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# A FAMILY GUIDE

hat Families Need to Know about Adolescent Depression







What Families Need to Know about Adolescent Depression

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The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI has more than 1,100 affiliates in communities across the country that engage in advocacy, research, support and education.

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# **Table of Contents**

Adolescent Depression	3
Causes and Symptoms of Depression	4
Differences between Adolescents and Adults Living with Depression	on 5
Understanding Self-harm	7
Talking about Depression with Your Child	7
Getting an Accurate Diagnosis	9
The Role of Primary Care Physicians	12
Treating Depression	14
Psychosocial Interventions	17
Cognitive Behavioral Therapy	17
Interpersonal Psychotherapy	19
Family Education and Support	19
Medications	20
Side Effects	22
Family History and Treatment	23
Risk of Suicide	23
When Your Child is Thinking or Talking about Suicide	24
The Black Box Warning	24
What Prompted the Black Box Warning?	25
Does the FDA Warning Mean Medications are Unsafe?	25
Creating a Good Monitoring System	26
Creating a Safety Plan	27
Research	28
Treatment for Adolescents with Depression Study	29
Treatment of SSRI-resistant Depression in Adolescents Study	32
Treatment of Adolescent Suicide Attemptors Study	34
Advocating for Your Child	35
Resources for Families	36

# **Adolescent Depression**



Adolescence is a time of many changes and challenges. Developing bodies and social and academic stresses make for a difficult period for many teens. Yet most teens get through these years with only short-term feelings of sadness or irritability.

While people sometimes use the word "depressed" to describe how they feel, there is also a serious mental health condition known as major depression or clinical depression. Unlike normal emotional experiences of sadness, loss or passing mood states, major depression is persistent and can significantly interfere with an adolescent's thoughts, behavior, mood, activity and physical health.

Approximately 8 percent of adolescents have a major depressive episode in any given year and 20 percent experience depression in the teen years. In adolescence, twice as many girls as boys are diagnosed with depression. The compounding issues of sexual identity and stigma often raise the risk of depression in gay, lesbian, bisexual and transgender (GLBT) youth. Children in military families also experience higher rates of depression than the general population with one in four of them experiencing symptoms of depression.

Depression tends to be an episodic illness, with some youth spontaneously improving. Yet it also tends to be recurrent, with one episode of depression raising the risk for another. Four out of 10 youth will have a second episode of depression within two years. Repeated episodes of depression can take a great toll on a young mind.

Major depression in adolescents can be quite serious. Untreated, depression can lead to devastating consequences for adolescents, including ongoing problems in school, at home and with friends, the loss of critical developmental years and increased risk for substance abuse, involvement with the juvenile justice system and suicide.

Yet, the majority of youth living with depression are undiagnosed and untreated.<sup>5</sup> In particular, Asian American/Pacific Islander children have the lowest rates of mental health services usage.<sup>6</sup> Latino and African American

youth in urban areas are less likely to receive mental health care.<sup>7</sup>

Depression should be addressed just like any other physical illness. If your child is experiencing depression, it is a good idea to get an evaluation followed by effective services and supports to prevent the social isolation, negative self-esteem and safety risks that result from persistent depression.

This guide is designed to help provide you with guidance on getting an accurate diagnosis for your child and on understanding the various treatment options that have been shown to be effective in treating adolescent depression. It also provides you with the information you may need to advocate for these effective services and supports if they are not readily available for your child.

#### **Causes and Symptoms of Depression**

Adolescent depression is nobody's fault. Several factors, including biological and environmental factors, increase the risk of depression. For example, a family history of mood disorders and stressful life events in those who are genetically vulnerable to the condition can lead to the development of depression. Some individuals develop depression because of a chemical imbalance in the brain started by a triggering event, including stress from loss, physical or sexual abuse, substance use, humiliation or failure, or seemingly nothing at all. These factors increase the risk of depression but have different effects on different individuals. For example, a relationship breakup may make one teen unsettled for a few days but send another teen with biological risk into depression. Whatever the specific causes of depression, scientific research has firmly established that major depression is a biological, medical illness.

As outlined in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, *4th Ed.* (DSM-IV), a major depressive episode involves at least two weeks duration (and usually more) of reduced functioning with five or more of the symptoms listed below. It is important to not dismiss any of these symptoms as "acting out" or "just a phase."

- sleep problems (commonly more sleeping);
- · loss of interest or pleasure in formerly fun activities;
- loss of interest in friends;
- appetite changes;

- energy loss;
- sadness or irritability;
- concentration problems;
- hopeless or guilty thoughts;
- body movement changes—feeling edgy or slowed down;
- persistent physical complaints and/or frequent visits to school nurses; or
- suicidal thoughts or preoccupation with death.

For many adolescents, suicidal thoughts are part of major depression. Suicide is seen as a permanent "solution" to what may be a temporary problem. Although teenage girls are at greater risk of depression, boys have a higher risk of suicide if they are depressed. But if diagnosed and treated promptly, almost everyone—children, adolescents and adults—recovers from depression. For more information on the risk of suicide, see page 23 of this guide.



All concerns about suicide require *immediate* attention. All statements about suicide need to be taken seriously and are a reason to immediately alert a health care provider or seek emergency help.

Depression often coexists with other conditions such as anxiety. Sometimes, especially for girls, eating disorders such as anorexia nervosa or bulimia coexist with depression. Learning disabilities and Attention-deficit Hyperactivity Disorder (ADHD) raise the risk of depression. Substance abuse is also common in adolescents who are living with depression.

Depression may also be the first sign of what later turns out to be bipolar disorder. Bipolar disorder has important and additional symptoms that often include periods of feeling irritable, high or powerful, needing little sleep but still feeling full of energy and grandiosity, euphoria and hypersexuality. Adolescents living with bipolar disorder may also talk loudly and fast. Risk taking can be a symptom of both depression and bipolar disorder. It is important to get a comprehensive evaluation to determine if your child has coexisting conditions or if his or her depression is actually a symptom of bipolar disorder.

# Differences between Adolescents and Adults Living with Depression

Adolescents living with depression often experience symptoms of irritability, anger and self-criticism more commonly than the feelings of sadness and loss of energy seen in adults. Also, school performance frequently drops off for adolescents living with depression—sometimes dramatically. They also often visit the school nurse more frequently with vague body complaints like headaches and stomach aches. They may engage in high-risk sexual activities and other risky behaviors, including shoplifting, physical fights and substance use. Adolescent males living with depression may mask feelings of sadness with anger. Loss of interest in peers is a "red flag" for depression in adolescents, as these relationships are key to normal development.

