



Children's Mental Health:

A Guide for Parents





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If you've taken the time and trouble to find this handbook, more than likely, you're searching for answers. You know a child or a teenager who may need help, but you're not sure where to turn.

Your child may be withdrawn or is very anxious and disrupts the family's life. He or she may be overactive and doesn't respond to traditional parenting. Or they may be having consistent problems with behavior at school. Maybe a more serious crisis happened and took you by surprise.

Sometimes these problems can be a result of stressful situations, such as a death of a family member, divorce or other separation, a high level of stress in the family, or a move. It could be the child is experiencing a mental health problem, but don't let those words scare you.

Mental health and wellness is integral to being human. A mental illness is a condition that disrupts a person's thinking, feeling, mood and ability to relate to others.

You may be feeling somewhat uncomfortable at the thought of facing a problem like this. Questions arise, like: Am I over-reacting? Is this just a phase? If I seek help, am I just going to make things worse? What can I expect?

We've been in your shoes before and know the challenges of that path. That's why we wrote this manual.

First, understand that you're not alone. Mental health problems affect one in five children and teenagers. That's 20 percent of ALL kids. It touches people regardless of the neighborhood they live in, parenting skills, IQ, education, race or income. Unlike a sore throat or a broken bone, it can be hard for a parent to find their way to a mental illness diagnosis.

But a mental health problem is a real issue — an issue that needs immediate attention just as you would a broken bone. Children and teens who experience mental illness have trouble functioning normally in family, school and social settings. And all the good intentions and efforts of their parents don't seem to be help.

Sometimes, the behavior of a child makes the issue very apparent, like those who are overactive or act out in obvious ways. But many are more difficult to detect, especially those who withdraw or suffer inside.

Children and teens who experience an illness and are not getting the help they need are at risk of resorting to destructive behavior to cope with their problem. We also know that a child or teenager's mental health problem won't simply go away with time. In fact, not doing anything can put the child at risk of more serious harm later in life. It may greatly limit the child's chance to succeed, and it can lead to destructive behavior.

Just like any other medical condition, a mental health problem can be assessed, diagnosed and successfully treated. Roughly, 70 to 90 percent of individuals treated for a mental illness have significant reduction of symptoms and improved quality of life. The earlier the problem is addressed, the better chance to succeed.

So what do you do? How do you know whether to wait or when to act? How do you take the first step? That's why we, as parents who walked this path before, wrote this practical guide to getting children mental health care. Our goal is to help other parents discern whether their child needs professional help or not, and if so, how to research and find help and how to get other support.



What is mental illness?

When we hear these words, a number of ideas may come to mind, many of them distressful and negative, and it helps to have a better understanding of what we're talking about.

First, it is important to understand what mental health or mental wellness means. The American Psychiatric Association explains that "mental health is the foundation for thinking, communication, learning, resilience and self-esteem. Mental health is also key to relationships, personal and emotional well-being and contributing to community or society." For all of us, our capacity to think, communicate, learn and cope fluctuates, and we can have good days and bad days. But for many people, including many children experiencing mental illness, every day is a tough day. The renowned Mayo Clinic describes mental illness as "a wide range of mental health conditions — disorders that affect your mood, thinking and behavior. Examples of mental illness include depression, anxiety disorders, schizophrenia, eating disorders and addictive behaviors."

They also explain that it is different from mental health concerns that happen from time to time (stress, sadness, etc.). An illness is frequent and affects one's ability to function.

What causes mental illness?

It is easy to confuse mental illness with the external manifestations of the illness. We may think the child is bad, has poor personality, or isn't smart. We also tend to feel guilty as parents and may believe the way we parent causes the child to behave a certain way. In reality, very smart people can experience serious mental illness. Children raised in optimal conditions can experience mental illness. Understanding mental illness is complex. There are three possible root causes. Sometime one factor is prevalent, but most often all three are present to some degree:

Genetic: Scientists' progress in mapping the human genome has helped to identify some genetic causes of mental illness. In 2011, a consortium of research organizations identified five genetic markers associated with the mental illness. A child born from two parents with bipolar disorder has 65 percent chance of developing bipolar.

Biological: In a 2012 article on the American Psychological Association's website, Eric Kandel, M.D., a Nobel Prize laureate and Columbia University professor, contends the root cause of mental illness is biological. "All mental processes are brain processes, and therefore all disorders of mental functioning are biological diseases," he writes. In other words, mental illness is caused by a brain chemistry unbalance. To function normally, the brain produces chemical substances that impact the way we think, feel and act. In the absence of these chemical substances, a behavior or action results.

Environment: In the same article, Richard McNally, Ph.D., a clinical psychologist at Harvard University, states, "Certain disorders such as schizophrenia, bipolar disorder and autism fit the biological model in a very clear-cut sense." He continues, acknowledging, "Yet for other conditions, such as depression or anxiety, the biological foundation is more nebulous. Often mental illnesses are likely to have multiple causes, including genetic, biological and environmental factors." Environment factors can include trauma, lifestyle, exposure to harmful substances and intense stress. A reduction in exposure can make a significant difference.

Mental illness is not laziness, bad behavior, hormones, attention seeking, or other teen drama. It is no less a physical illness than diabetes and must be treated just as any other physical illness must be treated.

Note that mental health disorders can vary in intensity, and are not always as severe as chronic illnesses such as bipolar disorder or schizophrenia. Conditions like ADHD, anxiety or mood disorders are more prevalent among children, and can have a serious impact if not treated. Lastly, while some mental illness may require lifelong care, know that many people become happy and productive members of society despite a mental illness. It is not a sentence to a wasted life or even death. Controlled studies show rates of recovery range from 70 to 86 percent for children with issues like ADHD, anxiety or depression who are treated with a combination of medication and therapy. However, absence of treatment can jeopardize the future of the child in many ways.

You're not alone

Society doesn't necessarily portray mental illness in an empathetic way. As a result, parents who see unusual or concerning behavior in their child may not want to believe their child has a mental illness. They try to rationalize the behaviors as part of being a teenager or as a phase. But that is not always the case.

One in five children will experience mental illness before the age of 18. The data is shocking and saddening, and it seems to indicate that incidences of mental illness among children are on the rise.

