TEEN

TEEN | Workbook for Program Participants

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(Wisconsin Initiative for Stigma Elimination)

TOURETTE SYNDROME CAMP USA
21 Years of Twitching!

BRAD COHEN TOURETTE FOUNDATION

Tourette Association of America
Wisconsin Chapter

Up to Me: Talking about Our Tourette and Associated Challenges?

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Preface

This is the workbook for the Teen version of the Up to Me program. We put these exercises together to help young people like yourself to talk about challenges. The strongest, current evidence for what works to reduce stigma is for people to have direct social contact with people who can talk about their experience with Tourette and the insights they have gained on the path to symptom management. This can also be a very helpful way to reduce self-stigma. **

We have set up the program so that it can be done briefly in five lessons, with each lesson requiring about 1 hour. In this workbook, you will find learning points for each lesson, discussion questions, and activities such as worksheets.

Materials in this workbook along with the videos can be downloaded for free from the Up to Me tab at WISEwisconsin.org.

All children have the right to be safe. As a participant in this program, you will have the opportunity to share information about experiences in your life during which you may not have felt/were not safe or protected. In order to support and protect all children, if information about abuse or neglect of a child is shared during this program, an adult group leader will share this information with local community professionals who will work to assure that child's safety. If you have questions about what this means, please talk with one of the group facilitators.

*** For definitions of public stigma, self-stigma, recovery and other terms used in this workbook, see Appendix A.*

For information and to download manual and workbook, contact WISE (wise@wisewisconsin.org) or visit the Manual and Resources page at wisewisconsin.org/up-to-me.

Setting the Tone: Starting Each Lesson

The first thing we want to do at the beginning of each lesson is set the tone. To do this, we will do an exercise that offers you a chance to focus your mind and engage in the session. It is also helpful to remind ourselves of the overall purpose of the *Up to Me* program:

> "Our goal here is to consider the choices that we have when it comes to disclosing, or talking about, our experiences with Tourette and associated challenges to others. We will also work together to learn helpful ways to disclose this information most effectively and protect ourselves against hurtful reactions from others, should we decide to disclose."

Some general ground rules that will help each of us to fully engage with the group are:

- **Confidentiality** – what is said in this room stays in the room,
- **Everyone's opinion counts**, and
- **We respect each other.**

We want to create an open environment where people feel comfortable sharing their opinions and feelings should they choose to do so.

One of the things you may have strong feelings about is how you discuss your Tourette and associated challenges. You may use words like emotional struggles, labels like Tourette Syndrome or OCD, or terms like tics. Throughout the workbook, we use the term "Tourette and associated challenges" to refer to people living with Tourette.

The stories in the workbook use many terms. These terms were not changed to honor the choice that individuals have in how they talk about their own experiences.

Consider the words you use. You may refer to yourself in any way that feels comfortable. The workbook may help you decide what words you want to use. You might find it helpful to discuss your preference with the group.

LESSON 1: The Story I Tell Myself

LESSON OVERVIEW

This lesson will help you identify the story you have been telling yourself about your Tourette and associated challenges and consider how to challenge any hurtful self-talk.

1. Helpful and Hurtful Self-Talk

Maggie and Darryl had an assignment to write a diary entry to summarize their lives during the past four years.

I am 17 years old and have been struggling with Tourette since fourth grade. I went through some really tough years where no one knew what was going on with me. I blinked my eyes and sniffed a lot. Doctors gave me glasses and allergy pills to help me but, I kept on blinking and sniffing. I'd get yelled at in school for making noises in class or tapping my pencil on my desk. I started getting bullied at school because of all this. Since I have been diagnosed, things are working out pretty well. I even helped talk to everyone at my middle school about Tourette with the help of a Youth Ambassador from the Tourette Association. My symptoms can be better or worse at different times. Sometimes this frustrates me. I see my therapist once every two weeks, to help me work through my frustration. I cannot wait to be out of high school and go on to college or a job. Yes, I am living successfully with Tourette, but I do not think many people realize how much work I put into managing my tics. I am part of a great group that meets at our youth center on Sunday afternoons. The other teens seem to like me and offer me lots of support. We don't hang out together at school. I don't think I will ever have good friends to hang out with. I shared my story for a speech class assignment and was asked if I wanted to share it again at the school's mental health month event. I feel pretty proud of how far I have come, but I am not sure if I am ready for the bullying that might come from sharing my story at the health month event.

I'm 15. Last year, a doctor told me I have Tourette. I knew something was wrong with me. I make this grunting noise and I stamp my foot. When I was younger I did other weird things. My family and friends have a hard time with my tics. They are always trying to get me to stop them. I hate places where I have to be quiet and sit still, like church. I take medication now and it helps some. It seems to me that I should be able to stop the rest.

Most kids at school don't bother me, except once when a kid was picking on me and I punched him. He got what he deserved. They gave me a week of detentions for that.

I have to do things in 3's and if I miss a step, I have to start over. So, I am late a lot and I make my dad mad. My grades are ok and teachers pretty much leave me alone. I like track and they needed a bigger team so, coach let me on the team. No one at school knows I have Tourette. I just take my meds and don't talk about it much. No one understands what this is like, so I deal with it alone.

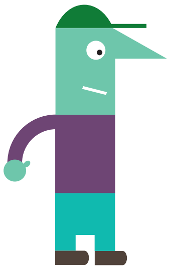
Worksheet 1.1

Analyzing a Story for Hurtful and Helpful Self-Talk

1. What are the **helpful beliefs** that Maggie and Darryl hold about themselves and their experiences with Tourette and associated challenges?

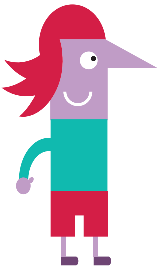
Maggie

Darryl



2. What **hurtful beliefs** do they hold about themselves and their Tourette and associated challenges?

Maggie



Darryl

Worksheet 1.2

Your Self-Talk Puzzle

On each puzzle piece, first list different parts of who you are (such as friend, artist, student, grandchild, athlete, singer, etc.) next to #1. Be sure to include “a person with Tourette” (or however you refer to that aspect of yourself) on one of the pieces. Next, list beliefs that you hold about yourself related to each #1. Write the belief as a self-talk quote on each puzzle piece next to #2. For example: #1 Student #2 “I work hard at math.” Or #1 Grandchild #2 “My grandmother thinks I am a freak.” Or #1 person with ADHD #2 “I cause trouble.”

#1
#2

#1
#2

#1
#2

#1
#2

#1
#2

#1
#2

After you fill the puzzle with examples of your self-talk quotes, place a ✓ next to each that you think is helpful and a ✗ next to each that is hurtful.

2. Five Steps for Changing Personally Hurtful Self-Talk

5.

The final step is to translate your findings into a belief statement that **counters** the hurtful belief.

Maggie's example of a counter: *"My Tourette will not keep me from having good friends!"*

Maggie may wish to write this saying down on a card so that she can remember it better. Then, the next time that she is questioning if she needs to keep her Tourette a secret in order to make friends, she can look at the card.