However, an adolescent's social relationships can be a double-edged sword—acting as an important source of support and normal development while also sometimes causing a great deal of pain and distress, particularly in adolescents who experience bullying. In general, those who experience verbal, physical or sexual assault or the threats of such assault are more vulnerable to mental health problems, including depression. GLBT youth fair the worse when it comes to bullying. Almost 90 percent of GLBT students have been harassed or assaulted during the past year. Acts of racism and discrimination have been shown to correlate with the development of depression in ethnically and racially minority youth.

Long-term bullying may cause so much distress for an adolescent that it becomes a contributing factor in a suicide attempt. To learn more about how to address bullying, visit Stop Bullying Now! at www.stopbullyingnow.hrsa.gov.



#### **Understanding Self-harm**

Self-harm includes cutting, picking, scratching, burning, biting or excessively piercing or tattooing one's body to reduce, express or cope with overwhelming, painful emotions. This behavior can be puzzling and scary to those who care for an adolescent who is self-harming.

Adolescents living with depression may self-harm if they do not have healthier alternatives in place to cope with or relieve negative feelings. Self-harm can also be used as a kind of "self-medication" for treating depression—not unlike drinking, using substances or overeating. Some individuals report that self-harm can be experienced as a "runners high" when "feel good" endorphins are released in the brain in response to the physical injury. Adolescents may also self-harm to communicate feelings of depression, hopelessness or worthlessness, exert control over their lives or combat feelings of numbness.

It is important to note that self-harm is not necessarily a suicide attempt. It can lead to unintentional, serious injuries, scarring and infections and become an ineffective coping tool. Thus, it is important to encourage adolescents to stop the behavior, but only if effective coping skills are in place. Since self-harming is a way to handle overwhelming emotions, it is important to offer alternatives and self-soothing strategies. To learn more about self-harm and how to treat it, visit NAMI's fact sheet on self-harm at www.nami.org/CAAC/selfharm.

#### Talking about Depression with Your Child

There are many points during an adolescent's development when effectively communicating with him or her may be difficult. Getting past these difficulties is never more important than when addressing depression. If you are concerned your child may be experiencing depression, it is important to talk to him or her about your observations and how he or she is feeling and to listen for key warning signs. Here are some tips for opening the door to talking about depression with your child:

- Get your child talking about his or her emotions by making gentle and open-ended observations (e.g., "I have noticed things have been especially hard for you recently, can you tell me about it?") and then listen to him or her without judgment.
- Ask your child if he or she feels "angry" "frustrated" or "upset" and

- see if your child starts accepting your suggestions and also uses words like "sad" "afraid" "numb" or "hopeless."
- Try not to talk your child out of how he or she feels or to put a positive spin on his or her painful feelings.
- Point out distinct changes in your child's behavior. He or she may not be aware of the changes or may be grateful you have noticed.
- Ask your child what he or she enjoys doing to help determine if your child is experiencing a loss of pleasure in daily activities.
- Collect as much information as you can from your child's teachers, friends, extended family members and others he or she interacts with. Try to enlist your child's confidantes as your allies in addressing depression with your child. Adolescents may behave or communicate differently with different people in different settings so this information seeking is critical.
- Let your child know that depression is a biological, treatable condition that can happen to anyone. Adolescents are very sensitive to suggestions that they are different or abnormal so it is important to address depression like any other medical condition that needs treatment.
- Emphasize your unconditional support for your child, maintain a positive attitude and applaud him or her for any small step he or she takes to get better.
- Avoid punishing your child for symptoms related to depression but set boundaries on his or her behavior if necessary. For example, find ways to encourage your child to spend time out of his or her room and with family rather than punish him or her for withdrawal and isolation.
- If someone in your family has had depression, it may be helpful to share this reality with your child so he or she feels less alone.
- Check back regularly. Sometimes it takes time for an adolescent to share information.

It is important to create an open, honest home environment where mental health issues are discussed and treated like any other health risks impacting adolescents. There are many resources available on talking about mental health issues with children at various ages. By opening the doors of communication about mental health early, before there is a problem, your child may be more likely to go to you when he or she is experiencing depression or another mental health related problem.

#### **Getting an Accurate Diagnosis**



If you are concerned that your child may have depression, the first step is to obtain an accurate diagnosis from a health care provider (primary care physician, therapist and/or child and adolescent psychiatrist). This evaluation should include a comprehensive understanding of your child's needs in multiple settings, including home, school and social settings. The health care provider should also take into account your child's cultural beliefs and their influence on his or her understanding of the symptoms of depression and the need for treatment.

Getting an accurate diagnosis can be challenging. Several factors contribute to this challenge, including the following:

- symptoms—often including extreme behaviors and dramatic changes in behavior and emotions—may change and develop over time;
- adolescents undergo rapid developmental changes in their brains and bodies as they get older and symptoms can be difficult to understand in the context of these changes;
- adolescents may be unable or unwilling to effectively describe their feelings or thoughts, making it hard to understand what is really going on with them; and
- it is often difficult to access a qualified mental health professional for a comprehensive evaluation because of the shortage of child and adolescent mental health care providers. This shortage emphasizes the critical role your child's primary care physician may need to play in the diagnostic and treatment process of adolescent depression, outlined in greater detail starting on page 12 of this guide.

Despite these challenges, there is still plenty you can do to help your child get an accurate diagnosis and ultimately receive the most effective treatment. Below are five areas you should consider when getting an accurate diagnosis for your child.

1. Record keeping. Organize and keep accurate records related to your child's emotional, behavioral, social and developmental history. The records should include observations of your child at home, in school and in the

community. They should be shared with your child's health care provider to ensure the best diagnosis. The records should include the following information:

- primary symptoms, behaviors and emotions of concern;
- a list of your child's strengths;
- a developmental history of when your child first talked, walked and developed social skills;
- a complete family history of mental illness and substance use disorders, if available. Many mental health conditions run in families, including depression;
- challenges your child is facing with school, social skill development, developmental milestones, behaviors and emotions;
- the times of day or year when your child is most challenged;
- interventions and supports that have been used to help your child and their effectiveness, including therapy, medication, residential or community services, hospitalization and more;
- settings that are most difficult for your child (e.g., school, home and social settings);
- any major changes or stresses in your child's life (e.g., divorce, death of a loved one);
- factors that may act as triggers or worsen your child's behaviors or emotions; and
- significant mood instability or disruptive sleep patterns.
- 2. Comprehensive physical examination. To make an accurate diagnosis, it is important to start the process with your child's primary care physician. A comprehensive physical examination should be done to rule out other physical conditions that may be causing symptoms that mimic depression. Additionally, your child's physician should also look for and interpret signs of physical or sexual abuse, which may contribute to or worsen depression.
- **3.** Co-occurring conditions. Your child should be evaluated for co-occurring conditions that may lead to the development of or worsening of depression. Such conditions include learning disabilities, alcohol and drug use and sensory integration issues.