Consider this: According to a 2016 interim report from the State of Texas' House Select Committee on Mental Health, there is no doubt that mental illness is taking a toll on the state's youth:

- Half of mental health conditions begin by age 14.
- Nearly 250,000 Texas children have a serious emotional disturbance (SED).
- Approximately 50 percent of youth in the juvenile justice system have been identified with unmet need for mental health treatment.

Between 1992 and 2001, emergency room encounters for suicide attempts and self injuries for all ages increased by 47 percent in the United States.¹ In the past 10 years, children's hospitals admissions for suicidal thoughts or actions have doubled.² Suicide is the second leading cause of death of adolescents ages 15-24.

So, what are we to conclude as parents? There are probably multiple answers to why the number of kids affected is growing. What is clear? Many are experiencing mental illness, and if that's what your child is experiencing, you're not alone. What is equally as clear is that ignoring the signs and symptoms can have very serious consequences.

What happens when a child is not getting help?

On average, there is an eight- to 10-year delay between the time a young person first experiences the symptoms of his or her illness and the beginning of treatment.³ Unfortunately, the lack of treatment can have dramatic consequences and sometimes increase the acuity of the illness. The statistics concerning untreated mental illness

• Approximately 50 percent of students age 14 and older with a mental illness drop out of high school.

are alarming:

- Youth who experience untreated mental illness are twice as likely to abuse drugs and alcohol.
- 70 percent of youth in state and local juvenile justice systems have a mental illness.

Once chronic illness has developed, the severe mental disorders associated with poor self-care can lead to worse health outcomes and higher mortality rates. There is an average 10- to 25-year life expectance reduction for individuals experiencing severe mental disorders.

Socio-economic factors exacerbate the situation.

Many individuals experiencing mental illness are at a higher risk for experiencing poverty, unemployment, stigma and isolation. These factors can then create barriers to accessing proper care and treatment. Further, some patients' symptoms of mental illness, such as a reduced ability to engage with and navigate the world around them, can create barriers, too.

A striking example is the way untreated ADHD can lead to homelessness. While ADHD is sometimes dismissed, new evidence suggests that this illness should be taken seriously and treated carefully, as ADHD in childhood may increase a child's odds of becoming a homeless adult.

¹ Source: Larkin GL, Smith RP, Beautrais AL. Trends in U.S. emergency room visits for suicide attempts, 1992-2001

² "Trends in Suicidality and Serious Self-Harm for Children 5-17 Years at 32 U.S. Children's Hospitals, 2008-2015," Plemmons, Gregory et Al, Pediatric Academic Societies

https://registration.pas-meeting.org/2017/reports/rptPAS17_abstract.asp?abstract_final_id=2766.5

³ Delay and failure in treatment seeking after first onset of mental disorders in the World Health Organization's World Mental Health Survey Initiative World Psychiatry. 2007 Oct; 6(3): 177–185.

Waiting too long to get help

Our daughter was in therapy and saw a psychiatrist throughout grade school. However, sometimes when she was feeling well, she didn't want to attend therapy. Quite honestly, not having to take her to and from therapy appointments was just one less thing for us to juggle in our schedules.

But then, before we knew it, we would be in the middle of a crisis and need to see a therapist quickly. We were in reactive mode rather than handling things proactively. Not having a therapist she was seeing regularly, even if just once a month, made it difficult to schedule any type of lastminute session. In hindsight, it would have been helpful to have a continuous working relationship with a therapist.

I wanted to get my son help. My husband didn't believe in therapy. He was convinced we needed to discipline him more ... take away video games and other electronics as punishment. The early years were very tough on our marriage and in getting our son the help he needed.

A study⁴ tracked 134 boys who were diagnosed with "hyperkinetic reaction of childhood" in the 1970s, when they were 6 to 12 years old. When they were re-evaluated 33 years later, nearly 24 percent reported they had experienced at least one period of homelessness that lasted a week or longer. The figure for a comparison group of boys was 4.4 percent. The research team concluded that childhood ADHD appears to be a predictor of adult homelessness.

Another consequence of untreated mental illness is the estrangement that results between parents and their adult children. Conversely, when parents face the reality of the illness, look for solutions and take action to get the right treatment and support, they may find it is hard work but it often results in closer relationships later on. Finally, a child with mental illness will become an adult with mental illness. It should be your goal to equip them now so they eventually survive independently with it. It is critical for a number of reasons:

- Services for adults are not identical.
- Adults cannot be forced to participate in the treatment.
- Insurance coverage differs especially if the child is covered by a family plan but later, as an adult, has no insurance.
- The stigma differs. As kids they are viewed as unruly. As adults they are viewed as dangerous and largely avoided.
- Support systems are generally stronger for kids family, schools, friends, etc.

It can be more difficult for parents to get help for their adult child who isn't receiving treatment or is in danger. That's one more reason to take mental health issues seriously.

How do you know there is a problem?

The signs of mental illness

The National Alliance on Mental Illness (NAMI) defines mental illness in an easily understood way: a mental illness is a condition that affects a person's thinking, feeling or mood. Such conditions may affect someone's ability to relate to others and function each day. Each person will have different experiences, even people with the same diagnosis. Many of us will experience mental concerns on occasion, but that concern becomes an illness when the symptoms are pervasive and affect your ability to navigate life in your usual way.

The signs and symptoms of a mental illness vary depending upon the specific disorder, the individual experiencing it, and the circumstances in which they live, work and play. However, there are symptoms and behaviors that can indicate that there may be something deeper. It is especially important to recognize signs and symptoms in children, so they can get the treatment they need as early as possible.

The Mayo Clinic provides a thorough list of signs and symptoms that could indicate a mental illness:

- Feeling sad or down
- Confused thinking or reduced ability to concentrate
- Excessive fears or worries, or extreme feelings of guilt
- Extreme mood changes of highs and lows
- Withdrawal from friends and activities
- Significant tiredness, low energy or problems sleeping
- Detachment from reality (delusions), paranoia or hallucinations

- Inability to cope with daily problems or stress
- Trouble understanding and relating to situations and to people
- Alcohol or drug abuse
- Major changes in eating habits
- Excessive anger, hostility or violence
- Suicidal thinking

Other signs can include increased irrational or dangerous behavior, seeing or hearing things that aren't real, paranoia – unexplained fear, self-harm – cutting, scratching, etc., increased defiance or disrespect, changes in appearance and interests, lying and/or manipulating behavior, or problems with hygiene and self-care.