4.

Collect evidence that challenges the true-false statement.

Maggie's example of collecting evidence: Maggie asked her sister's friends and a teacher if they have any friends who have a Tourette. She discovered that most of them have a friend with Tourette or OCD of some kind. Matter of fact, many said that they had more than one friend with a challenge, and two of them even disclosed that they have a challenge. After speaking with them, she understood that her hurtful belief *(that people without Tourette would not be friends with her)* is not true.

3.

To challenge a statement, you want to first **ask others** whether or not they believe it to be true. Ask people whose opinions you value. You will likely give up hurtful beliefs about yourself when you discover that your underlying beliefs are actually false.

Maggie's example of selecting people to seek out their opinions:
Maggie decided to ask friends of her college-aged sister and a trusted teacher at school.

2.

These negative beliefs about self can be **turned into true-false statements** about people with Tourette challenges in general.

A true-false statement from Maggie's example: "People with Tourette and associated challenges cannot be friends with those who do not have Tourette and associated."

1.

Begin with a clear statement of the hurtful belief using the formula:

***I must be* ___________ *because* ____________.**

An example of Maggie's hurtful belief:
"I must be *unable to make friends* ***because*** *people don't want to be friends with people who have Tourette."*

Now that we have addressed Maggie's hurtful belief, let's challenge one from Darryl. Darryl believed: *"I* ***must*** *be a bad person* ***because*** *I am not able to control my tics"*

Table 1 shows the process Darryl went through to challenge his assumption and change the hurtful belief.

Here is Darryl's completed worksheet.

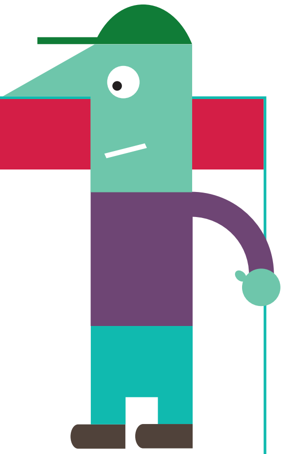


Table 1: Change Our Self-Talk Exercise

1. **State the hurtful belief.**
   I MUST BE a bad person **BECAUSE** I cannot control my tics.

2. **Define the true-false statements.**
   People who cannot control their tics are bad.
   The blame for the problems lies on the person, not the illness.

3. **Who are the trusted people you will ask to see if they believe the statement is true?**
   - I'll ask my football coach.
   - My older sister is usually honest and direct with me.

4. **Collect evidence that challenges the statements.**
   - My coach said he he does not blame me for my Tourette and that he is proud of how I face it.
   - My sister said people should not be blamed and that they often don't know the whole story. My sister said she does not blame me for my Tourette and is proud of me.

5. **Change the hurtful belief to a helpful belief statement. This is a COUNTER.**
   - I'm not bad because of my Tourette. In fact, I have reasons for having pride in how I 'tackled' my challenges.

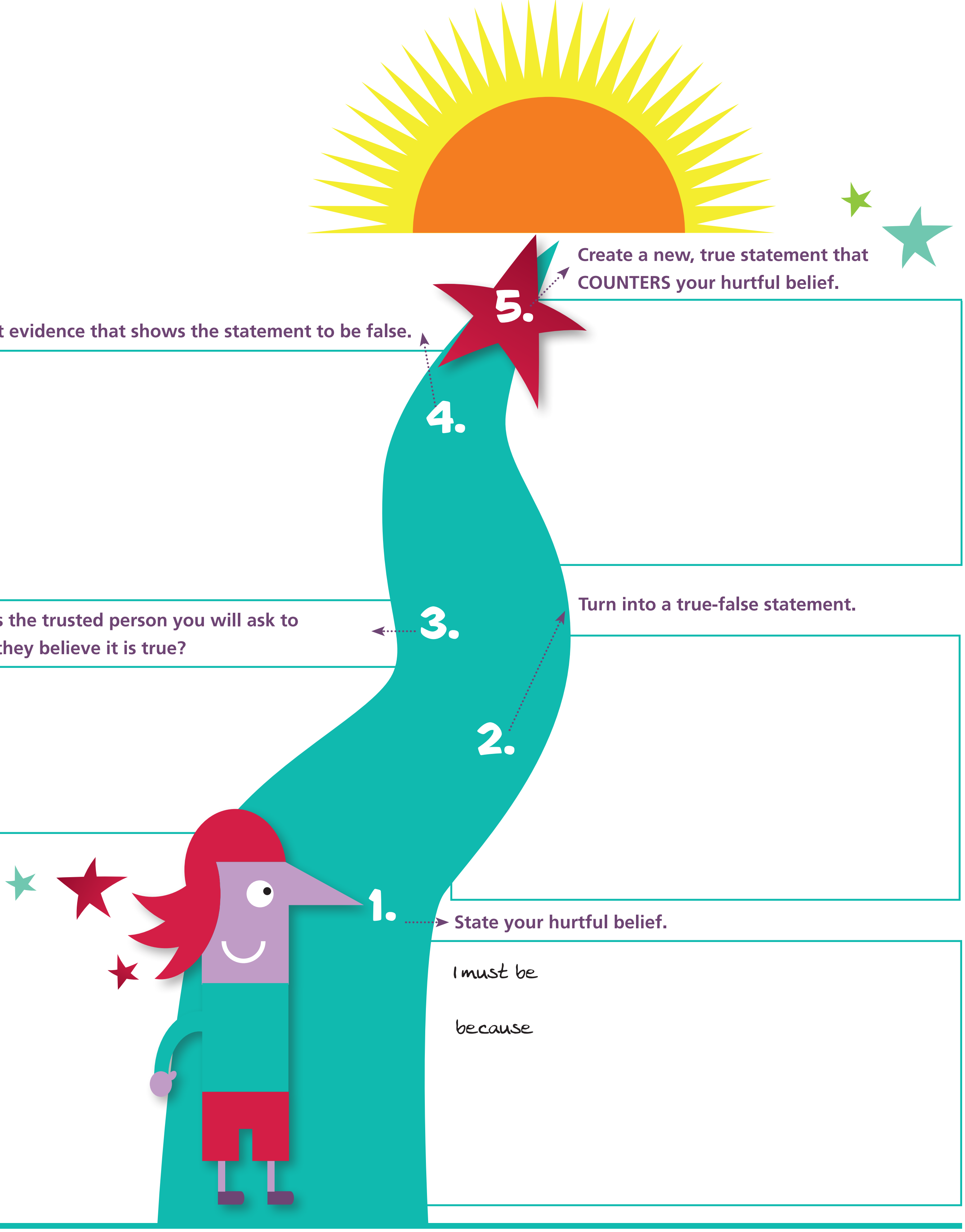
Use Worksheet 1.3 on the next page to counter a hurtful belief that you hold about yourself. Use the hurtful beliefs you checked on your self-talk puzzle.