4. Specialists in children's mental health. After your child is evaluated for other physical conditions and co-occurring conditions, it is time to meet with a qualified mental health provider (such as a child and adolescent psychiatrist) for a mental health evaluation. Your child's primary care physician may be able to refer you to one. You can also ask for referrals from families involved with NAMI or other advocacy organizations. To contact your NAMI state organization or local affiliate, visit www.nami.org/local or call the NAMI HelpLine at 1 (800) 950-NAMI (6264). To find a child and adolescent psychiatrist, visit the American Academy of Child and Adolescent Psychiatry website at www.aacap.org (click on "Child and Adolescent Psychiatrist Finder").

As a result of the national shortage of child and adolescent mental health care providers, you may not be able to locate any in your community who are readily available. This is especially true for people living in rural communities and those seeking health care providers that are culturally and linguistically competent. Fortunately, a movement to integrate mental and physical health care is underway in many communities. In some areas, primary care physicians are now becoming trained in and can play a critical role in the screening, identification and treatment of depression in adolescents. You can work with your child's primary care physician in diagnosing and treating your child's depression if no mental health care providers are available. To learn more about integration and the tools available to help primary care physicians address adolescent depression, see The Role of Primary Care Physicians section starting on page 12 of this guide.

Additionally, you may want to investigate telemedicine opportunities available in your community, which include appointments by video or telephone. Telemedicine is increasingly being used by mental health care providers to treat people in rural regions where mental health care providers are in short supply, however, its effectiveness has not yet been well established so it is important to proceed with caution.

**5. The diagnostic and evaluation process.** Your child's diagnosis should be made based on professional observation and evaluation, information provided by your family and other experts and the criteria found in the latest version of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM), which provides standard

criteria for the classification of mental health conditions. This evaluation should include a comprehensive look at all aspects of your child's life in school, church and the community and with family and friends. The health care provider evaluating your child is likely to ask you to fill out a checklist that provides a detailed profile of your child and the challenges he or she is facing. If the health care provider doing the evaluation does not share your culture, race or ethnicity, you may want to explain to him or her any cultural issues that may be important to consider during the evaluation.

Once an accurate diagnosis of depression has been made, it is helpful to focus on effective treatment options. The goal should be to achieve the outcomes that are most important to your child and family.



#### The Role of Primary Care Physicians

In recent years, the federal government and national pediatric organizations have called for significantly stepped up efforts to identify depression in adolescents within the primary care setting as outlined in the following subsections. You may want to share the resources included in these sections with your child's primary care physician so he or she is better equipped to address depression in your child if no mental health care providers are readily available.

An increased focus on the early identification of depression and other mental health conditions in primary care promises to help address the under identification and treatment of adolescents living with depression.

### The U.S. Preventive Services Task Force Recommends Depression Screening in Primary Care

In April 2009, the U.S. Preventive Services Task Force (USPSTF) released recommendations urging physicians across the country to perform routine depression screenings for adolescents aged 12-18 when appropriate services are in place to ensure accurate diagnosis, treatment and follow-up care. The task force indicated that screening, when followed by assessment and treatment, including psychotherapy, can help improve symptoms and help youth cope. Task force members also expressed confidence in the accuracy and safety of screening tests to identify major depression in adolescents.

The USPSTF is a panel of experts organized by the federal government to establish guidelines for treatment of a variety of health conditions in primary care. Its recommendations are considered the gold standard for clinical preventive services. To learn more about USPSTF's recommendations, visit www.uspreventiveservicestaskforce.org (click on "A-Z Topic Guide" and scroll down to "Depression in Children and Adolescents: Screening").

#### American Academy of Pediatrics Calls for Mental Health Screening in Primary Care

In June 2010, the American Academy of Pediatrics (AAP) released guidelines on mental health screening that included the following recommendations for pediatricians:

- pediatricians should screen children and adolescents for possible mental health issues and substance use at every visit to the doctor's office; and
- pediatricians should develop a network of mental health professionals in their community to whom they can refer families if they suspect a child needs further evaluation.

The AAP Mental Health Task Force was formed in 2004 to address children's mental health concerns in primary care and to ensure children are identified early and connected with effective services and supports. To assist pediatricians in meeting these recommendations, the AAP created a clinician's toolkit that includes multiple resources. To access these resources, visit www.aap.org/mentalhealth.

# **Treating Depression**



Having an adolescent diagnosed with depression can be a frightening experience, especially if your child attempts suicide or engages in self-harm. It may be helpful to find a trusted friend, family member or professional or a support group for support and guidance. This will help you cope with your situation and provide your child with the support and advocacy that he or she may need to get treatment.

The first step in treatment is to obtain an accurate diagnosis. The next step is to develop an effective treatment plan. A treatment plan must address your child's unique and individual needs and his or her strengths, goals and interests. In developing an appropriate treatment plan, it is also important to keep the whole picture of your child's life in mind.

You will want to choose a health care provider—whether a primary care physician, therapist or child and adolescent psychiatrist—to work with you and your child in developing and implementing a comprehensive treatment plan that may include several health care providers. When choosing a health care provider, be sure to ask about his or her training and experience in treating adolescent depression. Also, ask about his or her experience working with adolescents with your child's background (e.g., racial, ethnic, sexual orientation, coexisting substance abuse, etc.). If the health care provider is not experienced or knowledgeable in working with adolescents with your child's experiences, you can always educate him or her or look for another health care provider. Follow your instincts about whether your child will connect with the health care provider and then check in with your child about the relationship once treatment begins.

There are many factors to determining if a health care provider is a "good fit" for your child and if he or she is able to develop an effective treatment plan for your child. It is important that your child's health care provider understands and respects the way you and your family perceive depression and any treatment options. It is important to find a health care provider you and your child trust. You may want to make a list of questions or issues important to you and your child before meeting with a health care provider to ensure they are addressed during the development of a treatment plan. It is also vital that you and your family become educated

about depression so you can play an active role in the treatment plan. Ask your child's health care provider about the latest studies on depression and educate yourself about the latest research findings by visiting the National Institute of Mental Health (NIMH) website at www.nimh.nih.gov.