A mental illness also can involve physical systems such as headaches, stomach pain, etc. If a loved one is experiencing any of these symptoms – or a combination of them – and they are pervasive, you should schedule an appointment with a physician or mental health care provider.

Mental illness and substance abuse

There is a strong link between mental illness and substance abuse. People with mental illness resort to substances as "self medication" because they provide relief and escape. Individuals also are at high risk to develop substance addiction because they gain more from using than people without a mental illness. Substances impair judgment which is already impaired in people with mental illness. Use of alcohol and drugs can exacerbate mental illness symptoms. Some drugs also increase moods of depression and others increase irritability or aggression, or paranoia or anxiety – which can bring on mental illness episodes.

Warning signs

Our son showed many of the typical signs of needing help. He became disinterested in activities he had previously enjoyed, he started struggling in school and eventually dropped out of high school, his friends changed, and most dramatic was the change in the way he treated his family, and us as parents.

The signs of substance abuse

If your child were struggling with addiction, you would want to get them immediate help. But would you know if your child was struggling? Could you recognize the signs? Below are three major types of changes that could indicate that your child may be using or abusing drugs or alcohol.

Behavior changes

According to an article published in *Innovations in Clinical Neuroscience*, "one of the earliest warning signs that predicts teenage drug use is a change in behavior and mannerism." Other behavioral changes could include:

- Skipping class, declining grades, getting in trouble at school
- Missing money or valuables from the home, missing prescription drugs
- Clashes with family values and beliefs
- Preoccupation with alcohol and drug-related lifestyle in music, clothing and posters
- Demanding more privacy, locking doors and avoiding eye contact
- Sudden change in relationships, friends, favorite hangouts and hobbies
- Using incense, perfume, or air freshener frequently (to hide the smell of smoke or drugs)
- Using eye drops to mask bloodshot eyes and dilated pupils

Mood changes

Some teenagers who abuse drugs may become more irrational or dramatic in their actions. You may notice your child becoming more irritable, verbally abusive, or even violent with you or other children in the household. Additionally, your child may begin to threaten to drop out of school, run away from home, or destroy property. Depression, mood instability and apathy are also warning signs of potential drug abuse and shouldn't be taken lightly. Other mood changes to be aware of include:

- Unexplained, confusing change in personality and/or attitude
- Sudden mood changes, irritability, angry outbursts or laughing at nothing
- Periods of unusual hyperactivity or agitation
- · Lack of motivation and/or an inability to focus
- Appears fearful, withdrawn, anxious or paranoid, with no apparent reason

Physical changes

Drug use takes a physical toll on the body, and its visible signs are plentiful and varied. Some physical changes that could indicate drug or alcohol use or abuse include:

- Bloodshot eyes
- Widely dilated pupils
- Sudden weight loss (or weight gain)
- Poor hygiene
- Frequent nosebleeds
- Shakes or tremors
- Red, flushed cheeks
- Bruises or other unexplained injuries
- Drowsiness or fatigue
- Changes in appetite or sleep patterns
- Unusual smells on breath, body, or clothing
- Incoherent or slurred speech

These warning signs do not always indicate drug use. However, if you see any of these warning signs in your child, don't sweep it under the rug and hope it goes away. The best thing you can do for your child is to seek help from a trained professional. You can start by taking your child to your family physician to screen for signs of drug use and other related health conditions. You can also contact an addiction specialist directly. The <u>American</u> <u>Society of Addiction Medicine (www.asam.org/asam-homepage)</u> has a <u>Find a Physician (https://asam.ps.</u> <u>membersuite.com/directory/SearchDirectory_Criteria.aspx)</u> feature on its home page. You and the physician can decide if your child should be referred to treatment.

Deciding what to do

of unknown

Taking the first step to seek help for your child is not always easy. Mom and Dad may process this in a different way and may differ about the path to take. The following exercise helps you clarify whether or not you should seek help. The suggested answers are provided only as examples.

	Pros	Cons
What are the consequences to my child of getting help?	Understanding self	Miss school
What are the consequences to our family of getting help?	More harmony	Schedule/cost
What will be my child's reaction to and feelings about getting help?	Feel attended to	Defensive
What will be our family reaction and feelings about getting help for my child?	Relief	Fear of unknowr



Advice on seeking help

First, don't be discouraged if the initial contacts with professionals are inconclusive. It is not always easy to see and understand the reality of a child's mental illness, and sometime they are cautious about putting a label on behavior until they can spend more time with the patient.

Be aware of the difficulty of diagnosing children and teens due to other changes in their bodies, such as hormones and puberty, and in their environment, like peer pressure and school. A diagnosis may change over time and is a tool to help define a treatment approach.

It is also critical for you to tell as much as you can to the professionals. When "Sandi" first sought help with a psychiatrist, she didn't initially tell him about the fits of rage her teen was experiencing. It was a huge piece of information that significantly changed the treatment.

If you are not satisfied with the answers you receive from the professionals, do not stop seeking the right fit for you and your family. You are the one who knows the most about your child, and you are responsible for driving that process.

Seek help from peers. Other parents have walked that path and know about resources and options in your area. Seek a group that can give you support, encouragement and hope.urgent level of care first. Outpatient means occasional appointments like a medical doctor's appointment. Other levels of care are hospitalization programs.

Getting help: Where should you start?

If you have reviewed the list of warning signs above and they seem to confirm that you child may be experiencing mental health problems, what's the next step? Where can you go to check if he is OK and get help if he needs it?

First, if your child is in imminent danger of hurting themselves or others, take your child to the closest emergency room or call a local psychiatric hospital. Any local psychiatric hospital that takes children will generally offer round-the-clock assessments at its admissions department. A clinician will evaluate the safety of the child, get to know the child and the family, and decide if the child needs to be kept at the hospital for his or her safety.

In general, what are the options to get help for your child? Your pediatrician may help guide you for the next step of treatment. A school counselor may have insight about options available at school or nearby. But don't stop there if you don't feel like you are getting solid answers.

