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COPING WITH TOURETTE SYNDROME

A Parent's Viewpoint

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Introduction

This booklet has been prepared for parents and families of children who have Tourette Syndrome, a neurological movement disorder which usually afflicts patients throughout their lives, sometimes causing embarrassment, difficulties in maintaining a normal social life and employment problems. It is written in lay terms for lay readers. Its purpose is to inform and to let you know that you are not alone.

We have used "him" to refer to children of either sex, rather than burden the reader with him/her throughout.

What is Tourette Syndrome?

Gilles de la Tourette Syndrome (Tourette Syndrome) is a tic condition which begins in early childhood or adolescence between the ages of 2 and 16. The first symptoms usually are motor or involuntary movements of the face, arms, limbs and/or trunk, which are frequent and repetitive. The most common first symptom is a facial tic (eye blink, nose twitch, grimace), and is replaced or added to by other tics of the neck, trunk and/or limbs. While in most cases there are multiple tics, only one part of the body need be involved.

The involuntary movements may also be complicated, involving the entire body, such as kicking, stamping, hopping, etc. Other symptoms such as touching, repetitive thoughts and movements and compulsive behaviour can also occur, such as breaking objects, checking repeatedly to see if doors are locked or the stove is off, etc. In addition, there are verbal tics. These verbal tics or noises are usually added to the involuntary movements, or may replace one or more of the motor tics. They may include a wide variety of sounds such as grunting, throat clearing, shouting, barking, inarticulate sounds, sniffing, snorting, hissing, etc.

Echo phenomena are also reported. These may include repeating words of others, repeating your own words and repeating movements of others.

The verbal tics may also be expressed as coprolalia (saying obscene words involuntarily). Researchers estimate that coprolalia occurs in about 50% of Tourette patients at some time in their lives. Neither echolalia nor coprolalia are essential for the diagnosis. However, *all* Tourette patients have involuntary movements and some vocalizations.

While a motor tic usually appears first, involuntary sounds may be the first symptom, or movements and sounds may occur together. For all patients, however, the development and course of the symptoms follow the same pattern. The symptoms wax and wane. Old symptoms are replaced by new ones, or new symptoms are added on to the old ones. Symptoms may lessen during periods of pleasurable concentration. In some cases, the symptoms may disappear for a while (remission). There have been a small number of reported cases of complete remission occurring after adolescence.

Patients with Tourette Syndrome can expect to live a normal life span. Although the condition is generally lifelong and chronic, Tourette Syndrome is not a degenerative disorder.

The disorder is called a "syndrome" rather than a disease because its cause is unknown and the diagnosis is based on a group of symptoms.

Reaction to diagnosis

"Your child has Tourette Syndrome."

Each of us reacted differently to those words.

Some felt relief that, at last, there was a name for the disorder. Others felt anger and disbelief. People, being individuals, don't react in the same ways. It takes longer for some to adjust than others. Sometimes one parent has a harder time adjusting than the other parent. This can cause misunderstandings and tensions between the parents when they need to comfort one another and work as a team. Open communication, which means talking freely about your fears, feelings and frustrations, is vital.

It's easy to deny the diagnosis. Since the Tourette symptoms typically wax and wane... becoming more severe, then less severe ... it's normal to think, "Maybe it's just a "nervous habit" that will go away". Unfortunately, this feeling is reinforced by the many physicians and/or psychologists treating the child. Many professionals have been taught that tics are merely nervous habits (sometimes caused by "pushy parents") which eventually will clear up if the parents stop pressuring the child. This adds to your feeling of tension and guilt as you try to figure out what you're doing wrong.

Some parents deny their child's condition by keeping it a secret... often from the child. They continue to refer to the tics as "your habits" and excuse the vocalizations as "a cough" and the head jerking as a "stiff neck". Many refuse to tell grandparents, friends or teachers the nature of the child's condition. It makes it harder for the parent, difficult for the child, and impossible for teachers who might otherwise work with the youngster's problem if only they knew what it was.

Share the diagnosis! Once you are fortunate enough to finally learn the true nature of your child's condition, use that information to help him. Share it with your child's teachers. (We have an excellent book for classroom teachers. Ask for *Coping Book II*). Don't feel shame or guilt for your child's condition. Nothing you did caused it. Let the grandparents know; tell the parents of your child's friends so they can be more understanding; learn to call it by its real name, "Tourette Syndrome" not "a habit". The word habit means something a person can overcome by exerting discipline. Your child *cannot* turn his tics off by willing them away.

