

# Starting Treatment with Medically Unstable Children



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When all the behavior plans in the world won't help your child regulate his behavior, medication may be in order. Yet for some children, months and years pass while different drugs bring few or no results. Parents, terrified by their offspring's violent, seizurelike rages or fits of self-destructive anxiety, wonder where to turn next. If talk therapy doesn't work, what help can I as the outpatient therapist offer before the psychiatrist finds the right cocktail?

I am, of course, just a consultant putting in a cameo appearance in your life and that of your child. Bearing in mind that you, the parents, know your offspring best and will be the therapeutic troops on the front line for the long term, I target my efforts in seven broad areas.

## Teaching Your About Available Mental Health Services

Families need to understand the system. You need to know how outpatient therapy, intensive outpatient or partial hospital programs, extended day treatment, acute and subacute care, and residential treatment differ. You also need to know what the admission criteria are, how to use the various levels of care to advantage, how to command providers' respect, and, sometimes, how to lodge a formal complaint. To make the best use of therapists and psychiatrists, it helps to know what to expect, how to locate needed professionals, and how to size up newcomers as team players. I can help you choose from available resources at the national, state, and local levels.

You also need to familiarize yourself with your insurance benefits and to know how and when to seek help from the state health care advocate. It's absolutely essential for you to understand your contracts with managed care and to know how to demand your rights.

## Helping You Collaborate with Your Child's School

To increase your child's success at school, you also need to understand the educational bureaucracy. Perhaps you will want to supplement the regular education curriculum with a section 504 plan (special accommodations). Better

still, in terms of the legal safeguards, your child may qualify for placement in special education, which makes possible a variety of services, which include pullouts (the child periodically goes to a resource room), full-time instruction in a special education classroom, or—in worst case scenarios—an out-of-district placement. As a parent, you need to know how to prepare for meetings with school staff, how to educate teachers about your child’s illness and behavior, and generally how to make the system work for your family.

### Helping You Identify and Find Resources

Medical information is now available to the public not just from consumer-oriented books but also from the medical literature and from researchers, providers, and the local and online communities. If you join forces with other families, for example, through your local affiliate of the National Alliance for the Mentally Ill (NAMI), you will get extra support and be better able to advocate for needed research and improved DSM diagnoses, educational accommodations, and diagnosis-specific protocols in treatment facilities. Parents who become community activists can increase the availability of mental health resources and the flexibility and responsiveness of the bureaucracies that provide them.

Troubled children also need information to help them learn about their disorder and give it a context. How much your daughter understands will depend on her age and relative maturity as well as on the nature and severity of the illness. I can help her see her disorder as something that is separate from her identity, a problem that she did not deserve but that she is nevertheless responsible for managing. A four-year-old, for example, can learn about getting the “monster” off her shoulder. Videotapes sometimes help kids—in their calmer moments—see how their disorder looks to others.

During crises, children may be literally out of their minds and unable to process language. In moments of extreme distress, the frontal lobes of the brain, responsible for executive functions such as language and self-restraint, shut down. Cognitive and behavioral therapies won’t work until the child is cognitively available, which means able not only to comprehend the information presented but also to store it and retrieve it. Therapists sometimes use therapeutic vignettes, known as social stories, to present behavioral lessons in visual terms. Pictures are easier to remember than spoken words.

### Giving You Advocacy Skills and Information

No one makes a better advocate for your child than you, the parent. When there’s a brain disorder, you and I as your child’s therapist can team up to compile a complete bio-psychosocial history. This should combine information supplied by you with clinical material from me and past treaters. I can draft an updatable clinical summary, ideally no more than about five pages long, that lists providers, medication trials, and hospital stays. You and I will review the narrative together for clarity and accuracy. Once we have a complete document, it can be stored in a

computer file and kept up-to-date so that it can be used to educate new providers such as an emergency room psychiatrist who may be completely unfamiliar with the case.

The clinical summary helps bring providers together as a cohesive outpatient treatment team so that when and if the child moves to a higher level of care, everyone agrees about the interventions that are needed and the discharge criteria. The document can also promote communication and cooperation between temporary inpatient providers and long-term outpatient treaters.

Some psychiatric issues pack a wallop for the family on a daily basis. Children who become violent unpredictably need twenty-four-hour supervision, which may keep parents from getting enough sleep or from spending quality time alone together. I know of no communities that make respite available to parents at night on a long-term basis, but it's certainly a resource that needs to come into being.

In Connecticut, the prevailing assumption seems to be that behavior management plans and psychotropic medications will quickly eliminate crises, leaving the parents fully capable of managing the child in their home while they work at their jobs, run the household, and attend to siblings. If this description fits you, you are lucky.