The most common treatments for depression are psychosocial interventions, also called talk therapy, medication or a combination of both. These treatments are outlined in detail in the following sections. If your child is prescribed medication and is receiving a psychosocial intervention, make sure that there is a plan for all of the health care providers involved with your child's treatment, including primary care physicians, therapists and/or psychiatrists, to communicate with each other. Clear lines of communication, with you as the parent facilitating that communication, will improve treatment results. Also, you should talk with the health care provider/s about the need to protect your child's privacy, whenever possible, with the understanding that thoughts of hurting oneself or others will be shared with the family. You should also know that what you and your child share with any health care provider is confidential and should only be shared outside of the office with your permission or to protect your child's safety.

Addressing substance use is a key part of a treatment plan because it increases the risks associated with depression, especially the risk of suicide. It can be both a cause and a consequence of depression. Alcohol and substance use also impacts the effectiveness of medication. Ask your child's health care provider if he or she can suggest an effective intervention for any substance use. Alcoholics Anonymous (www.aa.org) or Narcotics Anonymous (www.na.org) groups that are tailored to young people can be extremely helpful for adolescents living with depression and substance use disorders. For more information on co-occurring mental health and substance use disorders, check out NAMI's article on the topic at www.nami.org/CAAC/substanceuse.

Having a connection to family members is a protection against depression. Keeping the lines of communication open can help to make treatment decisions more collaborative. Family therapy has not been well studied for the treatment of depression, however, if there are specific family-related stresses in an adolescent's life (e.g., divorce, serious illness or financial strains) or a lack of communication within the family, family therapy may

prove beneficial. Also, family therapy can be helpful because it gets the whole family involved in and supportive of treatment. With full family support, adolescents may be better able to participate in a treatment plan.



A sense of connection at school and with peers is also helpful for adolescents who are at risk of depression. If your child is depressed, talk with him or her about how to use his or her peers, extended family and other important people for support.

Aerobic exercise has had positive antidepressant effects in adults with mild to moderate depression and can also be a useful part of the treatment plan for adolescents. When teens exercise, it can help to improve their mood. Visit www.nami.org/heartsandminds to explore NAMI's free wellness program, Hearts & Minds.

Complementary and alternative medicine—those practices not generally considered part of conventional medicine—may also play a role in treatment. Complementary and alternative medicine includes dietary supplements, meditation, acupuncture, massage therapy, deep-breathing exercises and much more. To learn more about complementary and alternative medicine, visit the National Center for Complementary and Alternative Medicine at http://nccam.nih.gov/. Spirituality can also be an important component to include in a treatment plan depending on your child's beliefs.

Lastly, peer support groups can be beneficial to adolescents living with depression. They can help your child feel less alone, increase his or her social skills and stay positive. They can also be a powerful source of comfort while your child is seeking and waiting for treatment. Contact your NAMI state organization and local affiliate to see if there are teen support groups available in your community. There are also online support communities available for adolescents. One such community is StrengthofUs.org, NAMI's online resource center and social networking website for young adults living with mental health conditions. To access this community, visit www. strengthofus.org.

#### **Psychosocial Interventions**

There is an ancient expression, "pain shared is pain halved." When an adolescent is depressed, feeling alone and isolated makes it much harder for him or her to cope, but talking can help. There are several psychosocial interventions that have been demonstrated by research to be effective in reducing or eliminating depressive symptoms. They are outlined in the following subsections. These interventions are usually provided by mental health care providers, including therapists, psychologists and psychiatrists. If you are working with your child's primary care physician, he or she may need to refer you out for these treatments. You can also access referrals through your NAMI state organization or local affiliate (www.nami.org/local) or the American Academy of Child and Adolescent Psychiatry (www.aacap.org). It is important to learn about these interventions to ensure that your child receives the best possible care.

Although there is a growing emphasis on the importance of using these effective interventions in treating adolescent depression, these interventions are still not yet widely available in every community. You are encouraged to learn more about what interventions work for your child and family. Educated and informed families are in the best position to request the most effective treatments for their child, including the ones described in this guide, and ensure that these treatments are made available in their communities. Family advocacy promises to lead to the broader availability of treatments that work in communities across the country and to ultimately better outcomes for all children and their families. For more information on advocating for the broader availability of effective services and supports for your child, see NAMI's family guide on *Choosing the Right Treatment: What Families Need to Know About Evidence-based Practices* at www.nami.org/CAAC/ChoosingRightTreatment.

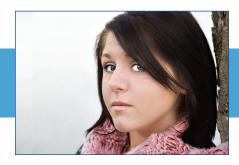
#### Cognitive Behavioral Therapy

One psychosocial intervention shown to be effective for adolescents living with depression is Cognitive Behavioral Therapy (CBT). CBT teaches youth how to notice, take account of and ultimately change thinking and behaviors that impact their feelings. In CBT, youth examine and interrupt automatic negative thoughts they may have that make them draw negative and inappropriate conclusions about themselves and others.

CBT breaks down negative thinking patterns and attempts to change them. For example, if an adolescent did poorly on a test and is thinking "I'm dumb and worthless," CBT helps him or her to think about what he or she could have done differently to do better on the test rather than focusing on negative thoughts about him or herself. There is good evidence to show that CBT helps to reduce symptoms of depression in adolescents; however, the best treatment outcomes are found when CBT is combined with antidepressant medication. More information about the research on CBT is provided starting on page 28 of this guide.

The average length of treatment for CBT is 12-16 weeks, with a 60- to 90-minute session each week. Youth participating in CBT are typically given homework with the expectation that they are working outside of the office. Family involvement in CBT includes parents reinforcing more sensible and positive thoughts and helping their child practice this new way of thinking at home.

To find mental health care providers qualified to provide Cognitive Behavioral Therapy for adolescents, visit the National Association of Cognitive-Behavioral Therapists at http://nacbt.org (click "CBT Referrals") or the Association for Cognitive Behavioral Therapies at www.abct.org (click "Find a Therapist").



