



How can I help?

a guide to effective support of parents dealing with a child's mental health crisis





You received this handbook because you are a relative or a friend of someone whose child experienced a mental health crisis. This guide is intended to help you understand and respond in helpful and appropriate ways.



I have worked in children's mental health for many years, heard many parents tell their stories, and was touched by their situation many times. However, it wasn't until my own child went through a severe crisis of psychosis (later diagnosed as bipolar) that I really understood what it meant to be a parent of a child with a mental illness. I tell people it's like you've gone to serve in Afghanistan and when you come back, only those who also were there can really understand what you experienced.

When my husband and I talked about the crisis our son experienced with family and friends like you, we received a variety of responses. Some didn't know what to say. Some were overbearing, sharing advice about what to do and think and feel and lessons to take from it. The best responses—those that provided the most support—were simply listening, expressing regrets for what was happening, and offering comfort. They also continued to ask not only how our son was doing, but also how we were doing.

In this guide you will hear how parents experience their child's crisis, and how relatives and friends often—without intention— increase parents' isolation by the way they respond to the news of the crisis. Frequently, parents refrain from discussing their child's first crisis and their own experience because they want to avoid the seemingly inevitable misunderstanding, ignorance and negativity from others. These parents weather the storm and struggle on their own, or if they're fortunate, they will join a support group made of other parents who share their experience. This type of support can and should come from loved ones as well.

This guide was developed to help you learn what it is like for the family who cares for these children, and ways you can be there for them. While mental illness can be complex and dealing with it difficult, children and teens who get help and support do well. You can be a part of this support.

What you do next for the relative or friend who needs you is of tremendous value. The following pages were written with the input of a group of ten parents who have been through this experience and want to help others. There is hope and a positive approach in the parents' comments, and realism as well. Not everyone will care enough to continue reading. Some may feel overwhelmed with this information, and others may dismiss it. But we trust that many more will become equipped to be a caring partner to their friend or relative.

So often, the isolation parents experience adds pain to the grief and loss caused by their child's diagnosis, the difficulties in managing the illness, the challenges of finding good medical and clinical help, and the complexity of maintaining a family life despite the illness. You can help provide relief through caring support.

Hannah Kohlman,
Editor, One in Five Minds

key facts about children's mental health

Children's mental illness is prevalent.

Of the 74.5 million children in the United States, an estimated 17.1 million have or have had a psychiatric disorder—more than the number of children with cancer, diabetes, and AIDS combined. 50% of all lifetime mental illness starts by age 14. We just don't talk about it.

Not all mental illnesses are the same.

There can be very significant differences. For instance, anxiety, depression or ADHD can be treated effectively through therapy, medication or a combination of both. Other illnesses like schizophrenia, bipolar or disruptive mood dysregulation disorder (DMDD) are often more acute and more like a chronic illness: the patient can regain a normal life but it will require life-long treatment and maintenance.

Prevalence of some of the most common categories of mental illness among children:

- Anxiety disorders: 31.9%
- ADHD and/or disruptive behaviors: 19.6%
- Bipolar and other depressive disorders: 14.3%

Mental illness is not a character defect.

When children with mental illness misbehave or act strange, it's not because of a lack of goodwill. These children want to fit in and do well but they have many invisible barriers. That's why therapy is essential.

Mental illness doesn't mean bad parenting.

While the child's environment is important, the reason a child becomes mentally ill is first and foremost typically a pre-disposition due to genetic and biological make-up. Often parents who have a child with mental

illness are also successfully raising other children. While children who experienced trauma are more likely to experience a mental illness, the root cause of mental illness is often found in the genetic make-up and the brain chemistry of the child.

If not treated, mental illness can have dire consequences on a child.

1,830 teens (10 to 18) committed suicide in 2015 in the US, and 105,000 were hospitalized for self-injury. Suicide is the second leading cause of death among youth 15 to 24. Youth who are not treated are twice as likely to abuse drugs and alcohol. Half of youth with a serious emotional disturbance will drop out of school. 70.4% of youth in juvenile justice settings meet criteria for a psychiatric diagnosis.