For the purpose of this exercise, use other group members to challenge and collect evidence against the true-false statements. Please also consider whom you might ask outside the group at a later date. If you decide to follow through with this exercise outside of this group session, you will need to make sure to go to someone who you think will prove these hurtful statements to be **false**.

Worksheet 1.3

Change Our Self-Talk Exercise

Complete all five steps to counter a hurtful belief that you hold about yourself.



Create a new, true statement that COUNTERS your hurtful belief.

Collect evidence that shows the statement to be false.

Turn into a true-false statement.

Who is the trusted person you will ask to see if they believe it is true?

State your hurtful belief.

I must be

because

LESSON 2: Disclosure Choices

LESSON OVERVIEW

In this lesson, you will look at the pros and cons of talking about your Tourette, associated challenges and your strengths to help you decide what the best decision is for you at this time. You will explore different options for disclosure and how different settings impact your decision, including social media.

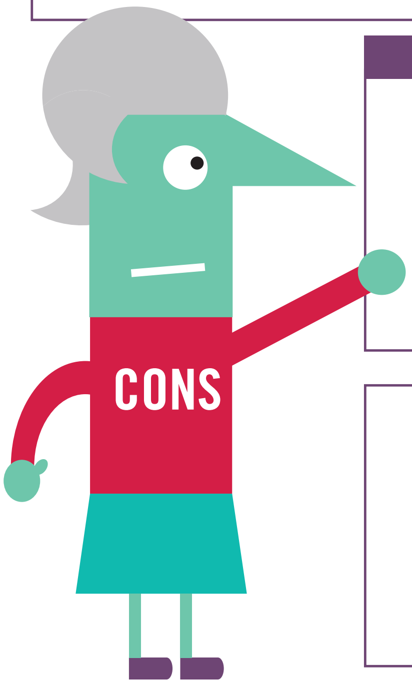
Worksheet 2.1

Pros and Cons of Disclosing

Team One: List of all the pros and cons of disclosing your Tourette and associated challenges to someone else.

Team Two: List all the pros and cons of talking to someone about your Tourette and associated challenges when someone else brings it up.

Team One	Team Two



Team One	Team Two

Five Points to Remember About Disclosure Decisions:

1. **Don’t dismiss any pro or con no matter how “silly” it may seem.**
Sometimes what you might feel embarrassed to say is actually important. If the item is really not important to you, you’ll ignore it in the final stage of your decision-making.

2. **Your decision depends on the setting.**
Pros and cons of disclosing your experience vary by the situation you are in. For example, telling people your history with Tourette is a lot different in your classes than with a close friend or with your teammates. You could decide to tell your close friends but not your teacher. You need to think about pros and cons of disclosing your experience with Tourette separately for each setting that is important to you.

3. **Your decision can be yes, no, or to decide later.**
Two decisions are straightforward: YES, I want to or NO, I don’t want to let some people know about my experiences with Tourette and associated challenges. Finding the right answer for you is not as simple as adding up the pros and cons. Some pros and cons will be more important and, therefore, should be considered more strongly when making a decision.

“Even though I came up with three pros and nine cons, I still hope that I’ll find other people who have similar problems. For this reason, I’ve decided to talk to my friends.”

You may not be able to decide about disclosing after reviewing pros and cons; you may decide to POSTPONE your decision and think more.

4. **Know your reason for disclosing.**
When you talk about your challenges and what helps you live with Tourette, what do you want to happen? Is your goal to be understood, to get assistance, to tell the secret you have been holding, or another?

5. **Prepare yourself for expected and unexpected reactions.**
People who decide to disclose have hopes about how the person or group will react to their disclosure. In what ways are you expecting people to react? Are you prepared to respond calmly and confidently to unexpected reactions?

Worksheet 2.2

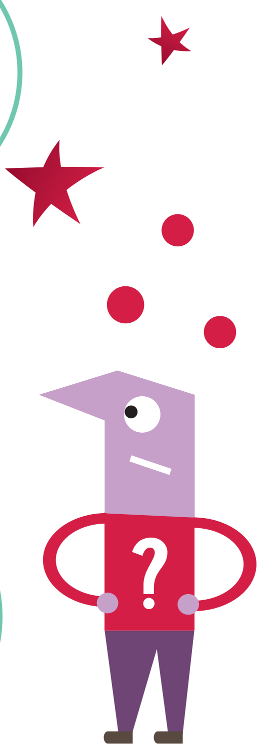
My Pros and Cons Worksheet

for Disclosing Tourette and Associated Challenges

Setting: ______________________ **To Whom:** ______________________

Don’t censor any ideas. Write them all down. Put a star (*) next to pros and cons you think are especially important.

PROS



CONS

Given these pros and cons:

- ☐ I have decided TO disclose my Tourette and associated challenges in this setting.
- ☐ I have decided NOT TO disclose my Tourette and associated challenges in this setting.
- ☐ I have decided to POSTPONE my decision to disclose in this setting.

What is your REASON/GOAL for disclosing?

What do you expect will happen after disclosing?

Worksheet 2.3

Social Media Disclosure

Media I Use the Most: ______________________________

In pairs or as a whole group, discuss pros and cons of using the media you listed as your means of disclosure.

PROS:

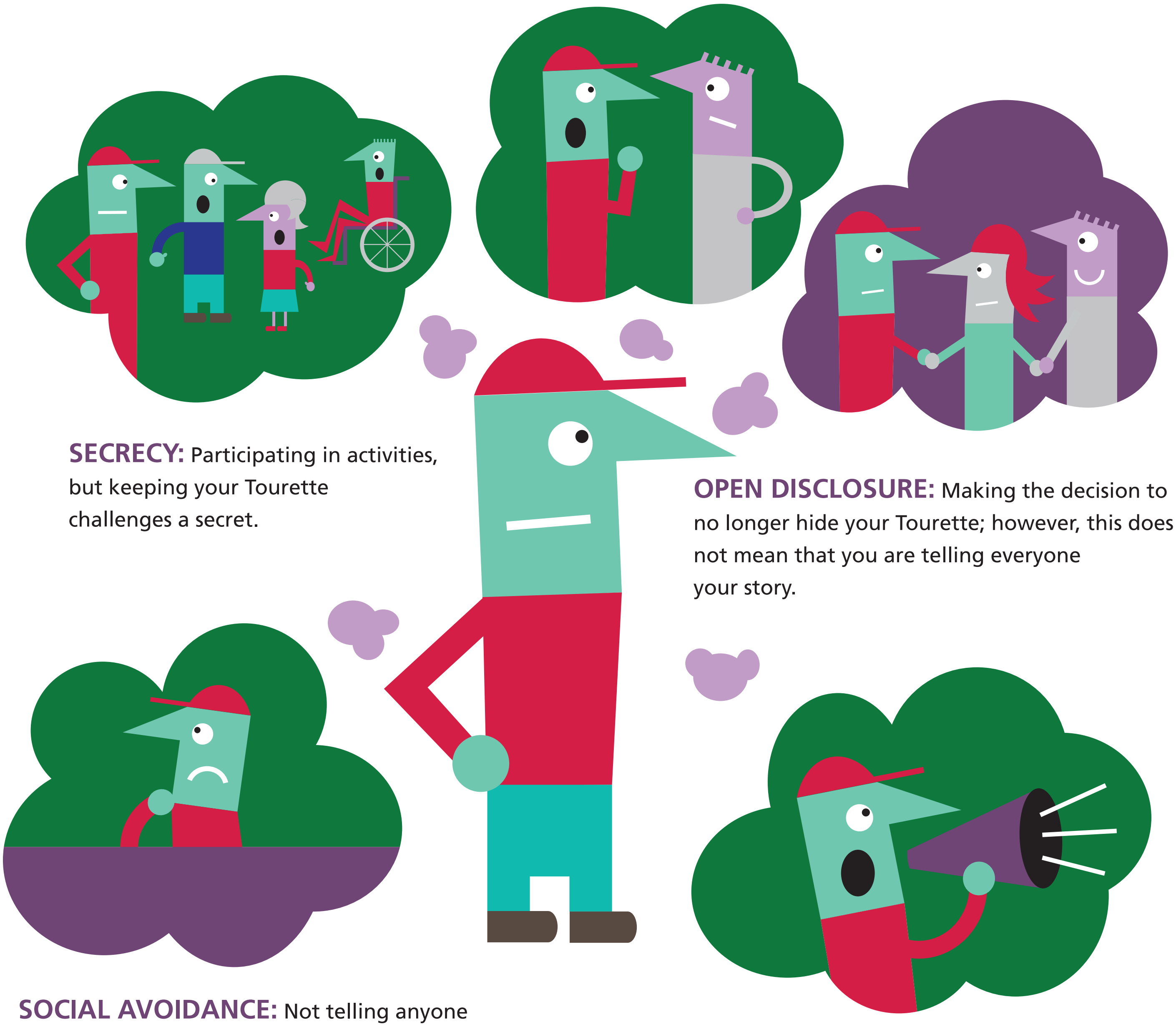
CONS:

Given these pros and cons

- ☐ I have decided **to disclose** my Tourette and associated challenges using social media.
- ☐ I have decided **NOT to disclose** my Tourette and associated challenges using social media.
- ☐ I have decided **to put off** my decision.

What do you expect will happen after disclosing using social media?

SELECTIVE DISCLOSURE: Disclosing your Tourette challenges to selected individuals, like a teacher or boyfriend/girlfriend, but not to everyone.



SECRECY: Participating in activities, but keeping your Tourette challenges a secret.

OPEN DISCLOSURE: Making the decision to no longer hide your Tourette; however, this does not mean that you are telling everyone your story.

SOCIAL AVOIDANCE: Not telling anyone about your Tourette and avoiding situations where people may find out about it.

BROADCAST YOUR EXPERIENCE: Actively seeking out and educating people about your experience with Tourette.

Table 2: Five Choices of Disclosure Pros and Cons

SOCIAL AVOIDANCE	**Pros:** You don't encounter people who will unfairly harm you.	**Cons:** You lose the opportunity to meet new people who may possibly be supportive.
SECRECY	**Pros:** Like social avoidance, you withhold information about your Tourette from others. But, you don't avoid important things like participating in sports or friendships in the process.	**Cons:** Some people feel guilty about keeping secrets. You may also receive less support from others because they are unaware of your Tourette.
SELECTIVE DISCLOSURE	**Pros:** You find a small group of people who will understand your experiences and provide support.	**Cons:** You may disclose to some people who then hurt you with the information. You may have difficulty keeping track of who knows and who doesn't.
OPEN DISCLOSURE	**Pros:** You don't worry who knows about your problems. You are likely to find people who will be supportive.	**Cons:** You may tell people who then hurt you with the information. People who you have disclosed to may break your confidentiality and tell others.
BROADCAST YOUR EXPERIENCE	**Pros:** You don't have to worry who knows about your history of Tourette. You are promoting a personal sense of empowerment in yourself. You are striking a blow against stigma.	**Cons:** You are going to encounter people who may try to hurt you with this information. You are also going to meet people who disapprove of your political statement.

Disclosure choices when someone else brings up the subject to you:

- Giving a medical explanation: "I have Tourette Syndrome" or "I sometimes have tics" or "I make movements and sounds I can't stop."
- Do not respond
- Using humor
- Make up another reason for your tics: Saying that you have allergies as a way to explain a cough or sniff

Consider the five disclosure choices in groups YOU are a part of by listing the pros and cons in *Worksheet 2.4*. For the setting, name a group you are part of.

Worksheet 2.4

Pros and Cons of the Five Choices of Disclosure for Me

Setting: ______________________________

SELECTIVE DISCLOSURE

PROS:

CONS:

SECRECY

PROS:

CONS:

OPEN DISCLOSURE

PROS:

CONS:

SOCIAL AVOIDANCE

PROS:

CONS:

BROADCAST

PROS:

CONS:

LESSON 3: Disclosure Decisions

LESSON OVERVIEW

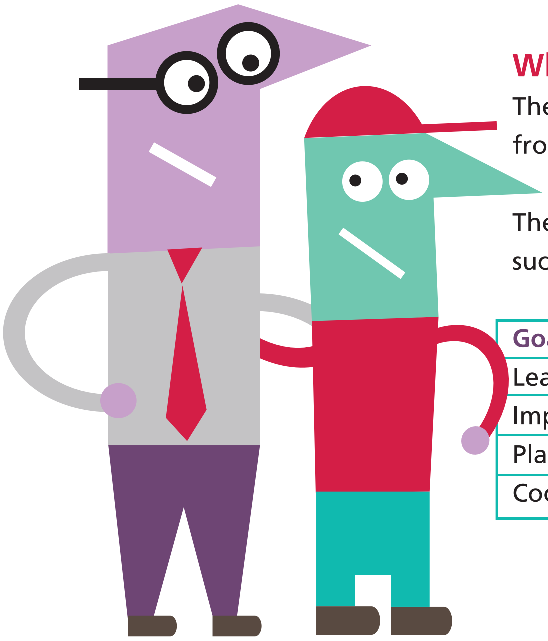
In this lesson, you will review what we did in the first two lessons using the Disclosure Decision Practice Game. Then, you will explore how to choose a safe and helpful person to whom you can disclose. You will consider how others might react to your disclosure and prepare for how you can respond to different reactions.

1. Disclosure Decisions Practice Game

You will practice considering disclosure choices further through an interactive card game.

2. To Whom Might You Disclose?

In the previous section, we showed that people might disclose their experiences with Tourette and associated challenges and steps of recovery in different ways. If you are considering selective disclosure, this section helps you to identify a possible person for disclosure.



Who is a Good Person to Disclose to?