Treatment generally requires more than one component, therapy and often medication, as well as family/friend support, and personal involvement by the child.

Here are the various levels of mental health care that are available to you. We start with the most critical and urgent level of care first. Outpatient means occasional appointments like a medical doctor's appointment. Other levels of care are hospitalization programs

1. Inpatient/acute care

Inpatient hospital care is also called acute care and is required when a child is at risk of harm to self or others. The goal of the treatment is to bring the child back to an appropriate level of safety and self-control. The treatment is typically a three- to seven-day stay, depending on the individual diagnosis and the progress of the child. Acute care treatment involves immediate evaluation, 24-hour nursing and physician attention, medication if needed and daily monitoring of medication, and a plan for future treatment. Depending on the hospital, the treatment may also include individual, group, and family counseling. Some programs offer school or tutoring.

Family visits are encouraged. The child does have a busy program of counseling, education and activities so family cannot stay an extended length of time.

An acute inpatient stay is usually three to seven days long and the goal of the treatment is the reduction of the acute symptoms also called stabilization. Your child will not leave the acute hospital cured from his illness. Diagnosis and medicine adjustments take time and may not be finalized in the acute setting.

2. Longer-term inpatient therapy

When a child or adolescent between the ages of six to 17 years of age has trouble functioning well outside of a structured and monitored environment, inpatient treatment or a residential treatment center (RTC) may be the answer. Such treatment can involve 24-hour care, a full schedule of individual and/or family or group therapies, and therapeutic activities in a secure, hospital-based setting.

3. Day treatment

If counseling or psychiatric intervention can't provide the help needed, a viable option could be a day treatment, hospital-based program, also called Partial Hospitalization Program or Day Treatment. This is designed for the child who is in between levels of care; needing more intensive therapy than an outpatient counselor can provide, but not a risk of harm to self or others. Day Treatment often involves individual, family and group therapy, typically over two to four weeks or more depending on the situation. The child attends the program during the day, and goes home with the parents each night, just like a school day. Depending on the hospital, the treatment may also include individual, group, and family counseling. Some programs offer school or tutoring.

4. Intensive outpatient

Intensive Outpatient treatment allows patients to continue their daily life while receiving group and individual services of 10–12 hours a week. It is a good option for youth who are not at risk of harm but need more support than only one or two therapy sessions a week.

5. Outpatient counseling

Outpatient counseling is provided by psychologists, licensed therapists, or licensed social workers. These professionals can help in different ways: understand the signs and the seriousness of the child's problem, identify the possible cause or the important questions to explore further, propose a treatment approach, and conduct the treatment. These individuals are not able to prescribe medications. However, if medication is needed, they work in tandem with a psychiatrist who is specially trained in prescribing medication.

When selecting a therapist, the most important factor is yours and your child's ability to build a rapport of confidence and trust with the professional you choose. You may ask them about how they assess the child, their treatment approach and how they measure progress.

Understand there are different levels of training among professionals. For instance, a psychologist is someone who earned a master's degree (M.S.) or a doctorate in psychology. Those with a doctoral degree (Ph.D., Psy.D. or Ed.D.) in clinical, educational, counseling, developmental psychology or research received more extensive supervised training. Social workers also may provide psychotherapy, and they have a bachelor's degree (B.A., B.S.W., or B.S.) or a master's degree (M.S. or M.S.W.).



6. Outpatient psychiatric care

The counselor may feel something more serious is going on, such as a mood or thought disorder. She would then refer the child to an outpatient psychiatrist, a doctor who can assess the child further and decide if it is necessary to prescribe medications so the child can function. Note that you can also call a psychiatrist directly or a pediatrician can refer you.

Medication treatment should always be accompanied with therapy so the child can build resiliency and learn to cope with the symptoms and environment on their own.

A psychiatrist is a physician, a medical doctor, whose education includes a medical degree (M.D. or D.O.) and at least four additional years of study and training. Psychiatrists are licensed by the state. Their role is to provide medical/psychiatric evaluation and treatment for emotional and behavioral problems and psychiatric disorders. As physicians, psychiatrists can prescribe and monitor medications.

The monitoring part is essential: taking medications should always be supervised by a medical professional who is responsible to make sure the child is safe. It is also likely that the type and strength of medication will be adjusted over time to fit the child's unique profile and needs. Do not be discouraged if medications are not a perfect fit in the first round. Because of the short supply of psychiatrists, getting this support will require efforts of research and persistence on your part.

What about medication?

When is medication necessary?

At some level, mental illness is a chemical imbalance in the brain, and the right medicine will help bring balance. It is especially critical when the child can't get to the point of participating in therapy until the chemical imbalance is at least partially resolved by medication. Medication can be used to help the child respond to treatment. The child's response is closely monitored by the psychiatrist to make sure that the child is benefiting from the medicine.

Will my child experience side

effects? Like any medication, psychiatric medications can have side effects. They could vary for each person. Do not hesitate to discuss the possible side effects with the doctor and make sure to monitor them and report them to the doctor. The dosage or formulation can be adjusted to insure the child can function normally with minimal side effects.

Can he stop and start anytime?

Some medications take time to build up and shouldn't be stopped abruptly. Children will sometime attempt to stop taking them. It is important that they understand the chemical and physical reasons for the meds and that they shouldn't stop taking them as soon as they feel better. In reality the reason they feel better is because of the medication. Taking medication as directed is important to obtain full benefit from the medication.

When first experience with treatment didn't go well

We had three visits with our first clinician. She said our child didn't have a mental illness but was profoundly gifted, and stated gifted children were different from other kids. For the fourth visit, I was out of town, and my husband took our son to the appointment. The therapist said that she worked with "sick kids" and our son wasn't sick. Two years later, he was diagnosed with ADHD, anxiety and depression. There were several incidents in school that led to this and a ton of heartbreak.

What I learned is that we should have started with our pediatrician. I honestly don't know why I didn't. I never connected mental health with physical health. I have a lot of guilt about that. I am the mom. I am the advocate for my child, and I failed him. Who knows how different things could have been had he been properly diagnosed earlier in his life?

What to expect at your child's first visit to the psychiatrist?