Mental illness is complex to identify, diagnose and treat.

There are so many factors that impact our brain: our genes, our body's make up and weaknesses, environmental stressors, etc. In a child, it's even more complex because the child's body is changing all the time and the brain is still developing until age 24. Depending on the illness, it may take more than one doctor visit to get a definite and clear picture of the illness and its treatment. It's a process of discernment that can take years.

Recovery and health is possible.

Controlled studies show that rates of recovery range from 70% to 86% for children with issues like ADHD, anxiety or depression who are treated with a combination of medication and therapy.

There is always hope.



Becoming Comfortable With What You Hear

Stories about mental illness are not easy. They can be unsettling, often defy social norms, and look like bad behavior or ill intent. A parent who has the courage to explain what their child is going through will likely experience some shame and embarrassment. You may have seen or experienced the child's behavior yourself and have your own feelings about him/her.

Maybe the child or teen is overactive, cuts off other kids while they are speaking, or is impolite with adults. Maybe he or she is very withdrawn, absent, or doesn't tell the truth. Maybe he or she is experiencing a substance abuse problem that only makes things worse.

It is not surprising that these behaviors make us uncomfortable. We believe that they shouldn't happen. It's not what you expect from a child. However, behavior is remarkably different when a child is ill. The illness causes her to lose—at least in part—her ability to control her actions. Despite their best efforts, parents' success with the child can be limited. You see this among families with several children: their other children seem “normal” and successful but the one with the illness, who lives under the same roof with similar education values, behaves in a very different way. Often, the child wasn't able to learn and retain basic interpersonal skills, or lost them when the illness progressed.

So what you will hear about from the parents or see for yourself is likely unsettling. It's important that you become aware of the feelings of discomfort that you will likely experience when this conversation takes place. When it happens, will you be able to deal with it in a helpful way?

There are many ways people try to stop such a feeling of discomfort: maybe it's trying to minimize what's happening ("it's just a phase"), maybe it's telling the parent what they should do, or it's talking about our own stuff, or rationalizing.

To prepare you for this conversation, we would like you to hear from parents what it was like to experience their child's mental illness, and then what they heard when they shared about it.

What Parents Experience, In Their Own Words.

It's not always easy to imagine the feelings of frustration, powerlessness, and tragic loss that a parent experiences when their child loses emotional and behavioral control and starts acting out. Interestingly, the child may be able to have enough control that he will not exhibit the full extent of his behavior outside of the home. Yet for those living with him or her, it's another reality.

To give you an idea, we asked some parents to share some of the hardships they went through. In turn, and with their permission, we share these stories with you to help you understand the extent of the situation's complexity and the difficulties these families experienced.

The symptoms associated with mental illness can start showing up very early, yet we may not understand the root cause, nor the extent of the illness at first. We often think it's temperament or a personality trait. One parent shares her experience.

"It was difficult knowing things were going on in her head that I could do very little about," reports this mom.