#### **Interpersonal Psychotherapy**

Interpersonal Psychotherapy (IPT) is a psychosocial intervention that looks at relationships and transitions for adolescents and how they affect their feelings and thinking. IPT focuses on helping adolescents manage major changes in their lives such as divorce or significant loss. In IPT, the therapist helps the adolescent evaluate his or her relationships and interactions with others. The average length of treatment for IPT is 12 weeks, with weekly face-to-face sessions and regular phone contact.

Because relationships are key in adolescence, IPT is an appropriate treatment intervention for adolescent depression. However, IPT needs further study in adolescents to better understand its full effectiveness in treating depression. It is, however, well established as an effective treatment for adults living with depression.

It is not known how well a relationship with one therapist is helpful outside of CBT or IPT—it is hard to study something as unique as a relationship. Some adolescents feel the relationship alone is helpful—the therapist is a safe person outside of their family with whom they can share their thoughts and concerns.

### Family Education and Support

Family education and support programs use experienced and trained parents of children receiving mental health services to provide education and support to other parents. The most common types of support include emotional support (empathy, reassurance and positivity to reduce distress, shame and blame) and information support (about conditions, treatment options, parenting skills, coping strategies, community resources and stress reduction). Through relationship-building, education, collaboration and problem-solving, these family education and support programs help adolescents and their families learn more about depression, master new and effective ways to manage the condition, acquire strategies for handling crises and relapse and much more. These programs also help families understand how best to support their child living with depression.

The evidence base for family education and support programs is growing and shows that these programs are effective in providing support and education to families.

In children's mental health, a limited number of studies have examined the impact of family education and support on children and families. One model of family education and support that has been studied is the Multifamily Psychoeducation Groups (MFPG) program, which is designed for children and adolescents living with mood disorders, including depression. MFPG focuses on working with families to identify symptoms and effective treatment for mood disorders and improving problem-solving and family communication skills. The program also includes sessions with children and adolescents that cover a number of topics, including symptoms, treatment, anger management, the connection between thoughts, feelings and actions, impulse control and improved communication skills.

There are also family education and support programs developed by family organizations and taught by trained family teachers. NAMI developed the NAMI Basics Education Program for parents and caregivers of children and adolescents living with mental health conditions. NAMI Basics is a sixweek, peer-led program that provides the information and support parents and caregivers need to make the best decisions possible for their children, families and themselves and to cope effectively. Research on the program concluded that participation in NAMI Basics appears to be associated with increases in knowledge about childhood and adolescent mental health conditions, treatment and advocacy. For more information on NAMI Basics, visit www.nami.org/basics.

#### Medications

Sometimes psychosocial interventions alone can effectively treat mild to moderate depression in adolescents. Other times, medications may be recommended by your child's health care provider to treat more severe depression. A primary care physician or a psychiatrist can prescribe medications. It is up to you to weigh the pros and cons of starting your child on medication. Many families try psychosocial interventions and other treatment options first before medication. It is important for you and your child to understand the potential risks and benefits of antidepressant medications to make an informed decision about treatment.

Many health care providers prescribe antidepressant medications to treat adolescent depression. The most commonly prescribed antidepressant medications are selective serotonin reuptake inhibitors (SSRIs). There

are currently two SSRIs that have been approved by the Food and Drug Administration (FDA) for use in adolescents—Prozac (Fluoxetine) and Lexapro (Escitalopram). Before the FDA approves a medication, it reviews the medication manufacturer's data and proposed labeling. If this review establishes that the medication works correctly and its health benefits outweigh its known risks, the medication is approved for sale. The FDA does not actually test drugs itself, although it does conduct limited research in the areas of drug quality, safety and effectiveness standards. To see a full list of FDA-approved medications, visit www.fda.gov (search for "Drugs@ FDA").

All physicians have the option of prescribing medications for "off-label" use based on their clinical judgment of an individual's treatment needs. Off-label use consists of using a medication for medical conditions that are not recognized on the FDA-approved labeling for that medication. It is a common practice. Other SSRIs used to treat children and adolescents living with depression that are not FDA-approved include Zoloft (Sertraline), Celexa (Citalopram) and Luvox (Fluvoxamine). In June 2003, the FDA recommended that Paxil not be used to treat children or adolescents living with depression because of a possible increased risk of suicidal thinking and suicide attempts associated with the medication.

If your child's health care provider prescribes a medication for off-label use, be sure to ask him or her questions about why he or she prefers this medication for your child. You should approach the decision about whether antidepressant medications are appropriate for your child with caution and care. This is true for all decisions related to the use of medications—antidepressants are no exception.

Below are some recommended questions you may wish to ask your child's health care provider if he or she recommends medication. It is not only appropriate to ask questions, it is expected.

- What are the potential risks and benefits of the medication and other treatment options?
- What are the anticipated side effects of the medication?
- How are the other elements of the treatment plan (such as psychosocial interventions and school and family interventions) integrated with the decision about medication?

- Who should be called with questions about the medication or changes in behavior or symptoms?
- How will we monitor progress, behavior changes, symptoms and safety concerns?
- How can we best ensure that our child is actively involved in the discussion and decision-making related to the use of medications (whenever possible)?
- How can we ensure open lines of communication between our family, you and other health care providers?
- How does any family history of mental health conditions (especially a history of bipolar disorder) factor into the decision to use medication?
- How will you know when it is appropriate for our child to discontinue medication?

It is also important for your child's health care provider to understand how antidepressants may impact certain ethnic groups. For example, Asian Americans and African Americans may metabolize medications differently. This can have implications on the overall effectiveness and side effects of any medications prescribed to these racial groups.

#### Side Effects

If your child voices new or more frequent thoughts of wanting to die or to hurt him or herself, or takes steps to do so, you should immediately contact your child's health care provider. For more information on the risk of suicide with antidepressant medication, see The Black Box Warning subsection starting on page 24 of this guide. You should also know that when starting a new medication or changing the dosage, your child may show signs of increased anxiety or even panic, agitation, aggressiveness or impulsivity.

You should also be aware of akathisia, a rare side effect that may exist in a small percentage of youth taking medications. Akathisia is an internal sense of restlessness coupled with a strong need to move about for no reason that your child may be able to identify. To a child, this may feel like a sense of agitation and nervousness. You should immediately contact your child's health care provider or should seek immediate help if you are concerned that your child may be experiencing this rare side effect.

While taking antidepressants, your child may experience involuntary restlessness, an extreme degree of unwarranted elation or energy accompanied by fast, driven speech and unrealistic plans or goals. If you see any of these symptoms, consult your child's health care provider. It may be appropriate to adjust your child's medication dosage, change to a different medication or stop using the medication. Research has shown that about 40 percent of children and adolescents will not respond to an initial medication, but many of these individuals will respond to a different medication.