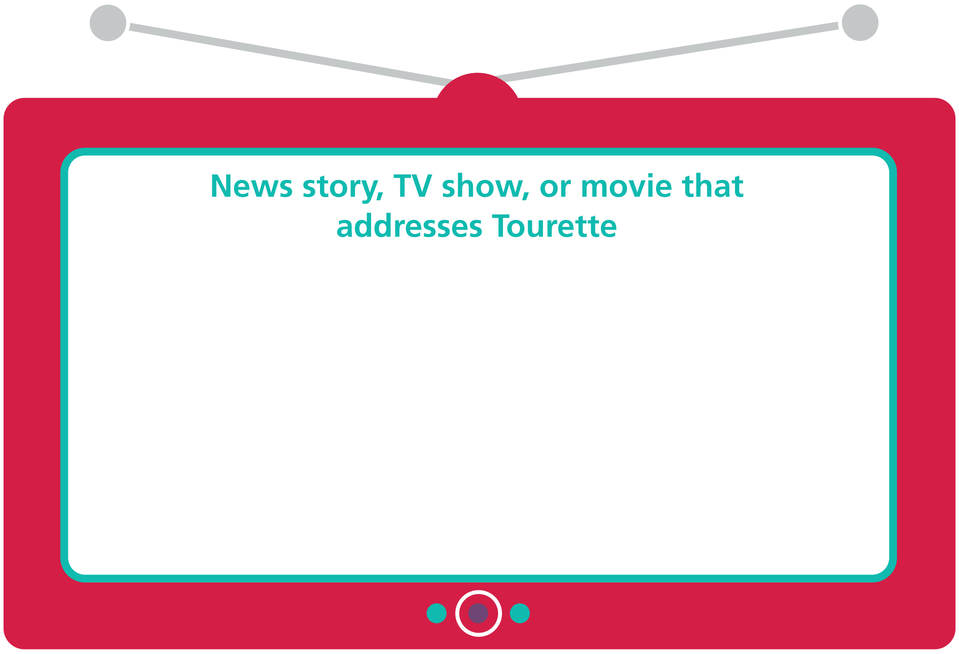
There are some people we might want to tell in order to get what we need from them.

These are relationships that you have because they help you reach your goals, such as:

Goal	Relationship
Learn at school	Teacher
Improve your health	School social worker, therapist, or psychiatrist
Play a sport	Coach
Cooperatively live with others	Family members

Worksheet 3.1

Testing Someone for Disclosure



News story, TV show, or movie that addresses Tourette

Name of Person:

____

Questions you might ask to test the waters:

What do you think of stories (shows, movies) like these?

What do you think of people like this in the story (show, movie)?

Do you know anyone like this?

Now rate the person's responses on the seven-point agreement scales below.

The person's responses were sensitive.

strongly disagree			moderately agree			strongly agree
1	2	3	4	5	6	7

The person's responses were kind.

strongly disagree			moderately agree			strongly agree
1	2	3	4	5	6	7

The responses are the kind of responses I would want to get if I disclosed.

strongly disagree			moderately agree			strongly agree
1	2	3	4	5	6	7

Add up the scores.

Enter total here:

Below are some suggested cut offs for the score totals.

16-21: Probably a good person to disclose to.

3-9: Probably not a good person to disclose to.

10-15: Uncertain.

3. How Might Others React to Your Disclosure?

Disclosure **will** impact the people around you. It is helpful to consider the ways in which people may react and plan how you want to respond. *Table 3* lists a variety of reactions to disclosure that are sorted into groups by helpful and hurtful emotional reactions. Think of examples of what these reactions might sound like.

Table 3: How People Might React to Your Disclosure

EMOTIONAL REACTIONS

Helpful	Hurtful
Understanding	Disrespect
Caring Support	Denial
Assistance	Punishment
Sincere Interest	Fear/Avoidance
	Blame

Ways to Prepare For and Manage Hurtful and Unhelpful Reactions

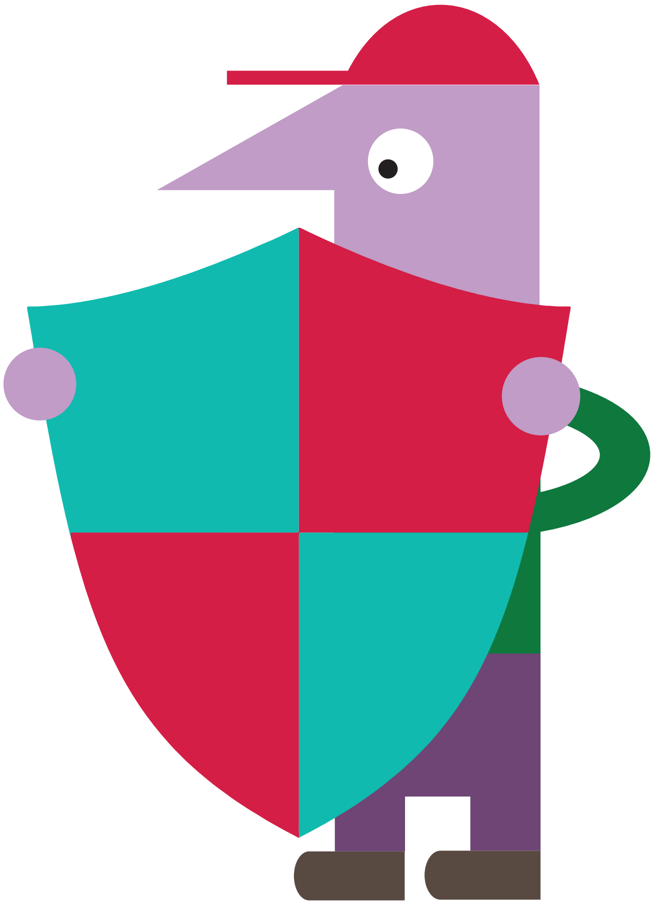
- Consider talking with someone who supports you about your disclosure before you disclose.
- Take a breath and allow yourself time to feel, process, and formulate your response to any hurtful or unhelpful reaction.
- Be kind to yourself by using positive self-talk (remember your "counters" from *Lesson One*).
- Walk away. Delay your response until you are ready or do not respond at all.
- Ask someone you already trust to help you think of effective responses.
- Remember that the person may be having a difficult time understanding what it has been like for you if they have not had a similar experience.
- Allow yourself to make mistakes in deciding to whom you should disclose. When you feel ready, review what went well, what didn't, and use what you learned in future opportunities for disclosure.

Respond to Reactions Activity

You will be given a set of cards with different relationships on them such as a coach, a grandparent, etc. You will consider how you would respond to the different reactions if someone from your own life said one of them to you when you chose to disclose to them.

Protections Against Unwanted Disclosure

In making decisions about disclosing your experiences with Tourette and associated challenges, you need to consider how your right to privacy is protected. Most governmental bodies have passed laws guaranteeing that interactions with mental health professionals remain confidential; however, if you are under the age of 18, a mental health professional is required to report any known or suspected child abuse, and they must report if they believe that you are a danger to yourself or others. Most teachers and other school workers are also mandated reporters. This means that if you disclose that you feel like hurting yourself or someone else or that you have been abused, a mandated reporter would have to share that information with people in your community who could keep you safe. Appendix B has further information for you about this topic.