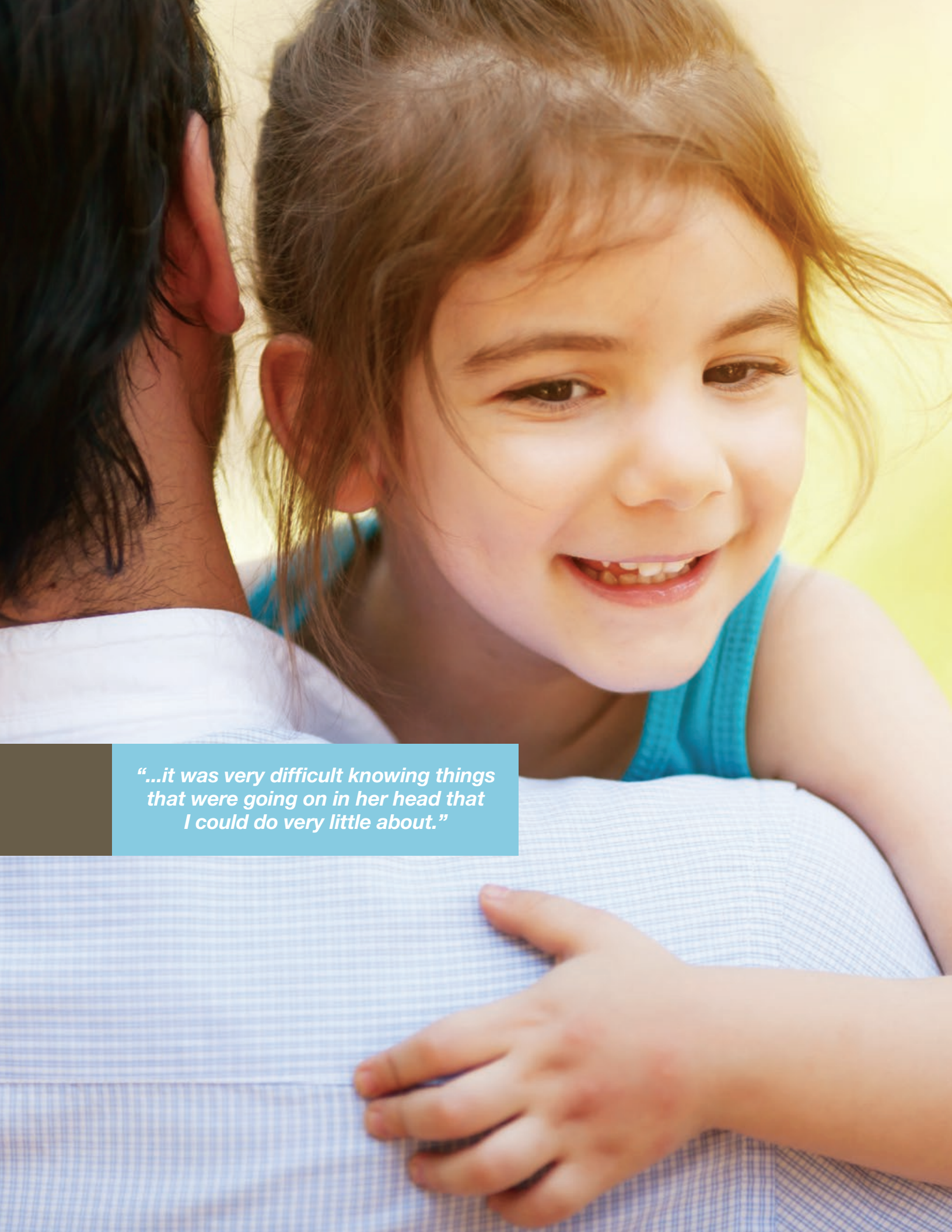
But in her daughter's case, despite early treatment, things continued to deteriorate. ***"When she was in elementary school, it was almost a daily issue to get her to attend school. She was a very good student and was usually fine once she was in class, but there was often separation anxiety with me leaving her. She was a perfectionist with her school work."*** It went to the point that her behavior became dangerous. ***"The older she got, the more violent she got. Throwing things in the car as I was driving—once breaking the windshield. Other things like tearing up photographs, trashing her room, breaking lamps and furniture in the house. In her early teens she became a cutter, so there was always the fear that she may accidentally go too far."***

You can imagine how difficult it must be for parents to watch their child experience these symptoms. And then, imagine not being able to tell anyone about these events for fear of judgment, rejection and contempt because of the child's behavior.

