

TEEN



Facilitator Manual



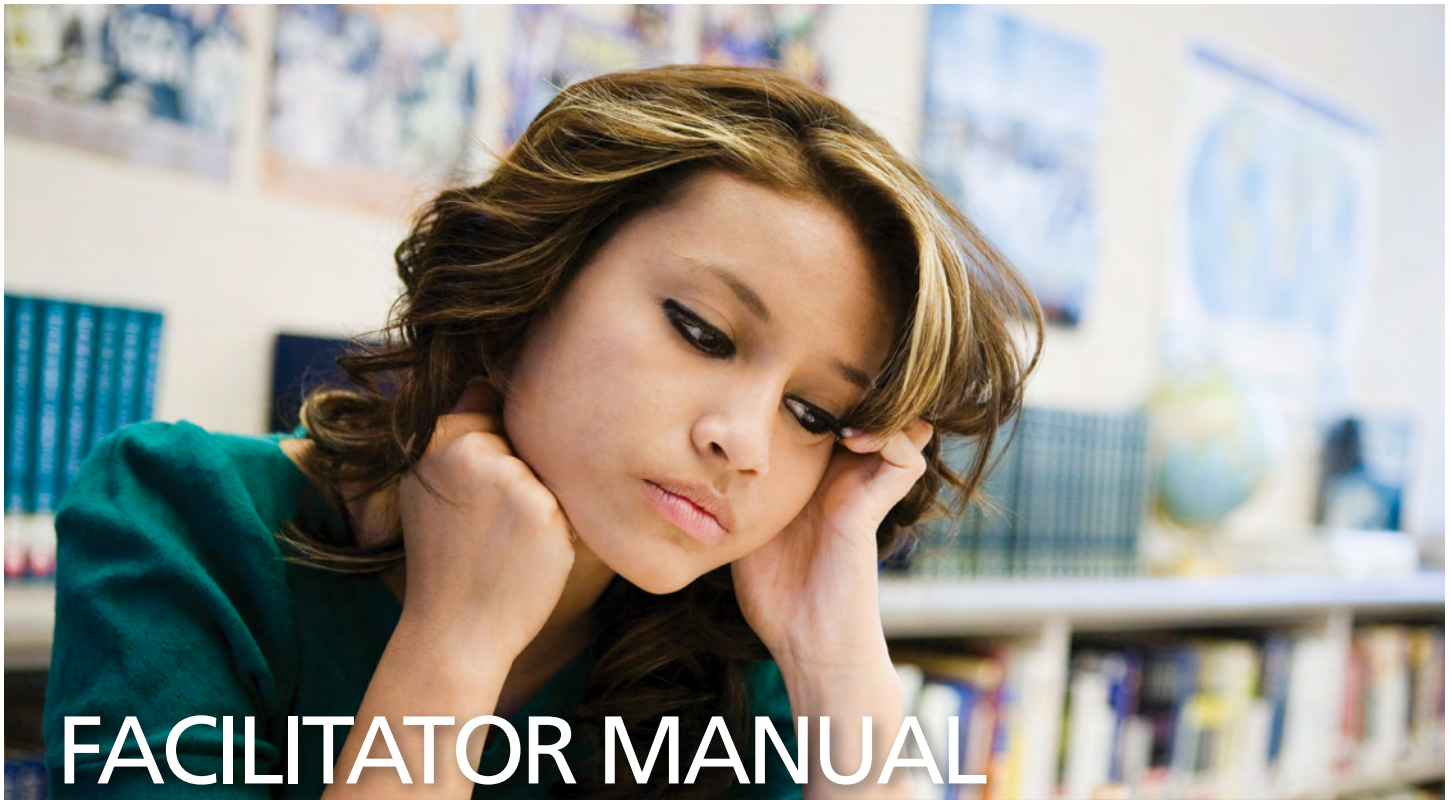
WISE and Patrick W. Corrigan
(Wisconsin Initiative for Stigma Elimination)



Up to
Me :