The first visit is a time for you, your child and the doctor to get to know one another. The psychiatrist will want to know about any difficulties or challenges your child is experiencing. They will ask your child about a number of possible symptoms, and also ask about any medical or previous mental health issues.

The initial visit will differ depending on the age of the child and the situation. For very young children, the parent will most likely be in the room to help the doctor understand the situation. Older children may benefit from having some time one-on-one with the psychiatrist without the parent present. Some kids may be able to talk more freely without Mom or Dad in the room ... and that's perfectly OK!

Whether you are in the room for the entire appointment or not, the doctor will review their assessment with you, along with the recommended follow-up plan. That might involve specific testing, more specialized assessment, or a medical therapy.

Be sure to ask questions if there's anything you don't understand. A good psychiatrist will be happy to explain and spend the time it takes until you are all feeling comfortable about moving forward.

How to prepare for your child's visit

Keep in mind that you aren't the only one who is anxious. Your child undoubtedly has questions and concerns, and maybe even fears. What kind of doctor is this? Will I get shots? Will it hurt? Talk to your child and ask them how they are feeling, and if they have any questions. Share what you are learning about the process.

When planning for your first visit, remember to bring:

- A list of any symptoms or concerns your child has; get the child's help in creating this list if they are old enough to do so
- Your insurance card and a list of any current medications your child is taking and if they are allergic to any medications
- Your child's physical and mental health histories

Trying anything new can be stressful. Help your child understand that visiting the psychiatrist is often the first step toward a happier, more successful life.



What about your family's spiritual needs?

Many people think that when it comes to mental illness, they should set aside their spiritual background. That's not the case. Of course, it is important to distinguish mental health and spiritual health: a pastor cannot prescribe a treatment for bipolar disorder, and a psychiatrist cannot provide spiritual direction. At the same time, many consider their faith and religion central to their day-to-day life. If their child had cancer, they would seek support and comfort in their spiritual faith and community. It is no different when dealing with a serious mental illness. The question is how. Here are a few simple do's and don'ts:

 Look for providers who display the professional expertise you need regardless of their faith background. Then, ask if they are open to your faith practices so they may encourage your practices and support your profession of faith.

DO

- Use your faith practices (like prayer and meditation, worship, sacramental life, etc.) to build resiliency and hope.
- Find support or spiritual direction from clergy familiar with mental illness.
- Find support from faith-based groups, when available.
- Think that your child's mental illness is simply caused by a lack of faith, sinful behavior, spiritual bondage, demonic possession.
- Think that their mental illness is actually caused by their faith. Studies show that spiritual activities are conducive to better mental health and faster recovery.
- Limit your search for mental health providers to only those who share your spiritual faith and beliefs. It will make it more difficult to find help and is not a guaranty of quality.
- Assume that someone who shares your faith is a qualified mental health provider. Check credentials and talk to your child's pediatrician or your family doctor if you're unsure.
- Assume everyone in your faith community will understand what you're going through. (See our handbook called "<u>How Can I Help</u>" (*http://info.1in5minds.org/family-and-friends-handbook*). But it may also be your experience that helps others to see the reality of mental illness and how to provide care for families and their children.

Not all religious groups or leaders are formally trained to understand mental illness, just like not all mental health professionals have a good understanding of religious faith. But increasingly, both worlds are learning from each other and collaborating, so there is hope.

How does one afford mental health treatment?

Accessing appropriate treatment for children experiencing mental health issues is a challenge in every part of the country. Navigating the sometimes-complicated pathways to get to the right care your child needs can be frustrating. Once you find the care your child needs, the inevitable next question is about affordability. How does the average family afford the care their child needs?

Historically, American families have relied heavily on private health insurance – predominantly employer-sponsored policies – to afford medical care and treatment. However, in the past many health insurance companies did not provide equitable benefits for mental health treatment as they did for medical care, and families bore a large share of the cost. In 2008, Congress passed a law to ensure parity, meaning equal coverage and benefits for mental health care, and in 2013 released rules for implementing that law. In short, if a health care plan covers unlimited doctor visits for a chronic physical illness such as diabetes, that same plan also must cover unlimited visits for chronic mental illness.

However, not all health plans have to follow federal guidelines for parity. This includes: Medicaid fee-for-service plans; "grandfathered" individual and group health plans that were created and purchased before March 23, 2010; and plans that received an exemption based on increase of costs related to parity. If you are unsure about the type of plan you have, talk to your company's benefits advisor or call the health plan's customer service line directly.

If an insurance plan is required to provide parity for mental health care, there can be many variables among insurance policies when it comes to co-pays, out-of-pocket expenses, and lifetime maximums. Here is a list of some of the questions you should ask your insurance provider:

- Is the provider you want taking insurance and covered by your plan?
- Are the "in-network" providers on your insurance list taking new patients?
- Are there limits of services imposed by your insurance (number of sessions, number of inpatient, residential or partial days)?
- What does your insurance plan consider medically necessary and, if you need pre-approval for coverage, what are those guidelines?
- What is your share of costs based on deductible and the type of service provided?

For those families who do not have private or employersponsored insurance, accessing affordable mental health typically requires government-funded subsidies to help defray out-of-pocket costs. Programs such as Medicaid and the <u>Youth Empowerment Services (YES) Waiver</u> *(https://www.dshs.texas.gov/mhsa/yes/)* can cover a large portion of the costs of mental health treatment, which is a significant benefit to families.

Unfortunately, fewer care providers are accepting patients with Medicaid as the fee reimbursement for the provider is often much lower than that of private insurance. This can make finding a provider for your child difficult or it can take longer to get an appointment.



What to do if you are denied parity

The good news is that some states have worked to create parity. Texas, for example, just passed a law that will help make sure that insurance companies in Texas truly respect the parity law in two ways: by increasing the Texas Department of Insurance's authority to enforce the existing parity law and by creating a position specialized in resolving issues families may encounter when seeking access to behavioral care.

<u>The National Alliance on Mental Illness (NAMI)</u> (https://www. nami.org/) provides this valuable list of five signs that your insurance company has violated parity. They include:

- 1. Higher costs or fewer visits for mental health services than for other kinds of health care
- 2. Having to call for permission to get mental health care covered, but not for other types of health care
- Getting denied mental health services because they were not considered "medically necessary," but the plan does not answer a request for the medical necessity criteria they use
- 4. Inability to find any in-network mental health providers that are taking new patients, but can for other health care
- 5. The plan will not cover residential mental health or substance abuse treatment or intensive outpatient care, but they do for other health conditions.