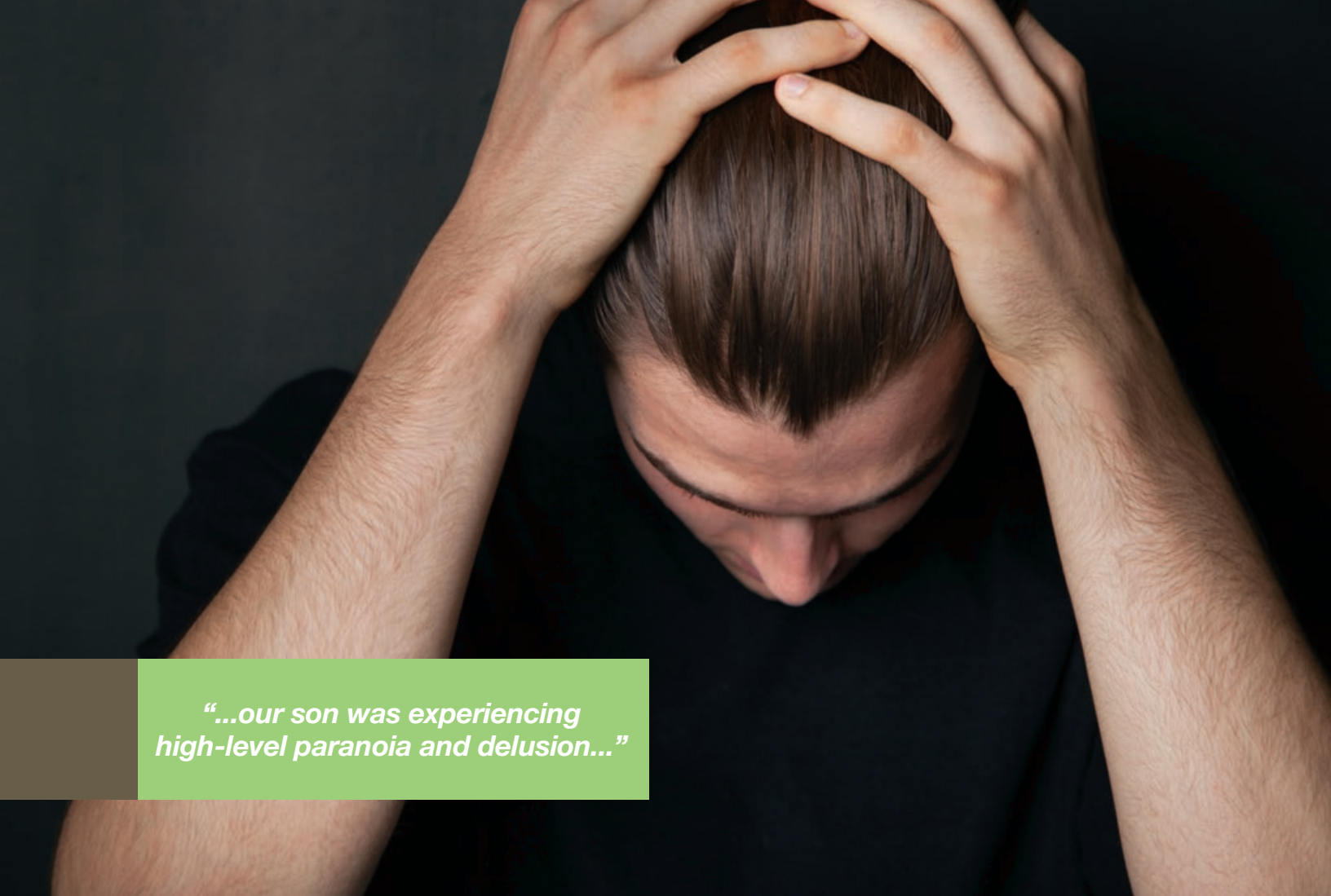
Our first reaction may be to discipline the child, but it doesn't work that way: a mental illness is not simply a parenting problem.

Another parent shared the following:

"With the symptoms they experienced comes a lot of unacceptable behavior that we see that is antisocial, hostile and even violent. I was sad that my family and church could not see this as symptoms of illness and have compassion, but I understood that they didn't know. However, the school was primarily punitive and I felt that they should have known more and been a better support."



“...it was very difficult knowing things that were going on in her head that I could do very little about.”



“...our son was experiencing high-level paranoia and delusion...”

