setting. To learn more, please contact support@epilepsyontario.org.

2. MEDICATION

Antidepressant drugs are commonly prescribed to treat anxiety or depression. Psychotherapy may also need to be augmented with medication depending on severity of the symptoms and the preferences of the individual. Selective serotonin reuptake inhibitors (SSRIs) are the first-choice medication for those with epilepsy and depression. These drugs increase brain levels of serotonin, a chemical that helps to regulate your mood.

Some doctors may be reluctant to prescribe antidepressants due to fear that they will cause or worsen seizures. However, most antidepressants can be safely used in people with epilepsy without increasing the risk of seizures.

It is recommended that you continue to take your medication for at least 6 months once symptoms start to improve. Counselling or therapy can also be used together with medication since the combination can be more effective than either treatment alone. If your depression is severe or you are having suicidal thoughts, you may be referred to a psychiatrist for urgent treatment.

For drug treatment of anxiety disorders, the most commonly prescribed drugs are antidepressants or benzodiazepines. To date, no studies have been done on the most effective medication for people with epilepsy and anxiety, but SSRIs are typically prescribed. SSRIs are usually the preferred treatment for anxiety disorders because they are generally safe and effective for long-term use. Benzodiazepines are also effective in treating anxiety, but they often cause side effects such as drowsiness and memory impairment and carry a risk of dependency.

3. COMPLEMENTARY THERAPIES AND LIFESTYLE CHANGES

Although these approaches have not been studied specifically in people with epilepsy and mood disorders, improving overall health and wellness can be an effective strategy for managing anxiety.

a) **Exercise:** Physical activity can increase serotonin levels and help to improve mood disorders. Aim for a minimum of 30 minutes, 3 times a week of aerobic exercises such as fast walking, running, cycling or swimming.

b) **Light therapy** delivers bright light from a special lamp and can help to relieve seasonal depression (i.e. depression that occurs in fall or winter when sunlight is low). However, the effectiveness in people with epilepsy is not yet known, and light therapy should be considered carefully in people with photosensitive epilepsy.

c) **Yoga, meditation and deep breathing** can reduce stress and help calm the mind and body.

d) A lack of **sleep** and a **poor diet** can create mood disturbances. Aim for at least 7–8 hours of restful sleep and a balanced diet that limits caffeine, alcohol and nicotine.

e) **Herbal treatments:** Hypericum (St. John's Wort) may be an option for people with mild depression; however, it can interact with anti-seizure drugs. In addition, the seizure risk in people with epilepsy is unknown. The use of any herbal treatments should be closely monitored by a health care provider.

f) **Electroconvulsive therapy (ECT)** is a treatment that involves applying small electrical currents to the head. It is given under general anesthesia, meaning you will be asleep during treatment. It is recommended for those with severe depression or those in crisis, in people who cannot take medication (i.e. pregnant women), or for people who have had a positive response to ECT in the past. However, ECT can cause memory loss, and it is unclear how this may impact people with epilepsy, many of whom already experience problems with memory.

4. NON-DRUG EPILEPSY TREATMENTS

In people with epilepsy who do not respond to anti-seizure drugs, treatments such as brain stimulation or brain surgery may be used. These treatments can also have an impact on mood.

a) **Vagus nerve stimulation (VNS)** involves implanting a device under the skin that delivers intermittent electrical stimulation to the vagus nerve (which communicates with the brain) to help reduce seizure activity. It can also lead to an improvement in symptoms of depression and anxiety. VNS is also approved to treat depression; however, the type or pattern of stimulation may be different.

b) **Repetitive Transcranial Magnetic Stimulation (rTMS)** is a treatment that delivers brief magnetic pulses to the brain through a coil placed on your head. Similar to VNS, rTMS can also be used to treat depression, but the type or pattern of stimulation may be different.

c) **Resective surgery** involves removing the part of the brain where seizures start. While some people may notice an improvement in mood, up to 25% of people may experience depressive symptoms after surgery. People at greater risk include those with a previous history of depression or anxiety, and those with poor family relationships.