Some parents feel resentment that their relatives or neighbours may have healthy children. They may withdraw or lose interest in others who have "minor" problems with their youngsters. This is a normal feeling, one that you will eventually overcome.

Adjustment may not come overnight, learning and accepting that your child has a chronic condition is tough. It takes some people longer than others, but this acceptance is important for your well-being and that of your child. You will have many questions. We did ... and still do. We also look around at other children and silently wonder, "Why mine? What did

we do to cause *OUR* child to be afflicted? Why does it sometimes seem as though he can control the tics? What will the future be for him?"

Many of the questions you have were asked by all of us. *WE* had no one to answer them. That's why we've prepared this booklet, to answer as many of your questions as we can.

Questions About Tourette Syndrome

Why my child?

No one knows exactly why. At this point no one really knows what causes Tourette Syndrome. Research suggests that a chemical imbalance in the brain may be a cause. This disorder is not "caught" like measles or chicken pox. In some cases Tourette Syndrome certainly seems hereditary. In others, scientists are presently unable to define a mode of transmission. There are numerous cases of more than one family member having tics or Tourette Syndrome and genetic studies are now being conducted. We will have to wait for the results of genetic studies to learn if environmental factors have an impact on Tourette Syndrome as they do with some birth defects, some forms of cancer, etc. One thing is *CERTAIN*, though; psychological factors, such as your method of parenting, *did not cause Tourette Syndrome in your child.*

Can the tics be controlled?

A patient can hold back the tics for a short time, but eventually they burst through. Many patients run into the bathroom where, in privacy, they can make the noises they have been inhibiting. A child may try to control the tics while in school and then relax at home. For this reason, the tics often appear worse at home than in the school situation.

Don't ask your child to "try to stop making those noises". It only puts more pressure on him, causing additional stress which, in the long run, may cause him to tic more!

Why do I feel so guilty?

If you're like most of us, you probably punished your child for making noises, or perhaps tried bribery to keep him from making the motor tics, etc. Through no fault of yours, you didn't know your child had an illness. Your child knows that. Try to accept the situation for what it was and go on with your lives. At times you may feel that you don't want to be around your own child....the tics are driving you crazy.

"I hate to take my boy to movies or sporting events"... said a father: "People turn around and glare at him when he tics. I get angry at them, feel helpless about the situation and take it out on my son!"

We have all experienced these emotions. You are not unfeeling; you're just being human!

How can I accept my child's condition?

It's hard, because you're human. It's difficult to see your child jerking and twitching, while you feel so powerless to help. People probably will stare and other children may make fun of yours. (It's unfortunate ... but it's reality.)

Understand that you'll find it difficult to ignore the vocalizations at times. Even the most controlled among us has put a hand on our child's shoulder, as though our touch could silence the sounds. Even the most understanding of us has looked away when our child's jerkings drew attention from strangers.

It may help to acknowledge that "it could be worse. My child *COULD* have a life threatening disease."

Talk about your feelings with your mate, understanding friends or seek professional help. Keeping it all inside does no one any good. The condition exists. Denying its existence won't make it go away, and worrying about it will only make your child's anxiety worse.

How do I explain what's wrong with my child?

It depends on the person with whom you're speaking. If you are at a movie, and your child is sniffing and hooting, the people in front of you may

turn around and say "Shhh". Obviously, this isn't the time to get into a discussion about the symptoms of Tourette Syndrome. But, if you're at a grocery store and your child begins to shout obscenities to the horror of the little old lady in front of you, it might be appropriate to say, "I'm sorry. He can't help it. It's a neurological disorder he has". She may snort and turn away, but more likely she'll murmur, "I'm sorry. That's really a shame. It is ... and you'll feel better; your child, though self-conscious, will feel better; and the woman may have learned something.

WHAT ABOUT FAMILY STRESS?

PARENTS: Tourette Syndrome is a family affair. In many ways it affects all members of a family. For most of us, finally having our child diagnosed came after years of wondering what was wrong, blaming ourselves, each other, the other child, stage of the moon, whatever. Now, once diagnosed, we begin to come to grips with ourselves, as individuals and as a family.