Talking about
Our Tourette and
Associated Challenges





FACILITATOR MANUAL

Preface and Implementation Details

This is the facilitator manual for the youth version of the *Up to Me* program. Participants receive the *Up to Me* Workbook. This program was put together to help young people to talk about their Tourette challenges. The strongest, most current evidence for effective interventions to reduce the public stigma is for people to have direct social contact with people who can talk about their experience living with Tourette and who they are beyond their Tourette experience. Talking about one's challenges and the insights gained on the path of symptom management can also be a very helpful way to reduce self-stigma. **

This program was designed so that it can be done in five lessons, with each lesson requiring at least 1 hour (and ideally spending one and one-half hours on the fourth lesson). You will find that Lesson Four (sharing stories) may take longer than an hour depending on the number of youth in the program. You may be able to carry over and share some of the stories at the beginning of session five or plan to extend your time for session four. If you do not have a full hour for each of the sessions, then spread the lessons out over six sessions. In this manual, the lessons are laid out with learning points, discussion questions, and group activities/exercises.

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](http://wisewisconsin.org/up-to-me).

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This program is best run with four to ten participants. One or two people should facilitate, preferably people with the lived experience of mental health challenges or Tourette, with strong facilitation experience, and who are familiar to the youth. It is also helpful if one facilitator is close in age to the participants and has lived experience. Examples of ideal combinations for the facilitation team would be: college students, recent graduates, or young adult peer support specialists paired with more seasoned facilitators. All that is needed to run this program is a private room, writing utensils, copies of the workbook for each participant, and flipchart/markers. If the optional videos will be shown, you will need a projector and lap top or a digital monitor/TV. Videos can also be accessed on a smart phone.

Materials in this workbook along with the videos can be downloaded for free from Up to Me at WISEwisconsin.org or Wisewisconsin.org/up-to-me.

CHILD SAFETY AND MANDATED REPORTING

Children in this program may disclose information that suggests neglect, or one of three kinds of abuse: physical, psychological/emotional, and sexual. All states in the United States and most nations around the world have mandated reporter laws that require a responsible adult to promptly report the abuse to authorities. Up to Me must include an authorized and responsible adult as a co-facilitator who is the mandated reporter of record. Most times, that adult will be an employee of the institution or agency offering Up to Me: school, clinic, faith-based community. That person is responsible for being fully informed about reporting responsibilities and timelines in their jurisdiction. (see page 6)

For information on state policies: <https://www.childwelfare.gov/topics/systemwide/laws-policies/state/>

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



From here forward, the words *in italics* are not in the youth workbook. Pages that are underlined refer to the page numbers in the participant workbook.



Setting the Tone: Starting Each Lesson

The first thing we want to do **at the beginning of each lesson** is set the tone. As facilitators, start by **sharing your names and any other introductory information you would like to share with the group**. Then, lead an **icebreaker** that will help everyone in the group learn each other's first name. If you don't know of any, a resource with good suggestions can be found at: <http://www.ultimatecampresource.com/site/camp-activities/name-games.page-1.html>. Last names and titles are not necessary unless the person chooses to share this information with the group. After introductions, you should **state 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.”

Point out the definitions located in Appendix A and suggest that the youth refer to them throughout the lessons.

Next, establish some group guidelines:

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

Write guidelines on newsprint and then lead the participants in brainstorming how they would know if these guidelines were being followed. **What behavior would they see in the group? Note these within the large balloons.** It is important that everyone feels ownership of the guidelines. If they are violated, the facilitator can remind the participants that everyone has agreed to adhere to them. The goal is to create an open environment where people feel comfortable sharing their opinions and feelings should they choose to do so.

Discuss who the youth can talk to about anything that comes up for them personally during these lessons. If you are not one of their advisors, counselors, or group leaders, then **establish which adults will be able to support them in any way between lessons.**



One of the things you may have strong feelings about is how you discuss your Tourette. You may use words like emotional struggles, tics, labels like Tourette Syndrome or OCD, or terms like associated challenges or serious health conditions. Throughout the workbook, we use the term Tourette and associated challenges. People facing Tourette and associated challenges include people who have received a diagnosis and people seeking to maintain their mental health. 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.