Other crises that often happen behind the closed doors of a home are the suicidal thoughts and attempts that often accompany serious mental illness. It's the worst nightmare for a family and what keeps them awake at night.

“It was hard to convince my daughter to go in to the emergency room when she was suicidal. I was so scared that she would refuse to go,” says another mother. ***“I was also very angry that she was suicidal. I'm not sure why.”*** Parents experience a mix of intense feelings when these events happen, and they can be traumatic. One father shared, ***“our son was experiencing high-level paranoia and delusion as he was driving himself 800 miles back to our home. It took three days. Twice we lost total contact with him for about 18 hours, fearing the worst. When he arrived home, we thought it was a miracle.”***

Parents share other painful or traumatic events:

- ***“Seeing police officers place him in handcuffs... not arresting him since he had done nothing wrong, but because his doctor was admitting him to a psychiatric hospital.”***
- ***“Hearing someone tell me that my son would never be able to read again because of too many years of not being treated appropriately for schizophrenia, stating that his cognitive functioning was gone forever even though he had been in treatment every day after first being diagnosed.”***
- ***“Having my son tell me that I had ruined his life by ‘putting’ him in a psychiatric hospital.”***

Another hardship is the strain on the parent-child relationship because of the illness.

“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.”

Parents have to get help from the school, which adds a layer of complexity:

“After our son was caught fighting, the high school assistant principle called us and said: ‘We have called the police and he will be arrested.’ The vice principal had not noticed that the problem occurred because the school did not follow the Behavior Intervention plan. He was not even aware that our son was in special education.”

Because parents are driven by love and don’t give up on their children, they pursue, attain and schedule the medical and therapeutic care their children need. And it’s very different from treating a broken arm or even a serious illness like cancer. It can take years, a lot of patience, and many trials and errors. From one parent’s perspective,

“Over the years, the exhaustion and time-consuming task of going to doctor and therapist appointments took a toll, along with the expense of treatment — even with good insurance. It has had a big financial impact on us.”

The system of care is certainly of great help, but is also demanding. One parent cites ***“the endless paperwork, especially when starting with a new provider; the never-ending family history questionnaires; the consent forms when she was inpatient — including some scary things to consent to like the possible use of restraints, etc.”***

The difficulties can be so intense that they take a physical toll on the parent like this one who shared, ***“I would have to leave work at a moment’s notice to deal with whatever the latest crisis was. I started having back pain from stress, sadness, and feelings of hopelessness. I was unable to concentrate at work.”***

Because these experiences are so difficult and personal, your friend or relative may not be able to share them with you as expressively as the testimonies above, or they may not be comfortable yet. When talking with your friend or relative, be open and patient but not inquisitive. Your ability to listen will help them gain confidence.



Responses Parents Often Hear When They Confide in Relatives and Friends

Unfortunately, many responses to parents sharing about their child's mental crisis and illness are not helpful. The same parents who shared their testimonies above share examples of **how not to respond**.

- *“Some hurtful comments were from extended family who said she was ‘faking it.’ That she was looking for attention, that she was playing me. Telling my husband and me that we should have spanked her when she was young. That she was spoiled and that we never told her ‘no.’”*
- *“The older she got, the more I was told to let her live on the streets and to cut off support for her.”*
- *“My own sister, a special education teacher told me, ‘He’s just manipulating you.’”*
- *“‘He will probably out grow this (ADD),’ said a special education coordinator at a school admission, review, or dismissal (ARD) meeting regarding our 10-year-old son, who is now 33 years old and has been incarcerated twice. Two years after this ARD, he vandalized a local school.”*
- *“We had a very close circle of friends, and they would come up to my daughter at church and ask how she was doing. She became weary of having to answer all of those questions. There was a big trauma that had preceded her depression, and she felt like she was having to revisit that trauma with every question. It heightened her PTSD.”*
- *“Throw him out. There’s no hope. Save the other children.”*
- *“Our pastor said to keep him at home because if he came to church ‘sick’, he might make other people sick. Besides, he was scaring good church members with his repetitive actions while talking to his voices.”*
- *“How can she be depressed? She’s too young, too pretty, too popular, too smart, etc., to be depressed.”*
- *“Most of our family is unfamiliar with the kinds of behaviors our son was exhibiting. They did not understand the complexity of his past wounds and the seemingly self-destructive and self-defeating behaviors he was engaging in. They simply saw that he was making bad choices and determined he needed to make better ones. They were not hurtful in their responses, but rather naïve and ignorant of the underlying causes for his behaviors, as well as the type of help he needed to truly get on the path to recovery.”*