#### **Family History and Treatment**

Family history is a clue to genetic risk for depression, but it is not enough to form a basis for a diagnosis or treatment plan.

If your family includes members living with bipolar disorder, you should be cautious about having antidepressant medications prescribed for your child and may want to talk with your child's health care provider about the appropriateness of combining antidepressant medication with a mood stabilizer. The chance that an adolescent could have undetected bipolar disorder is real, since the first episode of bipolar disorder can be depression.

A family history of depression or suicide may indicate the need for more aggressive treatment because these factors may lead to a heightened risk for suicide in your child. This is part of the risk-benefit analysis that should be discussed with your child's health care provider.

Sometimes it may be difficult to get a complete family history for your child since family members may hide their mental health condition or may not have been formally diagnosed. You may have to work off of your own observations to come up with a family history.

#### Risk of Suicide



It is estimated that about 3,000 youth die by suicide each year in our nation. <sup>10</sup> Suicide is the third leading cause of death in youth ages 10-24. Latino and African American female high school students have a higher percentage of suicide attempts (11.1 percent and 10.4 percent respectively) than their Caucasian and non-Latino peers (6.5 percent). <sup>11</sup> Suicide rates are 1.8 times higher than the national average among American Indians/Alaska Natives—making suicide the second leading cause of death within this

cultural group. <sup>12</sup> GLBT youth are up to four times more likely to attempt suicide than their heterosexual peers. <sup>13</sup>

Depression is a leading cause of suicide. Research shows that 90 percent of individuals who complete suicide have a diagnosable and treatable mental health condition, often depression. <sup>14</sup> Over one-half of youth living with depression will eventually attempt suicide, and at least seven percent will ultimately die as a result.

Untreated depression is the single most significant risk factor for suicide.

#### When Your Child Is Thinking or Talking about Suicide

Health care providers have found that when an adolescent talks about suicidal thoughts, it often opens the door to communication that increases the likelihood that special safety or protective measures can and will be taken. Therefore, any treatment intervention that increases discussion of hidden suicidal thoughts or impulses is helpful.

It is also important to remember that teens often prefer to talk with friends about how they are feeling. You should take comments related to self-harm or suicidal thoughts or behaviors seriously from your child or his or her friends. Encourage your child to share his or her thoughts and feelings; you should not ignore those that signal distress or early warning signs that your child may be experiencing depression.

#### The Black Box Warning

A "black box warning" is a form of alert used by the FDA to warn the public and health care providers that special care must be taken in certain uses of a medication.

In 2004, the FDA required makers of all antidepressant medications to have a cautionary label, or black box warning, placed on their product labeling that warns about increased risks of suicidal thinking or behavior in children and adolescents living with major depression. The greatest risks associated with the use of antidepressant medications exist in the first few months of treatment. The warning also states that youth using these

medications should be observed closely for a worsening of symptoms, signs of suicidal thoughts or behavior or unusual changes in behavior. Visit www.fda.gov to see the full warning label.

#### What Prompted the Black Box Warning?

During 2004, a FDA advisory committee reviewed data on the safety and effectiveness of antidepressant medications. As part of this process, the FDA analyzed data from 24 clinical trials involving more than 4,400 children and adolescents who had been prescribed antidepressant medications for the treatment of major depression, anxiety and obsessive-compulsive disorder. This review showed that a small number of trial participants given antidepressant medications experienced a heightened rate of suicidal thinking or behavior. Most often, this occurred soon after an individual started medication. It is important to note that there were no suicides in any of the clinical trials.

Although no suicides occurred in the trials, 78 (or 1.7 percent) of the 4,400 trial participants receiving antidepressant medications experienced suicidal thoughts or engaged in some form of suicidal behavior. Based on this analysis, about two children out of 100 might be expected to experience these symptoms when taking antidepressant medications.

#### Does the FDA Warning Mean Medications are Unsafe?

No. Researchers and clinicians have found that antidepressant medications, often in combination with research-based therapy like Cognitive Behavioral Therapy, are safe and effective for most adolescents. However, all treatment decisions must be made on an individual basis and in close consultation with a trained and qualified professional. Also, the FDA warning is an important reminder about the critical need for close monitoring and observation.



No individual should abruptly stop taking antidepressants. Parents contemplating changing or terminating their child's antidepressant medication should always consult with their child's provider before taking such action. If your child is currently taking antidepressant medication and doing well, he or she should continue with that treatment. Still, you should talk with your child about the possibility of rare and serious side effects, including suicidal thoughts and behaviors. Also, you, your child and your child's health care provider should discuss a safety plan. This plan should indicate whom your child will contact if thoughts of suicide or self-harm occur. It is also always important to closely monitor your child when he or she is taking medication.

# **Creating a Good Monitoring System**



First, you should make sure that your child understands whom to talk with about concerns related to treatment and understands the potential side effects of medications. It is also important to make sure that your child understands the possible impact of not taking medications once they are prescribed.

Medication may promote "activation," a phase in which an adolescent may begin to improve from treatment and begin to feel more energy to act on continued negative thoughts, leading to a heightened risk of self-harm. This often happens in the first few weeks of treatment and is the reason that health care providers and families must be particularly vigilant in observing changes in a teen's behavior and symptoms during this time period.

The FDA recommends the following general guidelines for the close monitoring of children and adolescents being treated with antidepressant medications.

- During the first four weeks of treatment, a child or adolescent should be seen by the health care provider prescribing the medication at least once a week, with face-to-face contact with the family.
- In weeks five through eight of treatment, a child or adolescent should be seen every other week by the health care provider, with face-to-face contact.
- A child or adolescent should then be seen again by the health care provider at week 12, with face-to-face contact.
- A child or adolescent should be seen by the health care provider as clinically indicated after 12 weeks of treatment.

The close monitoring should involve closely observing your child for a worsening of symptoms, suicidal thinking or suicide attempts and unusual changes in behavior, especially during the initial few months of medication treatment. To assist with this monitoring, the FDA directed manufacturers to develop medication guides for families that could help improve monitoring. Medication guides are distributed at the pharmacy with each prescription or refill of a medication.

Your child's health care provider should give you the contact information necessary to reach him or her 24 hours a day, seven days a week, should your child exhibit serious or concerning side effects, like agitation or akathisia. You should also understand when to take your child to an emergency room for safety-related concerns.