LESSON 4: Telling a Story of Challenge, Resilience, and Recovery

LESSON OVERVIEW

As a result of *Lessons 1-3*, you might have decided that you want to talk to someone or a group of people about your Tourette and associatedc challenges. Hence, this lesson has one goal.

If you are interested in disclosing, to become more comfortable in telling your story, and to practice methods for selective and/or broadcast sharing.

1. How to Tell Your Story

Different Ways of Telling your Story

There are a lot of different ways to tell your story depending on whether you are choosing selective disclosure or broadcast disclosure. You may feel comfortable giving a speech to a larger group or sharing in front of a small group. You may have decided you're only comfortable with selective disclosure to one person you feel you can trust. Below are many different ways to share your story.

When putting together your story, remember two key things:

1. **Consider your reasons or goal for your disclosure. *(from Lesson 2)***
2. **Use your counters to avoid sharing hurtful self-talk. *(from Lesson 1)***

Before going into the next section, we again want to stress that you are in control of what choice you make as to whether you will share or not. While we provide the opportunity for people to be able to share their story in front of the group, there is no requirement to participate if you've decided it is not the right time to do so.

EXAMPLE

Here, we provide one example of how Shoshi tells her story as a speech. *(pages 22-23)*
You can also view other stories at: rogersinhealth.org.

Shoshi's Story

My name is Shoshi. Until I was 12 I felt very "normal." I had a lot of friends, did well in school and was generally a very happy kid. One day, when I was in 7th grade, I walked into the cafeteria, heard someone make a loud noise and without thinking or knowing what I was doing, I echoed it. And echoed it. And echoed it. I couldn't stop making that noise and all sorts of other noises. I hissed like a cat, barked like a dog, made a deep guttural noise, and often repeated what other people said. Along with the noises came all sorts of uncontrollable movements. I jerked back my head, flung out my arms, twisted my body, scrunched my nose, and squinted my eyes. Within two weeks of that day in 7th grade, I went from having full control over my body to someone who felt like a string puppet being controlled by someone or something without my permission.

Over the next three years the noises and jerking movements came and went but, were always there in some form or another. Along with those things, I began having trouble focusing, became very anxious and depressed, and my grades started slipping. When I was in middle school the kids were nice to me because, they had known me for a long time. However, when I started high school, the new kids teased me constantly. Even some of my long-time friends stopped talking to me. During class, kids would yell out, "Shut up" when I made a noise and one time a group of kids tried to light my hair on fire. I was a freak. At least that's what it felt like. I was embarrassed and lived in my own world because, no one wanted to be a part of mine.

When I was 15, a doctor finally figured out what was happening to me and I was diagnosed with Tourette Syndrome. It felt so good to know there was a real reason why I was doing the things I was doing. I started on medication, which helped to control the tics, but the pills made me very tired. I would put my head down during class and sleep. And, the medication did nothing for my depression, anxiety, attention problems and lack of self-worth. Time went on and I finished high school and went to college. The tics started lessening, as they do for a lot of kids with Tourette. By that time, I had also developed better control over the tics that were noticeable. I still had to deal with the depression, anxiety and attention problems, however. Since I had never really learned how to study in high school, I ended up flunking out of college. I came back home, got a job, and was nearly fired because I was unable to sit at my desk all day and get my work done.

At that point, I realized that I had to rise above my symptoms -all of my symptoms- or I would not be able to succeed in my life. I started in therapy and I will never forget something my therapist said: "You are like a runner without a track record. You don't know how fast or how far you can go because you have never put your best foot forward." That helped me realize that my "failures" were only a reflection of what I had done and did not have to limit my future efforts and accomplishments. He also helped me realize that Tourette is only a part of me. That there are all sorts of other wonderful parts. If I could develop those other parts then, the Tourette part will start getting smaller and smaller and be less significant.

Over time, and with a lot of hard work, that is exactly what happened. I went back to college, graduated, and then went on to get two master's degrees. I'm now a school psychologist, am successful in my career, have a wonderful marriage and have raised amazing children. I am confident that the struggles I endured shaped the person I am today; and that's a good thing. It has increased my sensitivity to others and enables me to understand and help people, in a way that I don't think would be possible had I not endured the really tough years. Although Tourette and the other challenges certainly made my life more difficult, I, like many others who have learned to live with TS, demonstrate the possibility that it CAN be done. There IS life beyond Tourette. And it can be a very, very good life.

EXAMPLE

Consider the following questions:

1. **What are some of the things you liked about her story?**
2. **How does it reflect a story of recovery?**
3. **What parts of it might have been hard to tell?**
4. **What parts might you have said differently?**

Grenesha's story is an example of a person telling their story in a speech format, to a small or large group. Remember, there are a lot of other ways to tell your story.

Worksheet 4.1 provides a template to fill out to help you outline a story that might work for you. Your story will vary depending on where you tell it. For this exercise, select a setting and person/group you are thinking about talking to. You may wish to role-play a more natural conversation with a partner, where your partner takes on the role of the person in your life you are considering disclosing to.

Worksheet 4.1

A Guide to Setting Up a Story

Hi, my name is ______________________________ and I deal/live with __________________________________.

Here are a few things about me and my childhood. List some events in your youth that are typical of most people's lives and/or that might reflect the beginnings of your Tourette and associated challenges.

My Tourette and associated challenges started when I was about _____________ years old. List some of the things that you first noticed or experienced related to your challenges.

These challenges did not go away quickly. List some examples of how this impacted you in the past years.

This is how I found what works for me. List who and what were your sources of support.

What works (has worked) for me includes: List what you do that helps and what others can do to support your Tourette and associated challenges..

(Worksheet 4.1 continues on page 25)

Worksheet 4.1 (continued)

Along the way, I have experienced some unhelpful responses to my Tourette and associated challenges. List some of the unfair experiences and harsh reactions you have experienced from others. (stigma)

Despite my challenges and sometimes because of them, I have many strengths and have some achievements that I am proud of. List some of the things that you have accomplished in terms of your classwork, relationships, and other personal goals. Also list some of your strengths.

KEY POINTS

I want to end with these two key points:

1. **I, like all people with Tourette and associated challenges, live, go to class and study just like you.**
2. **So, please treat me like anyone else. Do not treat me differently based on any unfair stereotypes.**

WHAT DO YOU WANT TO SAY?

You probably do not want to communicate EVERYTHING in the worksheet. Remember your REASON/GOAL for disclosing (from Lesson 2).

1. **CIRCLE** the information in the sheet you think is important for the person or audience to hear.
2. **PUT A LINE** through any information:
   a. you believe is too personal or
   b. the person might not understand and isn't important for them to support you.

Let's try it.