If you think the insurance company providing your plan has violated parity requirements, your first step is to contact your insurance provider. Their reason for denials of coverage must be made available upon request. If your treatment is denied and you disagree, you should contact your plan's customer relations division right away. You may file a written formal appeal (ask your plan for details) or contact a local NAMI office if your informal attempts are not successful.

A list of affordable care options

There are affordable mental health care resources outside the traditional framework. Depending upon your family's circumstances, these may be practical options.

1. Mental Health America, an advocacy organization with over 300 affiliates in 41 states, works with people to

connect them with affordable mental-health services in their communities. Click on "local MHAs" <u>on their</u> <u>homepage</u> (*http://www.mentalhealthamerica.net/*) to find services in your area.

2. Community health centers. In addition to primary-care services offered in thousands of locations across the country, they are increasingly offering mental health services. Fees are charged on a sliding scale based on income. Find a center in your area <u>here</u>. *(https://findahealthcenter.hrsa.gov/)*

3. Community mental health centers. These centers serve Medicaid and other low-income patients. State income limits vary. Click on "find a provider" <u>here</u> *(https://www.thenationalcouncil.org/)*, and call to determine whether you qualify.

4. Employee assistance programs (EAP). Many employers offer a limited number of counseling sessions and referrals to mental health professionals through an EAP service. For some people, this may be all they need.

5. Churches, synagogues and other places of worship. Although they are not licensed therapists, clergy members are trained in counseling, and their services are generally free.

6. Group therapy. Many therapists offer group sessions, which can be a less expensive alternative to traditional one-on-one counseling.

Other options: Online cognitive behavioral therapy (CBT) services may cost less and may help for some conditions such as anxiety and depression.

Finding partners in advocacy

Navigating medical insurance can be time-consuming and frustrating. But remember, while you are always the best advocate for your family, support is available and you are not alone. Enlist your local chapter of <u>NAMI</u> (*https:// www.nami.org/About-NAMI/Our-Structure*) or the <u>National</u> <u>Federation of Families for Children's Mental Health</u> (*https:// www.ffcmh.org/our-affiliates*) (FFCMH), both of which can provide support, guidance and encouragement.

When treatment worked

We were fortunate to have our daughter see the same psychiatrist through most of her grade school and early teen years. As we noticed different symptoms, he would prescribe different meds. He would usually start off at a low dose and tell us side effects to watch for. Our family worked well with him to monitor behaviors. As needed, he would adjust the dosages. When the meds worked well, she was a regular, carefree child and we took advantage of that to enjoy fun family activities.

The psychiatrist immediately recognized the symptoms our daughter displayed. He properly diagnosed her and recommended a treatment plan consisting of intense inpatient therapy. I knew from that encounter we'd found the right place to genuinely help our daughter. That was 5 years ago. She's now a remarkable young lady, with many skills and leadership qualities.

We found a new normal when our pediatrician placed my son on a small dose of medication, and we found a fantastic psychologist to help with coping skills. Soon he was off medication, and we continued with therapy. Today my son has not seen a therapist in two years, and he is doing really well.

Staying connected to your child

Parents of young adults often see a shift when the child who was previously compliant becomes rebellious and refuses to listen to parental or doctors' guidance. On the contrary, they stop doing what can help them get better and do what makes them worse. In the case of a child with mental illness, it is usually very different from the normal distancing a teenager and his parents experience as part of the growing up process.

Here is how a parent described it:

The most difficult times were when we saw our son pulling away from us. He reached a point where for all practical purposes, we had no influence or affect on him. Our efforts to encourage and guide him were ineffective. We could not help him to get the help he needed. Our discipline also became ineffective. We saw him abandoning everything from family, to friends, as well as dropping out of high school. He lost his motivation, but he also lost his desire to connect with people who loved him and wanted to help him. A great help for parents can be found in the book called *I Am Not Sick I Don't Need Help* by internationally renowned clinical psychologist Dr. Xavier Amador. In this book he describes how he learned to become a partner to his brother who suffered from schizophrenia. He eventually developed an entire process that all parents and health care providers can use to stay connected and help young adults become the owners of their recovery process. We highly recommend this book to anyone who experiences such challenges.

At the same time, it is critical for the parent to find the environment factors that increase the child's distress and take necessary precautions to keep them safe. It could mean removing violent movies and games, restricting certain books such as tragic teen dramas, implementing regular bed times and exercise and diets. Parents have to be aware of and restrict dangerous behaviors like alcohol, drugs, sex, parties, certain peers, online activity, etc. For young people who are suicidal, even more precautions need to be taken to keep the child safe.

Our first reaction as parent is to beg, threaten, punish. We try to reason, put the child in front of the reality of their diagnosis, and tell them about the dangers of their illness. They don't seem to care. In this situation, parents feel very frustrated, helpless, and even sometimes hopeless. The reality is that it's not about them, nor about their child. Because of the illness, the child is not processing reality in conventional ways. The forces that drive their actions are stronger than our parental influence. It is time to change strategy.



How about school? Can they help?

Kids spend six hours a day in school, and mental health is essential to learning. So schools that are very data-driven understand that in order for some kids to succeed, their mental health needs must be met.

How to get support from your school

If you have a child experiencing mental health problems, don't keep it a secret from the teacher or the counselor. You want to share that information so they can better understand you and your child's need for support. Follow these steps to get your school into your circle of care:

- Request a meeting with both your child's teacher and the school counselor to discuss what your child is experiencing, request their support, and explore day-today assistance. In middle or high school, engage the teacher the student has the best relationship with and that teacher can coordinate with the other teachers, along with the counselor. Often, students have a close relationship with a coach, band director or someone not a classroom teacher.
- Communicate with the teacher and school counselor regularly to monitor your child's progress and performance in school, and to request an additional support or referrals to outside resources, if needed.
- 3. If you do not feel as though your child is getting the support he needs from his teacher and counselor, consider requesting another meeting, this time to include someone from the school's administrative team such as a vice principal or principal.