You can hear a lot of misunderstanding in these quotes. The parents shared the experiences below, which were not always hurtful but still made communication and sharing difficult.

- Family or friends talking about themselves and their own difficulties with their child, or bragging about their own successes with them.
- Family or friends trying to fix the problem, suggesting solutions, acting as case manager or therapist when they only know a small piece of the situation, and they have not been invited to do so.
- Family or friends avoiding the topic altogether, acting like nothing happened or was going on.
- Family or friends withdrawing from the parents.
- Family or friends reaching out to talk about other things in an attempt to “get your mind off the problem” right at the moment when they know the parents are in severe crisis.



*“...how can she be depressed?
She’s too young, too pretty,
too popular, too smart
to be depressed.”*

This is not an indictment or condemnation of anyone or their efforts to be supportive. However, it's not easy to understand how to help. That's why we wrote this guide. Let's talk about what you can do that would make a difference.

Responses Parents Hope to Hear

You can help parents. In fact, because you're a friend or relative, your help can mean a lot more to parents than that of a counselor or a doctor. So how can you be helpful with your words?

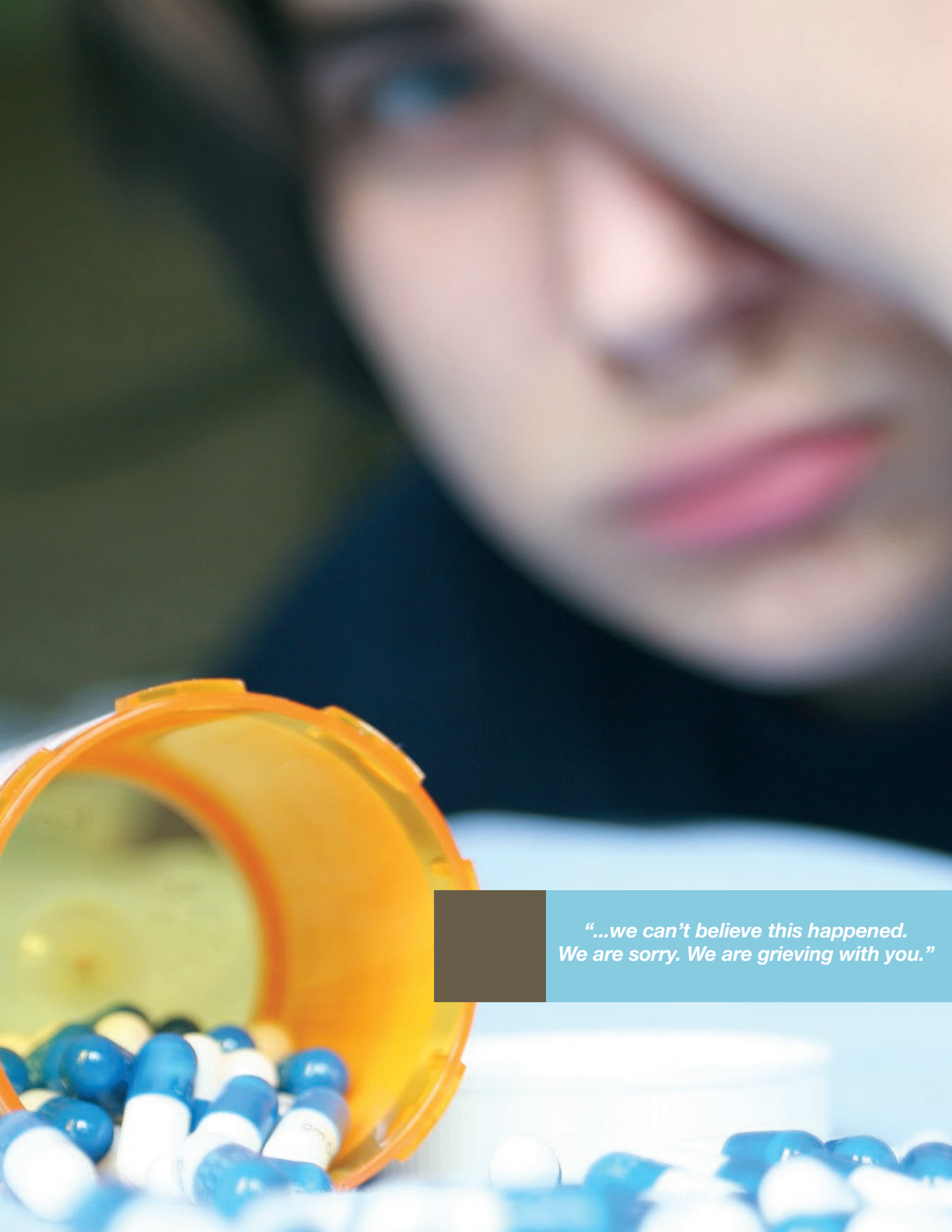
Here is what parents wrote regarding what helped them the most:

- *"When my daughter first attempted suicide, my friends called me even though it was late at night, and said, 'We can't believe this has happened. We are so sorry. We are grieving with you.' It really helped that they resonated with the shock and grief."*
 - *"I am very fortunate to have close friends and family who sometimes just listen. They pray with me, and for my family and me. Some ask how I am doing—their concern is about my husband, my son's and my well-being (not just focused on my daughter)."*
 - *"One helpful thing was that no one blamed us as parents. Everyone seemed to recognize that we have done the best we knew how to do at the time, albeit not perfectly. They were supportive in our decisions to get him help and acknowledged the scope of his problems was beyond normal teenage behavior."*
 - *"Some give advice when I ask for it. They've provided suggestions regarding different agencies or families I could talk to who were going through similar things."*
- *"My sister and dearest friend encouraged me to seek counseling for myself and to make use of our Employee Assistance Program (EAP) available through my employer."*
 - *"Offers such as, 'I will take him to the doctor so you don't have to miss work,' or 'I am going to pick him up and take him out to eat,' or 'I will watch your other children and feed them dinner so you can take him to the doctor,' were so helpful and welcome."*

In summary, parents wished their close friends would say or do:

- Very little. Just being here, listening attentively and patiently, and being empathetic. ("I'm sorry, I can't imagine, this must have been very difficult...")
- Ask how things are going for the parents themselves and are they being cared for.
- Send a short message every once in a while, even every day when you know they are in a severe crisis time, once a week if less so, to show you care (How are you doing? I've been thinking about you...)
- Take initiative to do specific acts of support, such as some of the ones listed below
- When you see your friend or family member going down a dangerous path, be there to help. Some parents can become depressed.





*"...we can't believe this happened.
We are sorry. We are grieving with you."*

Actions Can Speak Louder Than Words

Words are important and make a huge difference. However, actions can matter even more. Here are some of the actions that friends or relatives did that made these parents feel supported in the midst of the difficulty:

- *“My dear friend has always offered her home as a refuge and has told me I am welcome to stay an afternoon or a week— whatever is needed to help me.”*
- *“They came and sat with me at the hospital. It was so encouraging.”*
- *“They visited my daughter in the hospital and brought gifts.”*
- *“They accept him as a viable human being who happens to have a disease in his brain.”*
- *“They offered to give me one free hour once a month.”*
- *“Friends brought food and others brought gift cards to make sure we didn’t have to worry about preparing meals during stressful times.”*
- *“Family members gave us the space to deal with our son at times when his behavior became unexpectedly erratic. They listened to what we needed from them, e.g., remove the keys from all the vehicles and hide them. They did not act impatient or like we were overreacting as parents. They understood there was a greater context than they were to privy to. They listen to what we needed from them and acted without hesitation or judgment. They allowed us the privacy to not always explain every incident that had occurred. There was a feeling of respect for our privacy and the difficulties we were maneuvering through.”*

