

Since the mid 1960s medication has been the only real treatment option for children and adults with tic disorders. However, while helpful for many people, its use is often limited by side effects.

In 2001 the Tourette Syndrome Association Behavioral Science Consortium began developing and testing a promising behavioral treatment option. This work has led to the publication of the first large scale study showing that a non-medication treatment can effectively reduce tic severity. This treatment is called the Comprehensive Behavioral Intervention for Tics or CBIT (see-bit).

Although new treatments often bring great excitement and hope, some in the TS community are concerned that promoting behavioral approaches for treating tics may have negative consequences. There is concern that families, co-workers, and teachers will read about CBIT and conclude that tics are willful and easily controlled. We have known for years that this conclusion is incorrect and harmful to people with tics. Expecting people to “stop ticcing” or treating them as if tics are done “on purpose” increases distress and triggers efforts to voluntarily suppress tics, which is ineffective and leads to greater impairment. While there are likely to be people who misunderstand or misuse a powerful tool such as CBIT, we still need to let patients and families of those with TS know about CBIT so that they have choices. The purpose of this brochure is to clarify what CBIT is and isn't, what it can and can't do and how behavioral interventions are helpful in reducing tic severity.

### What is CBIT?

CBIT is a non-drug treatment consisting of three important components:

- (a) training the patient to be more aware of tics,
- (b) training patients to do competing behavior when they feel the urge to tic, and
- (c) making changes to day to day activities in ways that can be helpful in reducing tics.

It is important to note that many of these strategies are already commonly used in the management of TS symptoms. Upon hearing a description of CBIT, many adults with TS report that they have come up with similar strategies to manage their tics. CBIT takes the best of these ideas and blends them with strategies that allow people to quickly learn the techniques.

### How do you learn CBIT?

CBIT is a highly structured therapy that typically takes place in a therapist's office on a weekly basis. The standard treatment is 8 sessions over 10 weeks, but can be longer or shorter depending on the needs of the patient and his or her family. The first step in CBIT is to teach the patient to become more aware of his or her tics and the urge to tic. Next, the patient is taught to perform a specific behavior that makes the tic more difficult to do, as soon as the tic or urge appears. This “competing response” helps to reduce, and in some cases, even eliminate the tic. For example, a youngster with a frequent throat clearing tic would be taught to engage in slow rhythmic breathing whenever he felt the urge to clear his throat. A competing response chosen for a head-shaking tic might be gently tensing the head or neck muscles. Consistent and repeated practice of a carefully chosen competing response done at the appropriate time is necessary for the treatment to be effective.

The final step of CBIT, the functional intervention (FI), is based on the fact that certain situations or reactions to tics can make them worse than they might otherwise be. The goal of FI is to identify these situations and have the patient and family attempt to change them so the tics aren't made worse unnecessarily. For example, someone whose tics get worse when doing homework or before a presentation at work would be taught to manage their stress before and during these situations.

### We've always been told that TS is a neurological disorder and that tics are involuntary. If this is true, then how can CBIT work?

To be very clear, there is absolutely no question that tics are neurological in nature. However, and just as important, tics are often also extremely sensitive to the environment in which they occur. Every person with TS knows that a stressful or hostile environment can make tics worse. Similarly, positive and calming environments can be very helpful in reducing tic severity. In this regard, TS is like diabetes. Diabetes is clearly a medical condition, but is highly influenced by behavioral factors such as consistent diet, exercise, and the ability to monitor blood sugar and take insulin. What CBIT attempts to do is to help children and adults figure out those factors in their environment that make their tics worse; teach these individuals how to create environments that are more stable, predictable and easily manageable; and learn skills to cope with environments that are stressful and tic-challenging.

### Since CBIT works, does this mean that people with TS are able to suppress their tics?

Because a person can voluntarily suppress tics for a short period of time, some incorrectly assume that a person with tics should be able to control them all the time. This is not the case. Voluntary tic suppression can be done short term, but is not a very effective strategy for regular use. Voluntary suppression is stressful and people who do it become tired, frustrated and irritable. It is very important to realize that CBIT is **not** the same as voluntary tic suppression. Instead, CBIT teaches people with TS a set of specific skills they can use to manage their tic urges or behaviors, without having to use voluntary suppression. In CBIT we don't want patients to voluntarily suppress. Rather, we want them to practice the competing response that they developed with their therapist. When a person does the right competing response in a calm focused manner, the tic gets better, and they feel better and more in control, not frustrated and irritable. Initially, this requires some effort and concentration, but with practice, both adults and children can learn to do their competing responses and easily participate in routine activities. In this regard, CBIT is like other learned skills which often are effortful in the beginning, but quickly become second nature.