For those who are willing, you will now be given a chance to tell your story to fellow participants. Be sure that at least half of your time is spent sharing your strengths, wisdom and accomplishments. Tell the parts of the story that work for you. When listening to others' stories, the goal is to offer SUPPORT. Listen intently to your peer and praise the person for their message and their courage.

Take turns now.

After you are done, complete the *Quality of Experience Worksheet 4.2* on the next page. The worksheet lists a series of questions about your feelings related to telling your story. Use the worksheet to help you think about what you would say the next time you want to share your story.

Worksheet 4.2

Quality of Experience

Use the following 7-point scales to rate the quality of your experience telling your story about a Tourette and associated challenges.. If there were other feelings that you experienced while telling your story, please write them in at the bottom of the page. Don't discount any feelings you had, even if you think others may think they are silly; these are important in developing your strategy for disclosure.

How empowered do you feel after telling your story?

not at all empowered			moderately empowered			very empowered
1	2	3	4	5	6	7

How therapeutic was it to tell your story?

not at all therapeutic			moderately therapeutic			very therapeutic
1	2	3	4	5	6	7

How anxious did you feel while telling your story?

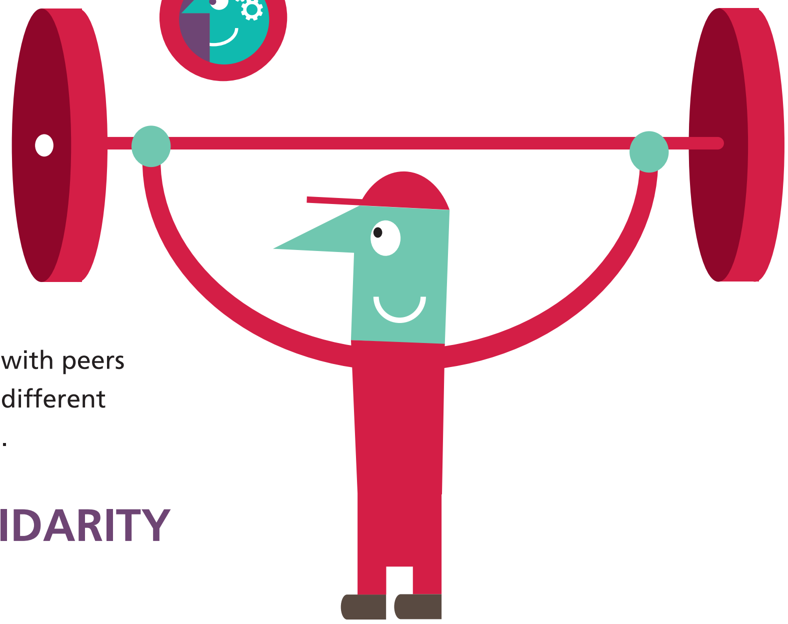
not at all anxious			moderately anxious			very anxious
1	2	3	4	5	6	7

How positive was your experience telling your story?

not at all positive			moderately positive			very positive
1	2	3	4	5	6	7

Please note anything else not already discussed about the quality of your story telling experience.

LESSON 5:
Moving Forward



LESSON OVERVIEW

In this lesson you will see that solidarity with peers may make disclosure easier and explore different types and characteristics of peer services.

Up to Me through SOLIDARITY and Peer Support

Up to Me promotes the idea that experiences with Tourette and associated challenges are a large part of who many people are. Instead of keeping it quiet, people may want to share their stories with others. Instead of trying to hide aspects of their lives, people want to be accepted for who they are. **SOLIDARITY** is the desire and expectation that the public stands with us as we are, for whom we are. People who speak out about their Tourette are doing just that. Solidarity has two meanings.

- Disclosure is easier when I stand proudly with peers.
- I'm in the right peer group if they support my disclosure decision.

The Safe Person Decal Seven Promises

By displaying this decal for youth and adults to see, I promise to:

1. Acknowledge that reaching out for support is a strength.
2. Listen and react non-judgmentally.
3. Respond in a calm and reassuring manner.
4. Reflect back the feelings, strengths, and ideas I hear when listening.
5. Ask how I can be helpful and respond as I am able.
6. Do what I can to connect to other supports if asked.
7. Maintain confidentiality and communicate if exceptions exist.

To order free decals or to learn how to put the promises into action, go to safeperson.org.

When you display the Safe Person decal it signifies to others that you pledge to provide a safe space for persons to discuss mental health, Tourette, and associated challenges. . A safe space is a space that is free of judgment, where every individual is treated as capable and valuable in our community. When you see this decal, understand that the person displaying it is not perfect. They have, however, made a commitment to provide a safe space and try to provide a listening ear. These individuals have agreed to abide by the seven promises detailed above.

Peer Support: Disclosures can be easier when a person decides to join together with others for support. This might happen informally, such as joining a group of friends who have shared experiences, or formally, through community programs often called peer-support services. Peer-support services, which include self-help groups, are perhaps the best kind of programs that promote empowerment. As the name suggests, peer-support programs were developed by peers for peers in school and the community.

Worksheet 5.1

Where do I go to find peer support?

List peer support programs you know of and learn about today.

Name of Organization	Location and contact info	What I/others like about it
1 Youth Ambassador Program		
2 Your State's Tourette Chapter		
3 Tourette Camp		
4 Facebook		
5		

Where do I go to find adult support?

List programs you know of and learn about today.

Name of Organization	Location and contact info	What I/others like about it
1 Tourette Association of America		
2		
3		
4		
5		

Worksheet 5.2

Insights and Future Directions

Reflect on what you have learned during this program and answer the following questions. These questions are meant to promote discussion, so please feel free to write down any other comments or concerns you would like to discuss with the group.

Discussion Questions

What did you learn about stigma and disclosure from this program?

What are the pros and cons of you disclosing? Might you disclose in some places? Where? ***(Worksheet 2.1 and 2.2)***

What disclosure choices might work for you? ***(Worksheet 2.3)***

To whom might you disclose? ***(Lesson 3 section 2)***

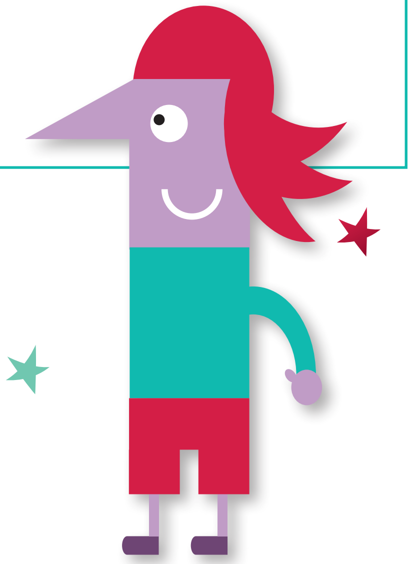
Worksheet 5.2 (continued)

What could you do to respond to stigmatizing reactions from others? ***(Lesson 3 section 3)***

What do you think of how you outlined your story? How might you improve it? ***(Worksheets 4.1 and 4.2)***

What organizations or groups at school or in the community might offer you peer and/or adult support? ***(Worksheet 5.1)***

Given all of this, what might you do in terms of disclosure in the future?