Lucky is the child who has parents who can talk with one another, acknowledge the tensions created when a child suffers from this disorder and occupy their minds with other things. Lucky are the parents, too.

But many parents find it difficult to acknowledge that their child has an illness. They feel powerless because they "can't make it better". Some react by ignoring the problem; others stay away from the child; still others want to over-protect the child. Some women will devote their lives to the afflicted child, slighting their other children and husbands as well. They will try to shield the child from the world around him.

Rather than trying to analyze a family, each one differing so greatly from another, we have listed some major do's and don'ts

1. *DO* try to encourage your mate to talk out his/her feelings. As the mother is usually with the child more, she may become more used to the symptoms and hardly notice them, whereas to the father, they may grate like a fingernail on a blackboard. Once you have expressed how you feel, it often makes things easier to accept.
2. *DO* arrange for some time alone as a couple. You need that time to keep in touch, to talk, to enjoy

each other.

3. *DO* continue to develop other interests so your whole life is not focused on your child. The disorder is his, he will have to learn to live and cope with it. Your role is supportive.

One mother expresses her feelings, in the following story.

PARENT NEEDS ARE IMPORTANT TOO By CAROL MCGUIRE

Our eleven year old son has a life altering condition called Tourette Syndrome. Victims of Tourette Syndrome are plagued with noises and movements they can't control. These are nerve-wracking at times. It is difficult to be patient and not show my feelings of irritation during those times when my son attempts to explain something to me. It's especially tough in the car when the screams, barks, and snorting, to name a few, get on everyone's nerves in that restricted environment.

While I NEVER lose sight of how tough it is for him (and the fact that HE can't get away from it while I can) and that HIS well-being and ability to cope with what he must live with are of topmost priority. I STILL try to remember that MY feelings and life needs are important also.

Some of the ways I help him to cope are effective for me as well. Since communication is the key to coping. I try to find a sympathetic listener with whom I can exchange thoughts and feelings. If I don't have someone to talk to who will listen without being critical or judgemental, I write it down. By writing down exactly how I feel, I find the pressure eases.

Since, as I said, MY feelings are important, too, I try not to deny or suppress them. During those times when I lack patience and understanding for his problem and ask his forgiveness, I also try to be as understanding, kind and forgiving of myself as I would be to a friend under similar circumstances. Once my feelings are acknowledged and allowed expression, I can go on to the next step of being thankful that our situation isn't as bad as it could be. I also pray that whatever else may come up I be given the strength to cope with that too, and the wisdom.

Other ways I try to help myself cope are these: I decide which stresses in life are absolutely necessary and which are not. The latter I eliminate when possible. I try to rid myself of as many "shoulds" as possible. I try to keep from backing myself into corners from which it's hard to get out. I try not to look ahead, for then I panic. I try to take one day at a time.... Even one hour at a time when the going gets tough. I try to take care of my needs and do the things I enjoy.

I'm not always successful, as witness my weight problem and those times when I let my emotions run me. I do my best to remember that if I don't take care to get away occasionally and do the things I enjoy, I'm definitely not going to be much help to my son. If I subjugate myself to his needs alone, resentment and martyrdom will be the result and I'll be ineffectual to everyone, including myself. That which helps me a great deal is my sense of humour. If I didn't see the humour in heavy situations at times (though often this is only in retrospect), I know I would have a much harder time coping.

It's my feeling that everyone in this world needs to realize that some things are too tough to cope with alone and we should help each other through whatever difficult times there may be. God knows, when we do help someone, we receive tenfold in return. My struggle to cope has been aided immeasurably by the help and empathetic understanding I've received from the members of our local Tourette Syndrome Association. Thank God for the people in organizations such as this!

SIBLINGS:

Explain the disorder to your other children. They also may be teased at school by their peers and need to understand why their sibling behaves as he does. If they can be frank and unembarrassed, they can help ease the way for the youngster with Tourette Syndrome. His siblings can be of great support. However, when the siblings get angry, as all kids do, they may attack at the most vulnerable spot ... the tics.