Introductions and guidelines should be repeated prior to all subsequent lessons.

Each lesson should end with a “grounding experience” that includes an opportunity for participants to:

- Relax their minds and bodies,
- Be reminded that what was said during the lesson is confidential, and
- Review the goal of the program to increase their confidence in their ability to make helpful decisions about if and how their story is shared.

Mandated Reporting

When you facilitate Up to Me - High School, you are a mandated reporter. Let the school or agency in which you are conducting the sessions know that you are a mandated reporter, and ask about their mandated reporting status and policies. Also ask what roles in the organization are not mandated reporters. Reports of alleged child abuse or neglect should be made to the county where the child or the child's family resides. Contact the county department of social/human services. Reports can also be made to local law enforcement offices.

It is important to immediately let the youth know that you are a mandated reporter in order to build and maintain their trust. If youth seek someone to talk to who is not

a mandated reporter, be prepared to share examples of roles or actual names that the agency gives you.

Below is a sample statement to youth to be made in the first session during the setting of ground rules and again at the beginning of Session 4:

“Before we get started, I want to let you all know that I am a mandated reporter. Some of you may know what this means, and it might be new for others, so I’ll just spend a minute or two to review it for everyone. As a mandated reporter, I am responsible for helping to keep young people safe. Because I care about all of you, if I hear anything that would lead me to believe that you or any children who are not here today might be at risk of being hurt by themselves or by someone else, I would report that to people in the community who could help to keep us all safe and healthy. Does anyone have any questions about this? If so, feel free to stop me at any time during this group, or find me during one of the breaks, and I’d be happy to clear up any questions you have.”

Here is a website that facilitators may find helpful to better understand mandated reporting:

<https://dcf.wisconsin.gov/cps/mandatedreporters>





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, associated challenges, and your strengths and consider how to challenge any hurtful self-talk.



We approach this lesson in two parts:

1. Understanding hurtful and helpful attitudes about living with Tourette and helping youth to identify their own helpful and hurtful attitudes (self-talk)
2. Practicing ways to challenge hurtful self-talk as the youth think about talking with others

* Have youth turn to Appendix A to read definitions of these terms. Suggest that they do so at any time during the sessions when words are used they do not know and ask about other unfamiliar terms not in Appendix A.

Lesson 1 Part 1. Helpful and Hurtful Self-Talk

LEARNING OBJECTIVES

- Participants will look at how two people describe their Tourette and associated challenges and to discover some important beliefs they hold about themselves.
- Participants will identify their personally helpful and hurtful self-talk.

ACTIVITIES

Introductory information and activities from [pages 5-6](#).

Begin the lesson with teaching about helpful and hurtful self-talk/beliefs.

Say: "**Helpful self-beliefs** recognize our strengths, even those gained from our mistakes or challenges. They recognize the work we have put into being who we are and support us in becoming the people we want to be. They often include words such as I am able, I am hopeful, I am learning, I am strong.

Hurtful self-beliefs focus on what we couldn't do in our past, they often are blaming of others or self, and use words like always, never, all or no one."

To increase understanding of this concept, read a brief example of one person's self-talk. Ask the participants to listen as you read. Ask them to be prepared to tell the group how they felt about the two different versions of

the same person's self-talk. Hearing what individuals say about themselves to themselves can help us to better understand how they perceive their experiences.

Example #1: "I used to cause lots of problems at school. Now I hate the fact that everyone thinks people like me are freaks. Having to go to the office to get my medication every day tells everyone that they are right about people like me."

Example #2: "I have come a long way since elementary school. Teachers didn't know how to handle me when I was younger. Since finding out that I have ADHD, I have learned some great ways to deal with all that I am expected to do at school. Taking medication is not so fun, but it really helps for now. If someone has a problem with that, I guess they have a lot to learn."

Lead a brief discussion on which version of this person's self-talk has more helpful self-beliefs in it. What are some of the helpful beliefs you heard?

Go deeper into these concepts using the diary entries of Maggie and Darryl on the following page. ([page 4](#)) Ask one person to volunteer to read Maggie's entry out loud and another to read Darryl's entry out loud to the group.