There are many different health care providers who may be involved in treating mood disorders. Your primary care provider, family doctor, neurologist, epileptologist, or other health care provider can diagnose depression and start antidepressant therapy. Or you may be referred to a mental health professional. A **psychologist** is a trained professional who can use different types of therapies to assist with anxiety or depressive symptoms but does not prescribe medications. You can make an appointment with a psychologist in the community on your own without a doctor's referral. However, psychotherapy is not covered by OHIP and will require payment, although it may be covered by private insurance plans. A **psychiatrist** is a medical doctor trained in the diagnosis and treatment of mental illnesses, and their services are covered by OHIP. A **social worker** has specialized training and can also provide mental health counselling, but these services may not be covered by OHIP. However, social workers who work in non-profit health care centres or epilepsy agencies may provide services free of charge. Some community epilepsy agencies may offer support groups, counselling or other services to those dealing with anxiety and depression.

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SECTION 4:

FOR CAREGIVERS: HOW TO SUPPORT SOMEONE LIVING WITH EPILEPSY AND MOOD DISORDERS

Feelings of stigma, anxiety, and depressive symptoms are more common in people living with epilepsy compared to the general population. These negative effects are also higher in individuals who are currently unemployed or never employed, have lower education, have lower incomes, are using three or more anti-seizure drugs, and those who experience frequent seizures.

Being a caregiver for someone living with these conditions can be stressful, confusing, and traumatic. Family members and other care partners of people with epilepsy may develop mental health issues and need help themselves. Studies show that mothers primarily take on the caregiver role and are particularly at risk of experiencing burden. This burden has been linked to sleep deprivation of the caregiver, in part due to the fear of their child having a life-threatening seizure in their sleep. Caregivers may also have to continuously supervise and assist the daily activities of the person living with mood disorders.

HELPFUL TIPS:

- Learning about the signs and symptoms can help reduce the stigma of epilepsy and mood disorders. Community epilepsy agencies (CEAs) and health care providers can provide more information about an individual's diagnosis and help individuals and families cope with burden and the unpredictability of seizures.

- A caregiver's mental health should not be neglected. CEAs may also provide educational programs, mental health resources, and additional support for caregivers.

- Health care professionals from various disciplines may assist in providing care and management of mood disorder symptoms (e.g., psychiatrists, clinical psychologists), caregiver stress (e.g., social workers) and issues with brain functioning, concentration, or memory (e.g., neuropsychologists).

- The Mood Disorders Association of Ontario (MDAO) has a free guide for families, friends, and supporters of individuals experiencing mood disorders: 'Family Matters Guide for Families'

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FURTHER RESOURCES:

The Canadian Epilepsy Alliance (CEA) – Provides support for living with epilepsy and depression. Call 1-866-Epilepsy to reach the agency nearest you for help and assistance.

Epilepsy Toronto – A place where Torontonians living with epilepsy can learn more about their condition, get the help they need and be a part of a family of caring and supporting people.

UPLIFT program – Using Practice and Learning to Increase Favourable Thoughts (UPLIFT) is a mindfulness-based cognitive behavioural therapy program that improves depression, anxiety, and overall psychological quality of life for adults living with epilepsy and their caregivers.

The Ontario Caregiver Organization (OCO) – Caregivers play a vital role in the physical and emotional well-being of a person with epilepsy. The OCO provides resources and tips that can help provide better care for someone living with epilepsy.

Hospital for Sick Children – Has a detailed list of epilepsy organizations, research, and books. A wide range of topics is covered, including guides for families and the ketogenic diet.

Hope & Me – The Mood Disorders Association of Ontario – Provides a range of peer-based, self-help support groups for those living with mood disorders along with support for their caregivers.

Mental Health Commission of Canada (MHCC) – Leads the development and dissemination of innovative programs and tools to support the mental health and wellness of Canadians.

Ontario Epilepsy Guidelines – These recommendations were developed to improve the quality and consistency of epilepsy care in Ontario. Find a variety of tools and resources for patients, families, and health care providers.

CHOICE-D Patient and Family Guide to Depression Treatment – The CHOICE-D Guide aims to help individuals understand the evidence-based treatments that are available for managing depression. The guide includes information about medications, psychological treatments, brain stimulation treatments and complementary & alternative treatments.