APPENDIX A

Definitions

Mental health is a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. Mental health is indispensable to personal well-being, family and interpersonal relationships, and contribution to community or society.

Mental illness is the term that refers collectively to all diagnosable mental disorders. Mental disorders are health conditions that are characterized by alterations in **thinking, mood, or behavior** (or some combination thereof) associated with distress and/or impaired functioning. E.g. Depression - alterations in mood and Attention-deficit/hyperactivity disorder- alterations in behavior (over-activity) and/or thinking (inability to concentrate).

First two definitions come from Surgeon General's report on Mental Health (2000)

Trauma is a reaction to a traumatic event or situation that overwhelms a person's ability to cope, and inhibits them from moving forward with life in a normal manner

As family, classmates, co-workers and friends, we seek to draw on the strengths of one's overall health to deal with mental health challenges or the effects of trauma.

Resilience refers to the capacity of people to succeed and thrive, despite experiencing illness, poverty, neglect and/or trauma. "Resilience" can apply to children, youth and adults. Resilient people are able to succeed because they have "protective factors" that help them survive the adversity.

Protective factors come from many things – they can be inherent qualities the individual possesses, such as optimism, self-confidence or a strong faith. Protective factors can also come from outside, such as the support of loving family, special friends or caring professionals.

Recovery is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential. Four dimensions include:

1. **Health** – overcoming or managing one's disease and living in physically and emotionally healthy way
2. **Home** – a stable and safe place to live
3. **Purpose** – meaningful daily activities, e.g., job, school, volunteerism, family caretaking or creative endeavors; and independence, income and resources to participate in society
4. **Community** – relationships and social networks that provide support, friendship, love, and hope

Recovery support components:

- **Hope** – recovery is real – can overcome internal and external challenges, barriers, and obstacles. Hope internalized and fostered by others – catalyst for recovery process
- **Person driven** – self-determination and self-direction foundations for recovery as individuals define their own life goals and design unique paths towards their goals.
- Holistic – Recovery encompasses individual's whole life, including mind, body, spirit, and community.
- Peers and allies – Mutual support and mutual aid groups, including sharing of experiential knowledge and skills, as well as social learning, play invaluable role in recovery.
- **Relationships and social networks** – important factor in recovery process presence and involvement of people who believe in person's ability to recover; who offer hope, support, and encouragement; and who suggest strategies and resources for change
- **Culturally-based and influenced** – culture and culture background, including values, traditions, and beliefs key to determining person's journey and unique pathway to recovery
- **Addresses trauma** – trauma precursor to drug use, mental health problems, etc – services and supports must be trauma informed
- **Individual, family, and community strengths and responsibility** – all resources and strengths serving as foundation for recovery and all have responsibility to help and offer support
- **Based on respect** – Community, systems, and societal acceptance and appreciation for people affected by mental health and substance use problems – including protecting their rights and eliminating discrimination – crucial to achieving recovery

Stigma can be described with three words-

- stereotypes (ideas),
- that lead to prejudice (beliefs),
- that play out in discrimination (behaviors).

It comes in the form of public stigma, internalized shame/self-stigma (for those experiencing mental health challenges), and structural stigma (policies and processes that reinforce discrimination). In relationships where there is a power differential, it is referred to as oppression.

Self-stigma happens when people who face mental health challenges believe the false ideas about mental illness and turn those hurtful attitudes towards themselves. Self-stigma can be a barrier to someone realizing their own resilience and finding their unique pathway of recovery.

Co-Occurring Experiences and Stigma

People living with mental health challenges are multi-dimensional and sometimes face stereotypes, prejudices and discrimination from more than one angle. Examples of other "stigmas" people face are: heterosexism, racism, sexism, ableism, etc.

APPENDIX B

Protections Against Unwanted Disclosure

Who Must You Tell?

No one! You are not required to tell anyone about the Tourette and associated challenges you've faced. After going through this program, you may decide to tell some people for reasons such as gaining support or accommodations; however, you do not have to tell anyone if you choose not to. You do not have to tell anyone simply because they are in a position of authority. You are bound only by federal and state law, as well as the rules of your school. For example, some schools require students to take their medications in the school office. Let's say you need to leave class at a certain time of day in order to take your medication. If a teacher asks you what medication you are taking or what you are taking it for, you are not required to tell them.

Similarly, you are not required to disclose this information to the police. If a police officer, teacher, or school official tries to pressure you to reveal information about yourself that you are not comfortable revealing, you have a right to ask for the presence of a parent or attorney before answering further questions.

If you believe that your rights have been violated in some way, reach out to your local chapter of the American Civil Liberties Union (ACLU) for assistance.

Confidentiality Laws

No one has the right to know that you have ever been in a hospital or attended a community mental health center, without your prior written permission; however, there are some exceptions to this in the case of minors. Laws vary somewhat by state. In many states, a provider may disclose information about your treatment to your parent or legal guardian as a result of certain conditions being met. For example, in the state of California, your provider may disclose information to your parent or legal guardian in the event that three conditions are met: your situation poses a substantial threat to the life or physical well-being of you or another; this threat may be reduced by communicating relevant facts to your parents; you lack the capacity because of extreme youth or a mental or physical condition to make a rational decision on whether to disclose to your parents. Again, laws vary by state.

Some may permit disclosure about your treatment to a parent or legal guardian under less stringent circumstances, while the laws of other states may be similar to California's. You can look into the laws of your individual state. In addition, there are some practical concerns. Even if you make the appointment on your own, if your parents get insurance statements or bills related to your care, they will know you are seeing a therapist.

Contact the ACLU, or ask for help from another trusted adult if you are unsure of how to do research about the laws in your state.

Who the laws do and don't apply to.

Confidentiality laws clearly apply to psychiatrists, psychologists, social workers, nurses, and other staff providing mental health services. In fact, these laws apply to all paid employees of an agency including receptionists, bus drivers, food service workers, and housekeeping staff. In addition, these laws apply to unpaid workers associated with the mental health program: recreation volunteers, therapy students, outside advocates, and members of the board of directors. Note, however, that laws do not apply to one group of people who you regularly encounter at a mental health program: the other people receiving services. Confidentiality laws do not apply to other people you meet in a psychiatric unit of a hospital, or who you meet in group therapy at a community program. Nor must family members attending therapy sessions protect your confidentiality. It is certainly the case that staff will request that fellow group members respect your confidentiality — they probably wish the same protections for themselves — but there are no laws requiring that they do.

There are clearly many legal protections to ensure your privacy. Unfortunately, these protections are not absolute; gossip may always spread. For example, there are no laws that prevent classmates from telling stories, and neighbors and friends may pass out information about you in a spiteful manner. These are all important things to consider as you make decisions about talking about your mental health challenges.