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.

1. Instruct the group members to find a partner and follow the instructions on Worksheet 1.1 (page 5).
2. Assess the participants' understanding of helpful and hurtful self-attitudes by asking for some examples of what the pairs wrote in the four boxes, one box at a time. Important points to highlight are listed on the manual version of Worksheet 1.1.
3. Before the youth complete worksheet 1.2, lead a brief discussion on self-stigma using the following:

Up to Me believes stereotypes and prejudice are false and unjust. Here are some stigmatized beliefs that exist:

- People with Tourette are **violent and unpredictable**.
- People can **choose** not to have Tourette.
- They are **weak and incompetent**.

Unfortunately, some people with Tourette and associated challenges may agree with stigmatizing beliefs like these and internalize them.

- I have a Tourette, so I must be **violent and unpredictable**.
- I have Tourette, so I **choose** to have Tourette.
- I have Tourette, so I must be **weak and incompetent**.

Now, ask the youth to complete Worksheet 1.2- Your Self-Talk Puzzle (page 6). It is important to guide the youth to think about beliefs that they hold about themselves. It can be helpful to prompt them with statements such as: What do you find yourself saying about yourself when you are frustrated with completing a task, when you have met an expectation that someone had of you, when things go right, when things go wrong, when you talk about tough times you have experienced? Write one phrase or word on each puzzle piece.

Be sure they remember to place a ✓ next to each statement/belief that they think is helpful and a ✗ next to each that is hurtful.



Analyzing a Story for Hurtful and Helpful Self-Talk

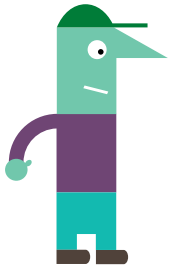
1. What are the **helpful beliefs** that Maggie and Darryl hold about themselves and their experiences with Tourette and associated challenges?

Maggie

I work hard
I feel proud
Teens at the youth center seem to like me



Darryl



I worked hard in therapy

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

Maggie



I will not have good friends because I have Tourette.

Darryl

I should be able to stop my tics
People don't like having me around
COACH let me on the track team



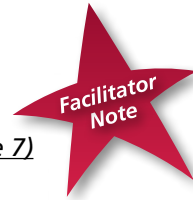


Your Self-Talk Puzzle

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."

<p>#1</p> <p>#2</p>	<p>#1</p> <p>#2</p>
<p>#1</p> <p>#2</p>	<p>#1</p> <p>#2</p>
<p>#1</p> <p>#2</p>	<p>#1</p> <p>#2</p>

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.



Lesson 1 Part 2. Challenging Personally Hurtful Self-Talk (page 7)

LEARNING OBJECTIVES

- Participants will explore a five-step process to challenge personally hurtful beliefs (self-stigma)
- Participants will apply the five-step process to their personally hurtful beliefs

Five Steps for Changing Personally Hurtful Self-Talk



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.



5.

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 Tourette. She discovered that most of them have a friend with Tourette or an associated challenge. Matter of fact, many said that they had more than one friend with Tourette, and two of them even disclosed that they have OCD. 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 and associated challenges in general.

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

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 (page 8) shows the process Darryl went through to challenge his assumption and change the hurtful belief.

Here is Darryl's completed worksheet.

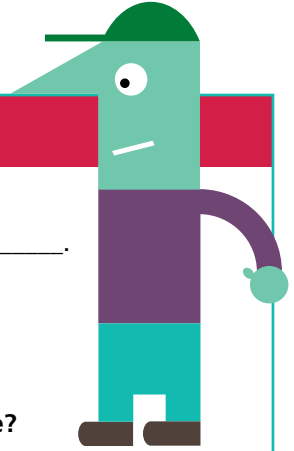


Table 1: Change Our Self-Talk Exercise

1. State the hurtful belief.

I MUST BE a bad person BECAUSE I am not able to 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 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 past problems. In fact, I have reasons for having pride in how I 'tackled' my challenges.

Use Worksheet 1.3 (page 9) 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.