CONTACT US

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EPILEPSY, DEPRESSION & ANXIETY

Epilepsy is a brain disorder where individuals experience recurrent seizures. Up to 50% of people with epilepsy will also have a mood disorder, such as anxiety or depression.

Symptoms of **depression** may include:

- Poor concentration or decisiveness
- Feelings of anger or worthlessness
- Loss of interest or pleasure in activities
- Change in appetite or sleep
- Excessive crying or suicidal thoughts

Why seizures are linked to mood:

Biology
Brain injuries, chemical imbalances, or our genes can cause changes in the brain that lead to both epilepsy and mood disorders.

Anti-seizure drugs
These help to control seizures but can also affect the mood centres in the brain.

Impact of epilepsy
Fear of seizures, worries about the future, stigma, a lack of social support, negative thought patterns or stressful situations can all contribute to mood changes.

Symptoms of **anxiety** may include:

- Disabling and persistent worry
- Fear of specific situations or objects
- Sudden and severe waves of fear and anxiety
- Recurrent, intrusive, or unpleasant thoughts and/or compulsive behaviours

What treatments are available?

Counselling or psychotherapy
Talk therapies with a trained counsellor can help you better understand your thoughts and behaviours

Medication
Antidepressant drugs are commonly prescribed to treat anxiety or depression

Complementary therapies and lifestyle changes
Exercise, yoga and meditation, light therapy, and dietary or sleep changes can help to manage symptoms

For Health Care Providers: Treating Depression & Anxiety in People with Epilepsy

Prevalence

- The prevalence of mood disorders (e.g., depression, anxiety) in adults and children living with epilepsy is higher than the general population, ranging from 25-50%
- Depression is the most prevalent mood disorder in people with epilepsy, impacting approximately one third of patients

Factors That May Contribute to the Development of Depression & Anxiety

1. Neurobiological Factors

- Brain lesions or structural abnormalities
- Alterations in neurotransmitter levels
- Seizure activity
- Genetic susceptibility

2. Anti-seizure Drugs (ASDs)

- Adverse cognitive side effects of ASDs:
  - -Depression and suicidal ideation are possible adverse effects of ASDs including pheonobarbital, primidone, levetiracetam, perampanel, vigabatrin and topiramate
  - -Anxiety is a less common side effect of ASDs but is sometimes seen with levetiracetam and brivaracetam

3. Psychological & Social Impact of Epilepsy

- Contributors may include:
  - -Stigma
  - -Social isolation
  - -Unemployment
  - -Loss of control
  - -Driving limitations
  - -Low self-esteem
  - -Constant worry/fear about the unpredictability of seizures

Diagnosing Depression & Anxiety:

Screening tools are used by health care providers to diagnose mood disorders in people with epilepsy, such as the **Generalized Anxiety Disorder 7 (GAD-7)** and **Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)**

Health care providers should develop **individualized treatment strategies** for patients, depending on the severity of their mood disorders. These treatments may be used **individually or in combination**.

Treatment Options

Psychological Treatment

- Psychotherapy (e.g., cognitive behavioural therapy, group-based interventions, and mindfulness-based cognitive therapy)
- Counselling

Pharmacological Treatment

- Selective serotonin reuptake inhibitors (e.g., citalopram, fluoxetine) and serotonin-norepinephrine reuptake inhibitors (e.g., venlafaxine, duloxetine) may be prescribed
- Most antidepressants are safe for people with epilepsy when used at therapeutic doses. However, amoxapine, bupropion, clomipramine, and maprotiline should be avoided.

Complementary Therapies & Lifestyle Changes

- Healthy lifestyle choices (i.e., adequate sleep, exercise, yoga, meditation)
- Dietary/nutrition changes (limit caffeine, alcohol, nicotine)
- Herbal treatments (e.g., St. John's Wort)
- Light therapy (note that this should be considered carefully for people with photosensitive epilepsy)

Brain Intervention Therapies

- Electroconvulsive therapy
- Vagus nerve stimulation
- Repetitive transcranial magnetic stimulation
- Resective brain surgery

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