In general, these types of requests are met with compassion and a sincere desire to help. However, some parents of children experiencing mental illness express frustration with trying to work with a school.

Fundamentally, school staff has a heart for children and want to provide support and resources whenever possible. The best way to get support for your child is to ask and ask often, if necessary. **Remember, as a parent or caregiver, you are the greatest advocate for your child's well-being.**

Special education curricula and programs

It may be difficult to accept that one's child should be moved to special education classes, but those services can open doors to additional support. There are myriad of programs within school systems through which children experiencing mental illness can receive support. Generally that support is provided through special education programs and academic accommodations. The Association for Children's Mental Health outlines examples of common accommodations from which students experiencing mental illness may benefit:

- A child with hyperactivity may benefit from working some activity into their daily classroom routine.
- A child with oppositional defiant disorder might benefit from their teachers being trained to interact with them in a certain way.
- A young person who struggles with disorganization might be helped by being taught planning skills.
- Children who may become aggressive and those who get overly anxious may benefit from exploring what things lead up to those feelings, how to recognize when it is happening, and things to do to prevent the problem from escalating.

School

My daughter tried an at-home program through the school with a mentoring component but that did not work for her. She ended up doing independent learning online in her counselor's office and was able to work ahead at home.

In addition, adjustments to the homework load or extra time to finish tests or tasks can be beneficial.

For high school students, alternative schools may be an option as they might offer longer or shorter classes, more flexibility and additional time for tests.

While schools in your state are likely required to offer special education services to children as a part of their general programs, accessing those services may be a precise and somewhat complicated process. Navigate Life Texas, a resource for children with special education needs and their families, explains: "The federal Individuals with Disabilities Education Act (IDEA) requires an Individualized Education Plan (IEP) any time a student is identified as having a disability and needs special education services. This is partially based on your child's special education evaluation."

A diagnosed mental illness is considered a disability. Parents need to help demonstrate the ways in which a mental illness is affecting the child's learning as part of accessing special education programs. If it is determined that the illness is impacting the child's performance at school, the school must participate actively in creating an environment that helps the child overcome their hurdles.

The process begins with a parent, guardian or school personnel requesting a full and individual evaluation of the student's needs, and proceed through eight more steps as described by Texas Project FIRST, an initiative of the Texas Education Agency to provide accurate information to parents. Key points in the process include parental consent, an evaluation, IEP planning, and determining ongoing evaluative measures. <u>The Texas Project FIRST</u> website *(www.texasprojectfirst.org)* contains a wealth of information parents and caregivers will find valuable throughout the process.

All along, we encourage you to communicate openly and cooperatively with your child's teacher and school administrators. The more information you provide about what you see at home and how it may harm your child's education, the better.

While services and support are available, the road to getting this support can be difficult. Schools have limited resources and prioritize based on most critical needs. They have procedures that make access time consuming and complex. For that reason, you may need to work with experts who can accompany you to obtain the needed help, especially if you tried on your own and didn't get the results you hoped for.

Search your area for organizations that offer parent education classes on how to best advocate for your child, such as the <u>National Alliance for Mental Illness</u> (NAMI) (https://www.nami.org/) or the <u>National Federation of</u> <u>Families for Children's Mental Health</u> (https://www.ffcmh. org/). Some local organizations can provide support with IEP meetings ,which in Texas also are called Admission, Review and Dismissal (ARD) meetings.

A child experiencing a mental illness has the same right to public educational opportunities as other children.

Some physical health factors of **behavioral and emotional issues**

A child may exhibit signs of mental health problems because of an undiagnosed physical impairment. It is very important to work with a primary care physician or a specialist to identify and treat such dysfunctions. For example, unidentified dyslexia, hearing impairment or learning disabilities can lead to a lot of frustration for the child who is under pressure to perform in school, and it can lead to serious behavioral or emotional problems. Imagine the anxiety, anger and depression you would experience if you were asked and pressured every day to perform as a nurse or an accountant if you had very low vision and no glasses to help.

Sensory deficits also are increasingly common among children, the most acute exhibited by children with autism spectrum disorder. For example, a child that can't sit still at the kitchen table and always rolls around on the floor when watching TV, may indicate that he is a sensation seeker — in other words, his brain under-processes some of his senses (touch in particular). This deficit is often mistaken for attention deficit hyperactivity disorder (ADHD). Some kids have elevated responses to their senses: they don't like to be touched, the label on their T-shirts irritates them, or they hear sounds much louder than normal. Imagine your frustration if your physical senses were experiencing two to 10 times more than what they are now. Because of these differences, these children tend to be more isolated, anxious and irritable. They don't have the tools to communicate what they experience, which is normal to them. Physical and or sensory-integrated therapy can make a huge difference for their physical health and resolve their behavioral issues.



Taking care of yourself and your relationship

As parents, we are so often focused on the needs of our children – especially when they're in distress – that we forget to take care of ourselves. We work hard on trying to fix their problems, and then we work hard on our other activities to not feel the pain and loss we experience from having a sick child.

But it doesn't work. Instead, you risk burn out, or even acting in ways that are not helpful. Maybe you suddenly have more arguments with your spouse, snap at coworkers or at store clerks, lose sleep, stop some of the good habits that help you function (like exercise, your spiritual routine, social activities) or may even go back to old ones that you are not helpful.

Taking care of a special need child is very demanding. It takes a toll on you, your health, and your relationship. You can't ignore it. Ignoring these needs ends up costing you and can affect the child mentally and emotionally.

Here is what happens if you do: you are not able to be present with your child, you lose patience easily, you are not providing the listening empathetic support he/she needs. As a couple, you are not supporting each other, you are not showing a united front to the situation, you are not showing each other respect in front of the children. You know intuitively these actions are not best for your family but feel unable to do otherwise.

It is important as you are making plans and scheduling care for your child, we encourage you to make plans and schedule care for you and for your significant other.



Couple support

The most important thing for us, as individuals and as a married couple, was to pray. Second was forming friendships with parents who had been through similar experiences. We gained a deeper understanding of our child and our family dynamics by learning that other families had similar journeys. Finally, taking time for ourselves as a couple was important. Relaxing, exercising, traveling and spending time with extended family and friends is healing and restoring.