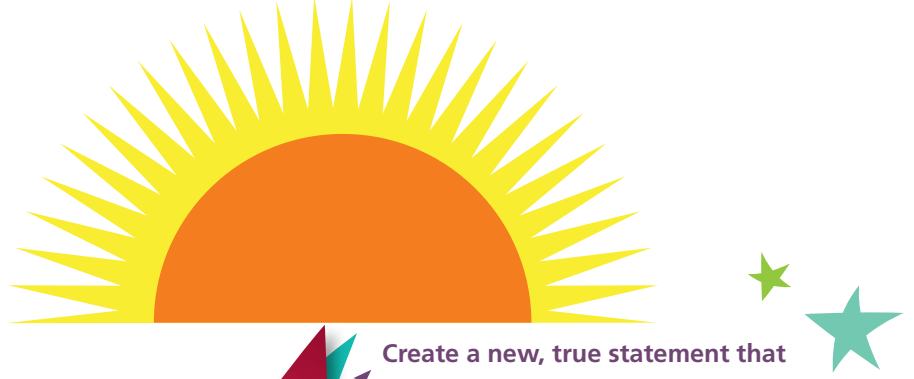
Facilitator Note

Note to facilitators – Optional Activity: You can use large puzzle pieces to create a more visual experience for the participants. When participants identify the hurtful beliefs from their individual puzzles, ask for some examples to be shared and write them on over-sized puzzle pieces. Use the participants' examples in place of, or in addition to, Darryl and Maggie's. When the "counter statements" are designed, write them on the flip-side of the puzzle pieces and state that "flipping" our self-talk is an on-going process, rather than an instant one, and that it can eventually leave us embracing these new perspectives. Extra-large dry erase puzzle pieces can be purchased through Amazon.com. When glued back-to-back, they serve as great "flipping boards."



Change Our Self-Talk Exercise

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



Collect evidence that shows the statement to be false.

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

4.

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

3. Turn into a true-false statement.

2.

1. State your hurtful belief.

I must be
because





Closing of Lesson One

Summarize what was done in Lesson One and give a brief preview of Lesson Two. Then guide the youth through a grounding exercise. One simple exercise is to ask them to sit with both feet on the floor, backs straight but relaxed and away from the back of the chair, palms on knees, and eyes either closed or softly open. If eyes are open, it is helpful to focus on one object such as a spot on the floor 6-10 feet in front of you.

In a calm and soothing voice:



- *Help them to relax their minds and bodies. Ask them to quiet their minds by simply noticing when thoughts come into their minds and allow them to leave without attention to them. Guide them to relax their bodies from head to toe, one area of their bodies at a time.*
- *After establishing a relaxed climate in the room, remind them that what was said during the lesson is confidential and express gratitude for their participation and respect for each other.*
- *Review the goal of the program to increase their confidence in their ability to make helpful decisions about if and how their story is shared in the future.*
- *Wish them all a good week (or whatever time frame before you see them again) and remind them of the people they can connect with in the meantime if they would like to talk about anything that came up for them during the lesson.*



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.

Facilitator
Note

In this lesson we will:

1. Weigh the pros and cons of disclosing so that youth can decide whether or not to disclose.
2. Explore how the decision to disclose might look different in the different settings of their lives. We will consider the differences in disclosing face to face versus over social media.
3. Consider five choices youth have when considering disclosure and the pros and cons associated with each.

Lesson 2 Part 1. Considering the Pros and Cons of Disclosing

LEARNING OBJECTIVES

- There are both pros and cons to disclosure.
- The youth are the only ones who can weigh them to decide whether it is worth disclosing.
- Pros and cons differ depending the setting; for example, in a classroom versus among their close circle of friends.

ACTIVITIES

1. After doing introductions/icebreaker, program goal review, summary of the objectives for today, you may choose to show the video: **Pros and Cons of Disclosure** to introduce the lesson. (<https://wisewisconsin.org/up-to-me/facilitator-resources/>)
2. **PROS and CONS:** Divide the group into two teams. Team One will complete Worksheet 2.1 (page 10) using question #1, and Team Two will use question #2. Explain that pros represent what you expect to happen that is positive. Cons are the negatives or harm that could result.