- *“Grandparents hosted a party for our son’s high school graduation. He had made so many efforts at completing, so many stops and starts that we weren’t certain he would ever finish. He finally was admitted to a school in their district where he graduated. Grandma’s suggestion to host the family party was acceptance of his difficulty and reward for his work to finish and a happy memory for him.”*

While these actions are sometime heroic, there may be simpler ones that you can take. One way to think of your relative or friend’s situation is that of a parent who has a child with a serious or chronic medical condition. Then ask yourself what you would do to help these parents based on your own gifts and talent. Think of actions that won’t add to their current load.

Here is a list of examples that can help you think of your own ideas:

- Check on them by phone.
- Bring a meal or a dish.
- Offer to drive them somewhere.
- Help the parents with respite (provide childcare for them).
- Take care of their pets for a weekend.
- Mow their lawn or offer other small services that save them time.
- Pray for them and their child, and let them know you are.
- Go with them to a difficult visit (doctor or hospital).



Your Action Plan

We hope that this tool is not a cause for discouragement or has made you feel criticized. We understand; most of us have been in your place before, where we heard someone who had a difficult experience but couldn't relate or know what to do. It's tough, and again, that's why we wrote this guide.

Now we invite you to think about the next steps you can take to be a support to your loved ones. The list that follows represents some suggestions. Before you make your personal action plan, start with a quick meditation on this booklet, and then write down your thoughts and feelings in the space below.

I want to:

- Learn more about families experiencing mental illness, by reading and watching testimonies from families on 1in5minds.org/stories, or watching the movie *No Letting Go* online.
- Prepare for a dialog with my relative/friend: draft what I would you like to tell him/her.
- Send a note or schedule a time to get together with my relative/friend
- Re-connect with my relative/friend through an open and honest dialogue when I am ready and the person is open.
- Learn more about the mental health field and resources available to people in my area. Check out resources at [1in5minds.org/getting help](http://1in5minds.org/getting-help). Caution: your friend or relative may have already done a lot of this research, but you can help if you see they are overwhelmed. Ask them if they feel they know about all the resources available to them. For example, advocating with a school is a huge task and a partner for it can be great support. Remember to ask first; don't just provide advice.
- Provide spiritual support, such as praying for the person (plan how you will pray and how often, put it in your calendar)
- Think of one or two ways to can make them feel loved by my actions and schedule them.
- Other ideas: _____

Child Mind Institute, 2015 Children's Mental Health Report

Age of onset of mental disorders: A review of recent literature, Ronald C. Kessler, PhD, et Al. HHS, Current Opinion in Psychiatry. 2007 Jul; 20(4): 359–364.

Merikangas, K., Hep, J., Burstein, M., Swanson, S., Avenevoli, S., Cui, L., Benezet, C., Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: results from the National Comorbidity Survey Replication—Adolescent Supplement (NCS-A). Journal of American Academy of Child and Adolescent Psychiatry. 49(10): 980-989. doi: 10.1016/j.jaac.2010.05.017

Center for Disease Control

US Centers for Disease Control

SAMHSA's 2005 National Survey on Drug Use and Health

U.S. Department of Education. Twenty-third annual report to Congress on the implementation of the Individuals with Disabilities Act. Washington, D.C., 2006

Shufelt, J. & Cocozza, J. (2006). Youth with mental health disorders in the juvenile justice system: Results from a multi-state prevalence survey. Prepared by:

National Center for Mental Health and Juvenile Justice.

Child Mind Institute, 2015 Children's Mental Health Report



www.1in5minds.org