DEALING WITH OTHER RELATIVES:

Often your family is the most difficult to handle. Grandparents may feel that "what that child needs is a good spanking," even though you've explained over

and over again what is wrong. Continue to sound like a broken record! "He can't help sniffing, Grandma, it's not his adenoids, it's Tourette Syndrome that causes him to make all those noises." If you say nothing your child may feel you really think he *COULD* stop if he wanted to. He needs to know you support him at all times. Explain to cousins and other relatives, so they support him as well.

How Can I Best Help my Child?

By being understanding and showing that you still love and care for him. Listen to his hurts and encourage him to talk out his embarrassments. Your child knows he's making noises and jerking. He wants to stop even more than you want him to!

Include him in all family activities and encourage him to participate in normal interpersonal relationships and to tell friends about his disorder. One man wears a medic-alert bracelet. "It makes it easier to talk about my Tourettes," he said.

Don't allow your child to hide from people. Too much solitude isn't good for anyone, especially a youngster who needs to learn to interact with his peers.

Don't let him refer to his tics as his "habit". That suggests that he could stop with self-control. He can't!

WHAT ABOUT DISCIPLINE?

Many parents think this is one of the most difficult aspects of the disorder. Obviously, you shouldn't punish your child for any of his tics. But many parents are torn between what is caused by Tourette Syndrome or the effects of the medication the child may be taking, and what is simply being naughty. "What is him and what's the disorder?" asked one mother.

"When my child throws a temper tantrum, I think: is it the disorder or her medication?" said one mother. "I tend to excuse everything because I don't know if it's her disorder or if she's being a rotten kid. It's safer to blame Tourette Syndrome."

While it's true that fatigue or stress will worsen some Tourette symptoms and consequently make the child irritable, children with Tourette Syndrome

or any other chronic condition soon learn how to manipulate their parents by playing on their concern.

On the other hand, scientific papers have recently been published stating that some of the extreme ranges of emotion may be a part of the Tourette symptomatology. Since there is belief that Tourette Syndrome might involve a dysfunction of the inhibitory process, some scientists have suggested that there might be a sub-category of Tourette children who have great difficulty inhibiting their moods. While every child gets angry at times, some Tourette children have difficulty "cooling down". Their anger grows out of proportion and becomes a temper tantrum. They may also have spells of laughter or silliness, which they cannot control.

Any behaviour that is unacceptable in a family, school, or work session must be controlled. Encourage your youngster to calm down by punching his pillow in the bedroom, rather than his brother in the kitchen; have a "quiet" room where he may go; remove him from the scene until he is once more in control. It's difficult enough having a child with Tourette Syndrome. If you don't maintain discipline, you'll have a spoiled youngster as well. You may show him you understand that his emotions are sometimes difficult to control, but at the same time these outbursts are unacceptable to the family as well as society. Therefore, he must learn to "explode" in private and rejoin the family when he has gained control.

WHAT ABOUT EDUCATION: WHAT DO I TELL THE TEACHER?

Parents must learn all they can about Tourette Syndrome by reading all available literature, reviewing the National TSA quarterly newsletter, and by going to local Tourette meetings. *YOUR KNOWLEDGE* about Tourette Syndrome is the main resource which will be used to benefit your child.

Teach those who come in contact with your child about Tourette Syndrome ... the teachers, school nurses, counsellors, physical education instructors, etc. They need to understand Tourette because if they don't, their mistaken perceptions of your child alter the way they feel about him, and how they interact with him.

If the teacher is understanding and explains the problems to the other students, chances are your child will be more readily accepted by his peers. "Being different", particularly in adolescence, is an even worse trauma to most youngsters than the disorder itself. An understanding teacher can do much to pave the way for a better self-image and greater personal adjustment. Also instruct the school nurses about the problems of the disorder and the effects of the medication.

Intelligence is not affected by this disorder, nor does the patient deteriorate mentally. I.Q. scores of Tourette Syndrome patients run the same as the general public. However, some medications may cause a dulling effect and achievement in school may be affected. In some cases I.Q. testing procedures must be modified for the Tourette child.

Don't feel you have to lower your "expectations" for your child because he has T.S. If a parent has low expectations for a child, the child will perform minimally. By encouraging him to achieve his potential, using supplemental aids (such as extra time on tests, special education services to strengthen weak academic areas, etc.) he will set the high goals for himself.