NOTE: having the groups look at this from two perspectives may help to generate more diverse answers. See the example on Table 2.A.

Once the teams complete their worksheets, create a “master list” of what the teams listed for the pros on question 1 and the cons on question 2 on flip chart. Give each team a marker and ask team members to take turns writing their answers on the master list. Ask them to be sure there are no repeat answers.

Once the teams run out of unique ideas from their lists, discuss how the pros of disclosing and the cons of not disclosing create a good picture of the REASONS (or GOALS) one might choose to disclose their Tourette and associated challenges.. The other two lists (cons of disclosing and benefits of NOT disclosing) create a good picture of reasons not to disclose. (If you have time, you can have the teams create a master list of the reasons for not disclosing.)

You may wish to summarize the reasons/goals to help the youth focus on a few key ideas. Table 2.B offers guidance on that. Be sure that in summarizing, you do not minimize the importance of any idea that the youth listed. Ask the youth if the summary included all ideas or if they can see another point to include.

KEEP THE REASONS/GOALS LIST FOR USE IN ALL FUTURE SESSIONS



Table 2A: #1 Examples of Pros and Cons of Disclosing

<i>Pros</i>	<i>Cons</i>
<i>You don't have to worry about others labeling your tics.</i>	<i>Others may think you should not have disclosed.</i>
<i>Others may express approval.</i>	<i>Others may gossip about you.</i>
<i>Others may have similar experiences.</i>	<i>Others may exclude you from social gatherings and other opportunities.</i>
<i>You may find someone who can help you in the future.</i>	<i>You may worry more about what people are thinking about you.</i>
<i>You are promoting your sense of personal power.</i>	<i>You may worry that others will pity you.</i>
<i>You are living testimony against stigma.</i>	<i>Future challenges may be more stressful because everyone will be watching.</i>

Table 2A: #2 Examples of Pros and Cons of Disclosing when other Initiated

<i>Pros</i>	<i>Cons</i>
<i>You can control the story told about you.</i>	<i>People might spread rumors about Tourette.</i>
<i>It can feel bad to keep a secret.</i>	<i>They may be asking but not really care.</i>
<i>You might get connected to others with TS.</i>	<i>People may think every experience you have is relate to Tourette.</i>
<i>Others may have ideas how to address your challenges.</i>	<i>Your self-stigma can get worse if people disrespect your disclosure.</i>

Table 2B: Some Reasons Why People Decided to Disclose

- 1. To Tell the Secret**
*"I don't want to have to feel like I'm sneaking around with a secret."
 "I felt bad for having to keep private. I don't want to feel bad anymore."*
- 2. To be Better Understood**
*"I hope others will understand my challenges and how hard it was to keep it a secret."
 "I'd like to know that my sister gets what I am going through."*
- 3. To Receive Support and Assistance**
*"Sometimes I get sad. I'm looking for friends I can talk to..
 "Can you give me a ride to the doctor?"*
- 4. To Get Reasonable Accommodations at School, on the Job, etc.**
"I can go to school administrators to get the extra time I need on tests because of my anxiety."