As a parent, and even if you are a mental health professional, you should be aware that some providers will greet you skeptically and without fully crediting your expertise regarding your offspring. Some providers would rather blame parenting skills than look for medical issues, particularly when there is a controversial provisional diagnosis. You can reduce the likelihood of such unprofessional bias by gathering and presenting your evidence strategically. Buy a small, portable notebook, and use it to document changes in the regimen, side effects, behavior problems (including duration, precipitant, and sources of relief), successes, and the child's and family's rating of the day (good to bad on a scale of 1 to 10), thereby creating a written daily record that you can share with physicians and other professionals. For tracking purposes, mood charts are also available.

If your child exhibits severe behaviors in one setting alone—only at home with her mother, for example—you may find it helpful to create audiovisual aids for providers. You can use tape recordings, videotapes, and even Excel graphs and charts that draw on the daily log to illustrate trends. Once analyzed, data may expose seasonal patterns that you can correlate with other events.

### Listening, Normalizing, and Validating Your Feelings

If your family has knocked on many doors seeking relief, you may be grappling with fear, sadness, disappointment, embarrassment, guilt, and anger. When your child is out of control, everyone—parents and therapist alike—is likely to feel

powerless and uncomfortable. Even when there's no solution in sight, I can keep you from feeling alone and hear your accounts of the struggle.

I can also help you and your partner make time for yourselves and your relationship. If your ill child has siblings, they may feel upstaged by constant crises. I can help well siblings find coping strategies that let them adapt to difficult circumstances without losing their childhood and their sense of self.

The ill child herself can be invited to talk about life at home and at school. How does she see the problems? Some children feel different and inferior, stigmatized, incapable and inadequate. Some say they hate their lives. You and I together can hear and acknowledge such feelings while holding out hope for change, reframing struggle as strength, and calling attention to overlooked successes.

Over time you will acquire remarkable skills, coping strategies, and hard-won insights, from which therapists and other families alike can benefit. I can guide you to multifamily groups where you and your children will meet understanding others, share wisdom, feel supported, and have fun.

### Helping You Anticipate and Contain Your Child's Distress

Prevention is worth more than cure. Even behavior problems with no known remedy can sometimes be averted. You can help me take stock of the signs that trouble is brewing—perhaps a staring look around your child's eyes, beetling of the brows, reddening of the ears, or other characteristics. Your child can be invited to play detective and to tell adults how she feels inside.

In any setting—home, school, daycare, or treatment program—an adult should be monitoring your child. When target symptoms appear in a school or other institution, this responsible person, calling for any needed support, can escort the child to a quiet room. The exit strategy needs to be prearranged so that everyone knows about it. It should be rehearsed with the child during his calmer moments. He should know ahead of time what will happen and start learning how to tell others when he needs to take a break.

During a tranquil moment the child can familiarize himself with the quiet room. He can tell staff which equipment—the beanbag chair, cloth tunnel, body sock, soft music, squishy balls, etc.—feels most soothing. After a crisis, when he feels calmer, he can be debriefed and invited to brainstorm ways of dealing with the next episode. Children always want to succeed.

Prevention should be the primary focus of attention in all settings. In moments of distress, cues should be visual rather than verbal, with a minimum of hands-on intervention. It may help to give the child space. In institutions, physical restraints are best avoided. They often increase the child's agitation and are often

implemented more because of adults' anxiety than because there is a genuine risk of injury.

Children with high anxiety levels frequently react to transitions and sudden changes with anger or oppositionality. On a daily basis, a home "agenda" (perhaps a simple list on a whiteboard) can help your child know what's in store today. It can list things to be accomplished and provide a lesson in time budgeting. Children can be briefed on plans in the morning and debriefed in the evening. Periodic reminders during the day can help the child get ready to shift gears.

A large wall calendar makes it easy for families to talk about the week or month just past and the one that lies ahead. Like the agenda, it can be used to help the child anticipate changes and special events.

### Building on Your Child's Strengths

I try to give your child (and your family!) opportunities to enjoy her strengths. Victories at competitive games and in solitary play confer a precious sense of mastery. Good games also make people laugh and build problem-solving skills. I am a firm believer in the social, developmental, and cognitive importance of play as well as the child's need to experience the rewards of appropriate behavior.

The best toys, like good art supplies, appeal to the brain and the senses and can lead to the discovery of special talents. A hobby pursued can become a passion, both a lifelong source of pleasure and a way of combating stress. I will never forget the ten-year-old diagnosed with four brain-based diseases whose curiosity about insects blossomed into an encyclopedic knowledge of the natural world.

The chronically ill child, like everyone else, needs to experience abundant successes. We grownups must highlight his successful behavioral strategies and help him dodge the failures. You and I, like parents and professionals elsewhere, can join forces to give troubled children and their families lots of chances to feel good about themselves and their future.

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