### I've been told to ignore my child's tics because making him more aware of tics makes them worse. Won't CBIT make tics worse?

Calling extra attention to tics at home, school or in the workplace makes people more self-conscious about their tics and subsequently tics get worse. The goal of CBIT is not to make children and adults more self-conscious, but rather make them more self-aware of their tics. Our experience with hundreds of TS patients is that as people with TS become more self-aware and understand what TS is, they often relax, feel more empowered and self confident – these emotions are all associated with decreased tics, not increased tics. In CBIT, the goal of self-awareness training is to help people understand their tics and what makes tics better and worse. This self-awareness is often described by patients as beneficial by itself, even without other parts of CBIT.

### I've heard that when people with TS try to stop their tics, it will make other tics worse or will cause a rebound in tics after the efforts to stop have ended. Won't CBIT cause these problems, too?

Every clinician who has worked with people with TS has heard a patient say that when they voluntarily suppressed

their tics, they couldn't keep it up and when they stopped suppressing, their tics “exploded.” CBIT does not teach voluntary suppression, but rather teaches techniques to control other behaviors that are incompatible with ticcing until the urge to tic or the tic decreases or goes away. Practicing behaviors that are incompatible with ticcing are very different from voluntary suppression. Researchers have conducted studies on these techniques and have shown that strategies used in CBIT do not cause current tics to worsen or new tics to emerge. That's not to say there won't be times when new tics will start or current tics will get worse; that happens in people with TS with or without treatment. However, it isn't the case that either of these things occur as a side effect of CBIT.

### Doesn't CBIT simply lead to the competing response becoming a new tic?

When people first hear about CBIT they become concerned that the competing response will become a new tic. There are two parts of a competing response that assure that this doesn't happen. First, we know tics are reduced when people are involved in calm focused activity. So individuals are taught to use the competing response in a calm focused manner for up to one minute or until the urge to tic goes away. Simply focusing on the competing response like this makes it less likely that the tic will occur. Second, practicing the competing response typically leads to a decrease in the tic urge or sensation. As the sensation goes away, the person can stop using the competing response. Once the urge is gone the chance that the competing response will become a new tic is slim.

### How effective is CBIT for somebody with TS?

The results from our large, multi-site, National Institutes of Health funded studies show that over half of people who undergo CBIT will have significant reductions in tic severity and improved ability to function. Complete elimination of all tics and other TS symptoms does happen occasionally in CBIT, but it is not what is expected. CBIT is not a ‘cure’ for TS, rather, CBIT is a tool that when used appropriately can help individuals better manage their tics and reduce the negative influence that tics may have on their lives.

### Is CBIT for everybody who has TS or tics?

Although the skills taught in CBIT can be used by everyone with tics, not everyone will necessarily benefit. At this time we don't understand exactly what makes

some people benefit from treatment while others do not. In our clinical experience, teaching this technique to children with untreated ADHD is more difficult because of problems with focusing, impulsivity and low frustration tolerance. Likewise, any other psychiatric or social problem that gets in the way of participating in treatment may make CBIT more difficult. We recommend that before starting CBIT, children and adults get a complete evaluation and address any symptoms that might make it harder for them to learn and practice CBIT. A person can learn CBIT without treating these co-occurring problems, but it might be harder for them and they may not be as successful.

### Is CBIT easy to do?

When they first hear about CBIT, professionals, patients and families sometimes say that the treatment seems simple and easy. Make no mistake, time and hard work are needed for CBIT to work well. As with any new skill, CBIT usually requires more work at the beginning to master the techniques and then becomes easier over time.

### Should CBIT be used as a first line of treatment, used with medications, or if I use medication can I stop using medication?

It is important to answer this question by first saying that **all** medication decisions should be made by the patient in consultation with his or her prescriber. Medication is and will likely remain the primary treatment for tic disorders. However, as it becomes more widely available, CBIT may be used increasingly as a firstline treatment, particularly in young children where side-effects and other safety concerns may limit the use of medication. We also know that those who are already taking medication can get additional benefit from CBIT, but we don't know whether someone who learns CBIT will be able to decrease or stop their medication. More studies will be needed to answer this question. It is not recommended to stop tic medications before starting CBIT unless this strategy has been recommended by the patient's prescriber.