A prescription for an antidepressant medication without close monitoring and follow-up is not a good treatment plan.

Whenever possible, you should make the home environment open to communicating about depression. Talk about what is working and what is not, make suggestions for additional supports and take action to minimize risk of self-injurious or harmful behaviors. You need to agree with your child that there can be no secrets when it comes to safety. The key is to keep the conversation going, because isolation is a risk factor for suicide.

# **Creating a Safety Plan**



Depression causes negative thinking and teens with depression may think about death. It is critical to develop a safety plan given the risk of suicide in teens with depression. Talk with your child's health care provider about what should be included in the safety plan. The plan should be specific and individualized to address the unique needs of your child. Your child needs to have a full working understanding of the safety plan, including who to call for help, what situations are most likely to cause a risk of self-harm and protective elements or people that can be brought into play during stressful times.

Talk with your child's health care provider about the risks in your home environment and how to reduce them. These risks can include guns, over-the-counter prescription medications and sharp objects. Additionally, ensuring the correct dosage of any prescribed medication is an important aspect of a safety plan.

"Self medication" (using alcohol or street drugs to change how one feels) is also a safety concern, as it increases the risk of suicide and other self-harming behaviors. It is important to talk with your child about getting support for sobriety if substance abuse is suspected.

Families sometimes must make extremely difficult decisions, including—as a last resort—the decision to hospitalize their child against his or her wishes. Taking this step may be the most painful thing that a parent or caregiver ever does. Be sure to get good input about safety-related concerns from a professional who is trusted and trained to treat adolescents living with depression. Many people who experience suicidality look back on it in the future with regret. Depression is a treatable condition and the goal of a safety plan is to ensure the worst outcome does not happen during a time of treatable vulnerability.

#### Research



There has been great progress over the past five to 10 years in determining the most effective treatment options for adolescents living with depression. There have been a number of research studies, some of which are outlined in the following pages, looking at treatment approaches for adolescent depression that show promising results. Families are encouraged to learn more about these studies and to seek interventions that have been found to be effective. For more information, visit the National Institute of Mental Health (NIMH) website at www.nimh.nih.gov.

#### Treatment for Adolescents with Depression Study

NIMH has funded multiple research studies examining effective treatment interventions for adolescent depression. The Treatment for Adolescents with Depression Study (TADS) assigned youth to one of four groups and looked at the effectiveness of the treatment in each of the groups over a 36-week trial.

- Group one received Prozac only—an SSRI antidepressant medication.
- 2. Group two received Prozac combined with Cognitive Behavioral Therapy (CBT).
- 3. Group three received CBT only.
- 4. Group four received placebo treatment (a sugar pill).

The following are the research results after the initial 12 weeks of study:

- 71 percent of adolescents receiving Prozac combined with CBT (group two) showed much or very much improvement.
- 60 percent of adolescents receiving Prozac only (group one) showed improvement.
- 44 percent of adolescents receiving CBT treatment only (group three) showed improvement, slightly more than those receiving a sugar pill.

By the end of the 36-week research trial, the positive response rate for combination treatment (Prozac and CBT) still remained the highest at 86 percent, while response rates to Prozac only and CBT only essentially caught up at 81 percent each. The majority of adolescents (82 percent) who reached a sustained positive response by week 12 of the research study maintained this level of recovery through week 36 as outlined below.

- 89 percent of adolescents receiving combination Prozac and CBT maintained improvement for the full 36 weeks.
- 74 percent of adolescents receiving Prozac alone maintained their improvement.
- 97 percent of adolescents receiving CBT alone maintained their improvement.

The high long-term success effect of CBT suggests that for adolescents who initially respond well to CBT, this therapeutic intervention may have a preventive effect that helps to sustain positive improvements and potentially avoid relapse or recurrence of depression.

#### What Does TADS Tell Us?

The TADS study suggests that the combination of CBT and medication is the safest and most effective treatment overall for adolescents living with major depression. This finding is consistent with the studies that have been done with adults living with depression that show that the best treatment outcomes occur with combined psychotherapy and medication.

After the TADS trial ended, the adolescents who had been assigned to one of the three treatment groups were assessed up to four times during the following year to determine if improvements were sustained over time. The treatment provided in the TADS research study was no longer offered, but teens were encouraged to continue to seek treatment within their communities.

By the end of the 36-week trial, 82 percent of all participants had improved and 59 percent had reached full recovery. During the follow-up year, most participants maintained their improvements and the recovery rate climbed to 68 percent.

In addition, CBT was found to have a protective effect over the long-term. However, about 30 percent of the teens who were in remission at week 36 became depressed again during the following year, indicating the need for continuous monitoring and further improvements in long-term treatment of adolescents living with major depression.





A small, separate NIMH-funded pilot study found that adolescents living with major depression who received CBT after responding to an antidepressant medication were significantly less likely to experience a relapse or recurrence compared to teens who did not receive CBT. The significance of this small study is that introducing CBT in follow-up treatment after an adolescent has responded to an antidepressant medication may prevent relapse. Currently, a larger study to further evaluate the effectiveness of this treatment strategy is underway.

# What Happened to Adolescents in the TADS Study with Suicidal Thinking or Suicide Attempts?

Suicidal thinking decreased substantially in all active treatment groups. However, during treatment, those taking Prozac alone had slightly higher rates of suicidal thinking or behavior (15 percent) than those in combination treatment (8 percent) and those in CBT alone (6 percent), particularly in the early stages of treatment. Suicidal thinking and suicide attempts occurred between the first and 31st week of the trial, indicating that the risk of suicide did not decrease after the first month of treatment.

Participants who showed serious suicidal thinking and severe depressive symptoms prior to the study were more likely to have suicidal thinking or suicide attempts during treatment. In addition, adolescents who experienced suicidal thinking or a suicide attempt tended to do so in the context of difficult interpersonal problems, such as conflicts with family members.



# Treatment of SSRI-resistant Depression in Adolescents Study

NIMH funded a multisite research trial to investigate treatment options for adolescents living with difficult-to-treat depression who had not responded to a previous two-month course of treatment with a selective serotonin reuptake inhibitor (SSRI) antidepressant medication. The Treatment of SSRI-resistant Depression in Adolescents (TORDIA) study looked at treatment outcomes for adolescents receiving one of four treatment interventions.