Some people may interpret your child's symptoms as behaviour abnormalities, and these misconceptions can serve as a barrier to his success. Most people with T.S. have overcome these barriers and can perform most jobs as well as any person, become good marriage partners and parents.

Your child may have difficulty concentrating, suffer from fatigue and actually fall asleep in class until he is used to the medication. If your child has poor concentration he should be given extra time on tests. If your child has an arm tic, suggest that he be seated on the opposite side to classmates so he won't hit them. If it bothers him to have children sitting in back of him, ask that he be seated in the back of the classroom. The common problem of poor handwriting due to motor tics can be corrected by doing work orally on a tape recorder. Poor relations with other students who tease can be corrected by teachers staying within earshot and stepping into provocative situations without delay, especially in the lunchroom and on the playground.

Some children have added difficulty in the classroom because they suffer from hyperactivity and/or learning disabilities in addition to Tourette Syndrome. It has been reported that some teachers cannot tolerate the child's behaviour in the classroom because the symptoms are so disruptive. Many of these children have been excluded from the classroom in the past and were either taught at home or sent to special schools or classes. Sometimes children in school are discriminated against by their peer group. Because their behaviour is incomprehensible to other children, they are frequently ridiculed, imitated and called names.

But times have changed and Federal Law P.L. 94-142, the "Education for All Handicapped Children Act" mandates a "free, appropriate education" for all handicapped children in America. Thus a child with Tourette Syndrome can and should be educated in the "least restrictive environment", using supplementary aids and services.

Find out what your rights in school are and talk to other parents who have fought their battles at the principal's office. Be a visible and vocal advocate assuring that your child receives the best education possible. If you don't, the school will not offer him services he needs.

For more information about education, write to our Association requesting "Coping with Tourette Syndrome in the Classroom" and information regarding special education services.

WHAT ABOUT MEDICATION?

The symptoms of Tourette Syndrome can be reduced in many cases through the careful use of drugs. Medication can control about 70% of symptoms for most patients, as long as they continue to take the medication. In about 5% of cases, there has been complete remission, with medication no longer required.

It is not possible to predict at present what the response to any medicine will be for individual patients. Some children and adults have mild symptoms and are able to function well without the use of medication.

Haloperidol (Haldol) is presently the "treatment of choice", but Clonidine (Catapres) has recently been reported to effectively reduce Tourette symptoms. Pimozide (Orap), not yet approved by the FDA, has also been used with some success. The dosage of these drugs varies for each patient and must be carefully titrated by a doctor skilful in the use of chemotherapy. Haldol is administered in very small doses, gradually increasing to the point where there is a maximum decrease of symptoms and a minimum of side effects. Some patients do not suffer from any side effects.

Side effects of Haloperidol may include muscle rigidity, fatigue, depression, motor restlessness and increased appetite. There is medication available to reduce some of the side effects.

Obviously you should follow your doctor's instructions concerning medication for your child. Yet, there are many things your doctor may not tell you ... or that you will forget. For example:

Once your child is old enough to take responsibility for taking his own medication, he should be allowed to. Yet, a child may often forget to take it occasionally. Help him remember by using a pill container with sections for each day or by marking a calendar. The latter is effective because he can also list comments such as new tics, reactions or side effects, etc. The only problem with this may be his becoming overly concerned with his condition.

The medication may make your child tire easily. Bedtime may need to be moved up.

Check with your doctor about taking other medicines along with the medication being taken for Tourette. Most doctors will agree that aspirin may be taken with Haldol and other medications, but it is important to ask the treating physician.

Don't overmedicate your child with the hope of eliminating all symptoms. Realize that no medication will eliminate 100% of the child's symptoms. There is no pill that will remove all trace of the disorder and there is no magic cure for Tourette Syndrome. A certain number of symptoms (in varying degrees) will always be present, especially when your child is under stress. Before seeking other therapies, ask yourself if you are doing it for your child or for yourself. Does HE want to take more medicine? Do the symptoms

bother you more than they do him? What are the effects of symptoms on his life? ON yours?

We increasingly hear of parents seeking alternative treatments for their child when commonly used therapies don't work, or when well-meaning relatives or friends try to convince you that a "new method" they read about can help. People afflicted with any chronic illness are often desperate and may seek unconventional treatments, services, or devices, (i.e. the great market for any product which claims to alleviate the pain of arthritis, even though there is no scientific basis that it works).