### Once mastered, will CBIT last a life time?

Our results tell us that most of those who benefit from CBIT will keep their gains. In a recent study, 87% of those who did well in treatment, continued to do well 6 months after treatment. The important thing to remember is that CBIT isn't a cure...it's a management strategy. During CBIT, patients are taught a set of management skills that can be applied for the rest of their lives as needed.

### Since CBIT is a behavioral treatment, does that mean I should punish my child for having tics and reward him for not having tics?

For over 30 years, professionals have rejected the use of punishment procedures as a firstline treatment for any problem. CBIT does not employ or advocate punishment for tics! Just the opposite. Punishing a child for ticcing or for not suppressing his/her tics is mean-spirited, short sighted and ineffective. Scolding a child, raising one's voice, or taking away privileges because he/she tics is not helpful and will likely result in psychological problems and worse tics. It is also unhelpful to reward children for not having tics as this encourages children to voluntarily suppress, which doesn't work well either.

One of the great joys of helping children learn CBIT is sharing in their excitement when they really master the techniques and begin to experience a reduction in tic symptoms. To get to that point we want children to practice their competing response and we want parents to reward and support their child for their efforts. CBIT may be a challenge to learn, so parental and professional support and positive feedback for good effort can be critical in helping the child early in treatment.

### What should I do if my child refuses to do his CBIT exercises?

How many of us always do what is in our best interest – exercise, eat right, get a good night's sleep, etc.? Doing something new for oneself is not always easy. Some kids with TS might really struggle to learn CBIT. Recognizing how hard it is for them, helping them keep their spirits up, motivating them to keep trying, are all roles parents can play. Although pushing, pestering, and prodding your child to do CBIT exercises may seem like a good idea at the time, it often backfires by making the child even more angry, nervous, or disheartened about therapy – all things that are associated with worse, not better, tics. Encouraging and rewarding children for doing their CBIT exercises is a much better way to go. Part of the CBIT training for parents is to help them understand how best to encourage and reward so the parent doesn't become a "nag" and the child has the best chance of learning.

We are also making a special effort to educate teachers, school personnel and employers about CBIT, not because we want them to perform CBIT, but because we want them to get the best information about CBIT from the right source. We have noticed that people often have opinions about CBIT without knowing the facts. We want people who live and work with patients with TS to have the facts – CBIT is an important skill for people with tic disorders that is taught by skilled and trained therapists. Telling people to "stop ticcing" is wrong and

unhelpful, and not what CBIT is all about. That is not to say that teachers, parents, co-workers, and bosses won't have a role in CBIT. In fact, they may play a pivotal role in helping to create and maintain the positive environment necessary for CBIT to be most effective.

### Where can I go to have CBIT performed?

CBIT can be taught by a trained psychologist, doctor, nurse, social worker, or other therapist. As with any treatment, the training and skill of the clinician are critical to outcome. It is our recommendation that only therapists who have been trained in the principles of cognitive behavior therapy and have received specific training in CBIT should provide this treatment. Unfortunately, right now, few clinicians have been trained in CBIT.

Now that our collaborative research project has shown how well CBIT can reduce tic severity, we are working closely with the TSA to get the word out to the professional community and to establish training programs in CBIT across the country for professionals who work with TS individuals and their families. Until this is done, there will likely continue to be a shortage of therapists trained in CBIT. Some professionals who are not well-trained in CBIT will try to do the treatment, and it is important to understand that their results may not be as good as the results obtained from a trained and experienced CBIT clinician. We encourage you to select your therapist carefully and ask about their training in CBIT.

### Summary

CBIT is a potentially powerful technique that has been demonstrated to reduce tic severity. That a behavioral treatment helps reduce tic severity is a step forward and reflects modern understanding of how the brain can be shaped by the environment. The TSA and the TSA Behavioral Science Consortium is committed to communicating clearly what this research means so the treatment will be used correctly and effectively.

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### About the TSA Behavioral Science Consortium

The TSA Behavioral Science Consortium was established in 2001. Members are previous recipients of TSA grant awards who were brought together to enhance progress in this field by testing CBIT. The mission of the Behavior Science Consortium is to develop, test, and disseminate evidence-based behavioral treatments for children and adults with Tourette Syndrome.

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