- 1. Group one switched from the SSRIs they were taking to a different SSRI medication (Paxil<sup>i</sup>, Celexa or Prozac).
- 2. Group two switched to a different SSRI medication combined with CBT.
- 3. Group three switched to Effexor—a serotonin and norepinephrine reuptake inhibitor (SNRI) antidepressant medication.
- 4. Group four switched to Effexor medication combined with CBT.

After 12 weeks, about 55 percent of adolescents who switched to a different antidepressant medication and added CBT responded positively, while 41 percent of those who switched to a different medication alone responded positively. Adolescents with co-occurring conditions also responded positively to medication combined with CBT treatment, suggesting that CBT is effective with those who have complex diagnoses.

After 24 weeks, nearly 40 percent of adolescents participating in the TORDIA study recovered, regardless of which treatment they had been assigned. However, those who achieved recovery were more likely to have responded to treatment early—during the first 12 weeks.

Although none of the antidepressant medications seemed to be superior over the others, Effexor was associated with more adverse effects, such as skin infections and cardiovascular side effects. Thus, switching to a different SSRI rather than Effexor should be considered first.

<sup>&</sup>lt;sup>i</sup> Although the FDA does not recommend the use of Paxil for children and adolescents, it was included in this NIMH-funded study for youth that were not responding to other antidepressant medications.

Adolescents who had severe depression at the beginning of the study, higher levels of suicidal thinking, a sense of hopelessness, anxiety, family conflict or were prone to self-harming behavior, were less likely to respond to treatment. This emphasizes the importance of early treatment in adolescents before the depression becomes more serious and chronic.

#### What Does TORDIA Tell Us?

The TORDIA study shows that adolescents living with treatment-resistant depression are more likely to get better when they switch from antidepressant medication alone to combination therapy (antidepressant medication and CBT). These results are similar to those found in the TADS study. It also shows that adolescents living with treatment-resistant depression can get better by trying several different treatment strategies. In light of this, adolescents living with major depression and their families need to be persistent and not give up in seeking alternative treatment options. Recovery is possible.

The study also underscores the importance of early treatment when it comes to addressing adolescents living with treatment-resistant depression. The study suggests that clinical guidelines recommending that adolescents stay with treatment for at least eight to 12 weeks before trying another treatment approach may need to be revisited. More research is needed to clarify the optimal time to change a treatment strategy for adolescents living with treatment-resistant depression.

# What Happened to Adolescents with Suicidal Thinking or Suicide Attempts?

The study found that adolescents who had higher levels of suicidal thinking, higher levels of parent-child conflict and who used drugs or alcohol at the beginning of the trial were more likely to experience serious suicidal thinking or suicide attempts during treatment and less likely to respond to treatment. They were also less likely to complete treatment. Moreover, most serious suicidal thinking or suicide attempts happened early in the trial.

No statistically significant difference in suicidal thinking, suicide attempts or non suicidal self-injury were found among the four treatment groups. Additionally, although CBT was found to have a protective effect over the long-term among adolescents living with depression in the TADS study, it

did not appear to reduce suicidal thinking or recent suicide attempts in the TORDIA study.

#### Treatment of Adolescent Suicide Attemptors Study

NIMH funded a multisite pilot study, Treatment of Adolescent Suicide Attemptors, to identify factors that may predict and help prevent suicide reattempts among adolescents. The study used a new psychotherapy intervention, Cognitive Behavioral Therapy for Suicide Prevention (CBT-SP), to address the need for a specific psychotherapy designed to prevent or reduce the risk of suicide attempts in adolescents.

CBT-SP consisted of a 12-week acute treatment phase focused on safety planning, understanding the circumstances and vulnerabilities that lead to suicidal behavior and building life skills to prevent suicide reattempts. The study also included a maintenance continuation phase.

In the six-month study, 124 adolescents who had recently attempted suicide were either randomly assigned to or given the option of choosing one of three intervention groups:

- 1. antidepressant medication only;
- 2. CBT-SP only; and
- 3. antidepressant and CBT-SP.

Most teens chose the intervention they wanted to be placed in and most chose combined antidepressant medication and CBT-SP.

During the six-month treatment period, 24 of the 124 adolescents experienced a new onset or worsening of suicidal thinking or a suicide attempt—a rate lower than what previous studies showed among suicidal individuals, suggesting that this treatment approach may be a promising intervention. In addition, more than 70 percent of the adolescents—a population that is typically difficult to keep in treatment—completed the acute phase of the therapy.

The study found that most of the suicidal thinking or suicide attempts occurred within four weeks of the beginning of the study, before the teens received adequate treatment. This suggests that more intense therapy should be provided to suicidal adolescents early in treatment.

The study also revealed characteristics that could predict recurrent suicidal thinking or suicide attempts, including:

- high levels of self-reported suicidal thinking and depression;
- a history of abuse;
- two or more previous suicide attempts; and
- a strong sense of hopelessness.

In addition, a high degree of family conflict predicted suicidal thinking or suicide attempts, while family support and cohesion acted as a protective factor against suicidal thinking and suicide reattempts. These results echo those found in the TADS and TORDIA studies.

# **Advocating for Your Child**



You are your child's strongest advocate. You have a right to any and all information available about the nature of your child's depression, the proposed treatment options and the risks and benefits of treatment. Do your best to ensure that your child receives a comprehensive evaluation and an accurate diagnosis. You should have no qualms about seeking a second opinion if you have questions or concerns. Ask a lot of questions about any proposed diagnosis or treatment. Help your child learn, in an age-appropriate way, about depression so that he or she can be an active partner in treatment.

Depression can sometimes affect a child's school attendance or performance. If this is the case for your child, it may be necessary for you to work with your child's teachers to advocate for school-based services and supports for your child. This will help ensure he or she succeeds academically, socially and functionally within the school environment. To access resources on advocating for your child in school, visit NAMI's Child and Adolescent Action Center website at www.nami.org/caac (click on "Schools and Education").

NAMI and other family advocacy organizations stand ready to help families with a loved one living with depression and other mental health conditions. Together, we can make a positive difference in the lives of our loved ones and friends. To learn more about NAMI and to connect with a NAMI state organization or local affiliate, visit www.nami.org.

#### **Resources for Families**



For more information on depression and referral services, contact NAMI's HelpLine at 1 (800) 950-NAMI (6264), Monday through Friday, 10 a.m.-6 p.m. Eastern Time.

NAMI has developed a complete resource list for families at www.nami.org/CAAC/resources.

For Spanish language resources on child and adolescent mental health conditions and treatment options, visit NAMI's Spanish language website at www.nami.org/espanol.







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