Be aware that every time you take your child to a different doctor or try a different medication, you are reinforcing the child's feeling that he is "different" or "sick". He soon becomes a perpetual patient. This isn't to say that a change of doctors or medications isn't sometimes warranted, but to do so on a habitual basis can often cause real harm to a child, whose main goal should be to learn to cope with varying severity of symptoms throughout his life.

Since 1825, when leeches were used in a desperate effort to reduce the tics of Tourette Syndrome, many other treatments have been tried with little or no success. These include stimulants, muscle relaxants, electric shock treatments, lobotomies, behaviour modification and hypnosis. Other medications are being experimented with in controlling the tics of Tourette Syndrome. Our TSA Newsletter will keep you informed of new research and treatments as they are found to be effective.

HOW RARE IS TOURETTE SYNDROME ?

Tourette Syndrome is found throughout the world. It is estimated by some experts in the field of neurology that they may be as many as 100,000 undiagnosed cases in the United States alone. Recent genetic studies suggest as many as 3.5 million people might be affected by tics or Tourette Syndrome, leading some scientists to conclude that Tourette Syndrome and more simple tic disorders may be a continuum of one disorder.

History, has documented many possible cases of Tourette Syndrome. Dr. Samuel Johnson is now thought to have suffered from this disorder in the 18th Century, yet he is known for being the greatest English writer of his day.

The first reported case was written up in 1825, but it wasn't until 1885, that Dr. George Gilles de la Tourette, a French neurologist, described nine patients and observed that they all seemed to be suffering from the same disorder, the one that now carries his name.

As more cases are described in the media, and as doctors become more aware of the disorder, more diagnoses are being made.

WHAT IS THE TOURETTE SYNDROME ASSOCIATION?

The Tourette Syndrome Association, Inc. is a voluntary national organization comprised of individuals with this disorder, their family and friends, health care professionals, and other interested people. The goals of the Association are:

- To educate physicians and the general public about Tourette Syndrome with a view toward promoting more accurate diagnosis and better treatment.
- To stimulate and support research on Tourette Syndrome to find the cause, a cure, and better means of treatment.
- To be of service to patients and their families.
- To raise funds to support the three main goals.

TSA members share more than the common feelings all parents of handicapped children experience. Sometimes they share their resentment of the well-meaning professionals who misadvised them before their child was properly diagnosed. One doctor suggests that 80% of Tourette Syndrome patients make the diagnosis themselves after learning about TS from the press, on TV or radio.

Association members share the tremendous guilt felt by TS parents, who, like any parent, try to find a medicine, a treatment, or a bandage for their hurting child. The frustrations they faced alone are faced together when TSA chapters meet at local gatherings throughout the nation.

One of the greatest resources you'll find for coping is the other TSA parent who will understand your feelings before you express them!

Conclusion

Naturally, each case of Tourette Syndrome is unique to the person who has it. It's important to realize that you are not alone, and your child is not the only one who suffers from this unusual disorder. Many women, men and children have suffered the taunts of others, the puzzled looks and the embarrassments that Tourette Syndrome often creates. Usually, if other people know your child suffers from a physical disorder, they tend to be understanding and sympathetic.

Yet, there are many unfeeling people in our world, those who tease the crippled, mock the stutterer and taunt the sufferer of Tourette Syndrome. You can't change people like these ... but you CAN learn to tolerate unkindness, by taking strength from the numerous people who support you... others you don't even know by name, who also suffer from Tourette Syndrome, their friends and relatives, the many volunteers who work to spread the information so badly needed by those yet undiagnosed ... and the hundreds of doctors and researches who are working toward helping those patients who now suffer, and looking forward to finding a cure for Tourette Syndrome.

Remember, you are not alone!

The Association invites anyone with interest in this disorder to write for further information to:

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Glossary

Akathisia	A state in which a patient feels an inner restlessness
Akinesia	Extreme body tiredness
Compulsion	An irresistible impulse to perform some act
Coprolalia	Saying obscene words involuntarily
Echolalia	Repeating words
Remission	Period in which symptoms disappear
Tic	Involuntary movement in one or more parts of the body
Titration	Process of determining (by measuring) how much of a solution is required to produce a given reaction