My husband and I rely heavily on each other. We make it a habit to talk several times a day about anything at all. It doesn't matter what. What matters is that we're communicating. We practice self-care a lot too. He will take the girls swimming or to a movie while I have some down time. Or he'll keep them and allow me to go on a church retreat. When he comes home for a weekend, we make a point of having him choose activities that are important to him.

Taking care of yourself

Self-care takes a number of different forms:

Physical: Are you getting any exercise? And no, running errands doesn't count. Make time for a good long walk in a beautiful park. Or, get out for a walk after dinner every night.

Emotional: Being a parent can be isolating. Even in the midst of all we have to do, it can sometimes feel like we're all alone. Get some support. Talk to other parents in your neighborhood, or join a mom or dad's group and find some like-minded individuals. Find someone you trust and respect and make sure to get together on a regular basis (at least once a month).

Mental: As your child struggles with mental health issues, are you tending to your own? Many parents find it really helpful to connect with someone who understands the challenges and anxieties you face while your child is suffering. Ask your own doctor for a referral or ask your insurance for a list of providers and select someone you trust.

Spiritual: Don't neglect your spiritual habits, the religious service you attend, the study or prayer groups, the time of quiet meditation, the family prayers.

Taking care of your relationship with your partner

The list below is not exhaustive but includes important reminders to make sure you continue caring for each other and the relationship:

- Communicate about your understanding of the child's diagnosis and be supportive of each other's views, even if they differ
- Come together and stay united about the way you respond to the child's behaviors and the limits you set for the sake of your family
- Set a time every day during which you just focus on each other, not the child, and discuss dreams, fun thoughts or events, little things
- Deal honestly with your feelings and needs, learn to listen to each other, to apologize when you're wrong, to forgive quickly
- Notice your spouse's efforts, hard work or small things they do and be grateful to her/him
- Have fun, laugh, talk about small stuff, and schedule time when you can enjoy each other's company, be creative in finding ways to be romantic
- Be proactive and get help if you feel that resentment is building and you are no longer communicating.
 Family or Marriage Therapy can play a critical role in helping your child.





Getting support from loved ones

Family and friends may not always be equipped to support you. Sometimes they judge, they give misplaced advice, they don't relate to your struggles. One in Five Minds designed an entire handbook about this topic so that these relatives can be more informed. You can find it here: http://info.1in5minds.org/family-and-friends-handbook

Finding peers who can understand

What can help the most is peer groups made of parents who are walking the same road, or are even further down the path. They have similar experiences, motivations and interests. Usually, they have done research about some of the situations that you're wondering about, and maybe found some of the services you need. Being part of a team makes it easier to find solutions. Most of all, they are usually the most effective emotional support. A group also can be a safe place to share and express deep feelings. Look for such groups in your area. The National Alliance for Mental Illness (NAMI) offers classes such as NAMI Basics that help parents understand their child's illness and navigate the system of care, as well as support groups for parents. <u>Check out their website</u> *(https://www.nami.org/)* to find out what is available in your area.

In closing

It is likely that you find this information a bit overwhelming, and that's normal. There is a lot to know and to learn in this field. Take your time, circle or highlight what matters to you the most right now, and make one or two resolutions. Taking care of a child with mental illness can be a long road. It also can be very enriching, as the relationships you will build can be deep and lifelong. You also may find that it helped you eliminate or disregard superfluous information and come closer to what is important in your life. Most of all, don't be discouraged; stay hopeful. There is help. There are good treatment options and many people committed to making a difference for children and their parents.

Overview chart

Your child is showing signs of mental illness/substance abuse

Start with a list: Make notes of what you observe (what, when, how often, when it started), collect information from other adults involved with the child, talk to the child about what he experiences, what makes him behave a certain way. Is the child suicidal, or at risk of harm to self or others?

- 1. If so, call 911, an emergency room or a local psychiatric hospital immediately. If your child is hospitalized, work with your case manager to get a treatment plan and initial appointments in the community.
- If not, talk to your pediatrician. Does he have a list of recommended providers? Look for a mental health provider on your insurance plan and in your area (go to <u>http://www.1in5minds.org/find-help/resources-2</u> for sources).

Check the local MHMR, offices funded by the state that provide mental health and intellectual and developmental disability services, including assessments and counseling.

Talk to a mental health provider

- Therapist
- Psychiatrist

Get their professional opinion of your concerns and perhaps a diagnostic assessment

Talk to your school about the results of your visit with the professionals and the specific symptoms that prevent your child from being as successful in school as he could be.

- Talk to a teacher
- Talk to a counselor
- Ask for accommodations, and if necessary ask for an Individual Education Plan (IEP)

Don't avoid medications: they can be life saving. Ask about side effects and important follow-up appointments, making sure there is doctor's supervision.

Ask for family therapy to learn how to create a family environment that will help your child do well.

Learn on your own about mental health issues, prevention and treatment options. Your active involvement will make a big difference for your child's future. <u>Find a list of online resources here</u>. *(http://www.1in5minds.org/find-help/ resources-2)*

Don't stay isolated. It can happen to anyone, and many other families have experienced it. Talk to trusted people who can give you moral and personal support.

Connect with a peer support organization like <u>NAMI</u> (*https://www.nami.org/*), <u>National Federation of Families for</u> <u>Children's Mental Health</u> (*https://www.ffcmh.org/*), or <u>other groups in this list</u> (*http://www.mentalhealthamerica.net/ find-support-groups*), so that you can learn from other parents who recovered from a similar experience.

Consider seeking counseling for yourself or for you and your partner/spouse to process the trauma and build strength and knowledge for the future.

My plan

As a result of reading this handbook, here are three things that are most important for my child and my family:

1.	
2.	
З.	
Here is the o	ne thing my spouse/partner and I are committed to doing right now:
What:	
Here are add	litional things my spouse/partner and I will work on in the near future:
What:	
When:	
What:	
When:	
What:	
When:	
Here are sor	ne things we can stop doing or put on hold for now so that we can take care
of our child, a	purselves and our relationship:
Here are the	most important contacts and groups to help support us:
Name:	Phone number:





www.1in5minds.org