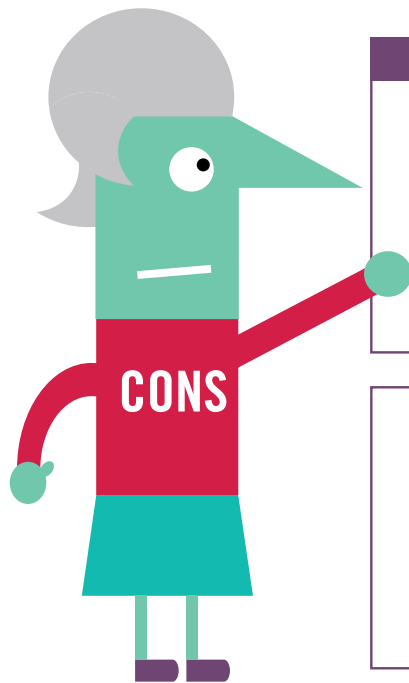


Pros and Cons of Disclosing

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



3. *Once the participants complete Worksheet 2.1 and you compile the master list of reasons, state that while each reason is important, each person in the room may have different ideas about which ones are most important to them. Encouraging the participants to consider which reasons are most important to them, individually, will increase the likelihood that their decisions will be right for them in a given situation.*
4. *Explain that the impact of the pros and cons are sometimes relatively immediate; at other times, the impact is delayed. Share the example for Darryl, outlined for you on Table 2.C. People tend to be more influenced by short-term pros and cons because they happen sooner. But, long-term pros and cons frequently have greater implications for the future.*

Table 2C: Example for Darryl		Setting: Classroom	
Short-Term Pros		Short-Term Cons	
<i>Others will understand why I tic.</i>		<i>Classmates won't ask me to lunch.</i>	
<i>Don't have to keep it hidden.</i>		<i>Worry about others talking about me.</i>	
<i>Find classmates with similar problems.</i>		<i>Classmates may bully me because of my tics.</i>	
<i>Make more friends in class.*</i>			
Long-Term Pros		Long-Term Cons	
<i>I learn how to get accommodations to support my learning.</i>		<i>It will be harder to find friends in high school</i>	
<i>Avoid failing the class.*</i>		<i>Rumors start about me.*</i>	
<i>The friends I have know and accept me for who I am.</i>		<i>I start skipping class and fail.</i>	

5. *Walk through the **Five Points To Remember** in the participants workbook ([page 11](#)). These five points will assist the youth as they complete Worksheet 2.2 ([page 12](#)). If time is short, suggest they complete on their own time.*

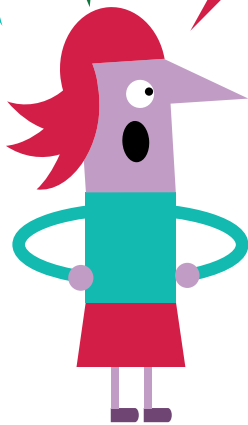


Five Points to Remember About Disclosure Decisions:

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 and associated challenges 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.

**YOU CAN CHOOSE
 YES NO LATER**



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 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 to 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?





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?



Social Media: Setting for Disclosure?

The pros and cons of disclosing can be applied to either in-person disclosure or disclosure over social media. To help you learn, Table 2.D. describes the three different categories of social media that can be used to disclose and some examples of pros and cons of each.

Table 2D: Social Media Disclosure		
Media	Pros	Cons
1. Online Video Chat: — Skype — FaceTime	— What is said cannot be shared with others — Can show emotion — Recipient gives immediate response	— Not as personal as in person — Speaking in the moment (off the cuff) — Others may overhear the conversation, even if you cannot see them on-screen
2. Private Messages: — Email — Phone Text Message — Private Facebook Message	— Less intimidating — Carefully planned out what is written — Less stressful	— No emotion conveyed — Confidentiality issues (messages can be shared by recipient and may be seen by an unintended audience)
3. Public Messages: — Twitter — Snap Chat — Instagram — Public Facebook Post — Blog	— Educate the public — Can tell everyone at once and be “out” — Carefully planned out what is written	— No emotion conveyed — Everyone can see/comment in a short period of time — People might not take it seriously

Use Worksheet 2.3 ([page 13](#)) to guide a discussion with the participants about disclosure on social media.



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?





Lesson 2 Part 2. Choices and Settings for Disclosure

LEARNING OBJECTIVES

- Recognize that people have choices when faced with a decision to disclose or not.
- Understand the pros and cons of the five disclosure choices.

The graphic below (page 14) and table on the following page (page 15) summarizes the five choices that participants have about whether to disclose their Tourette and associated challenges or not. Present and discuss these choices with the youth.

Refer to what they found out about social media, reminding them that even when an individual selectively discloses on social media to specific people, those individuals can quickly broadcast the shared information without permission



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

SECRECY: Participating in activities, but keeping your Tourette 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 associated challenges and avoiding situations where people may find out about it.

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

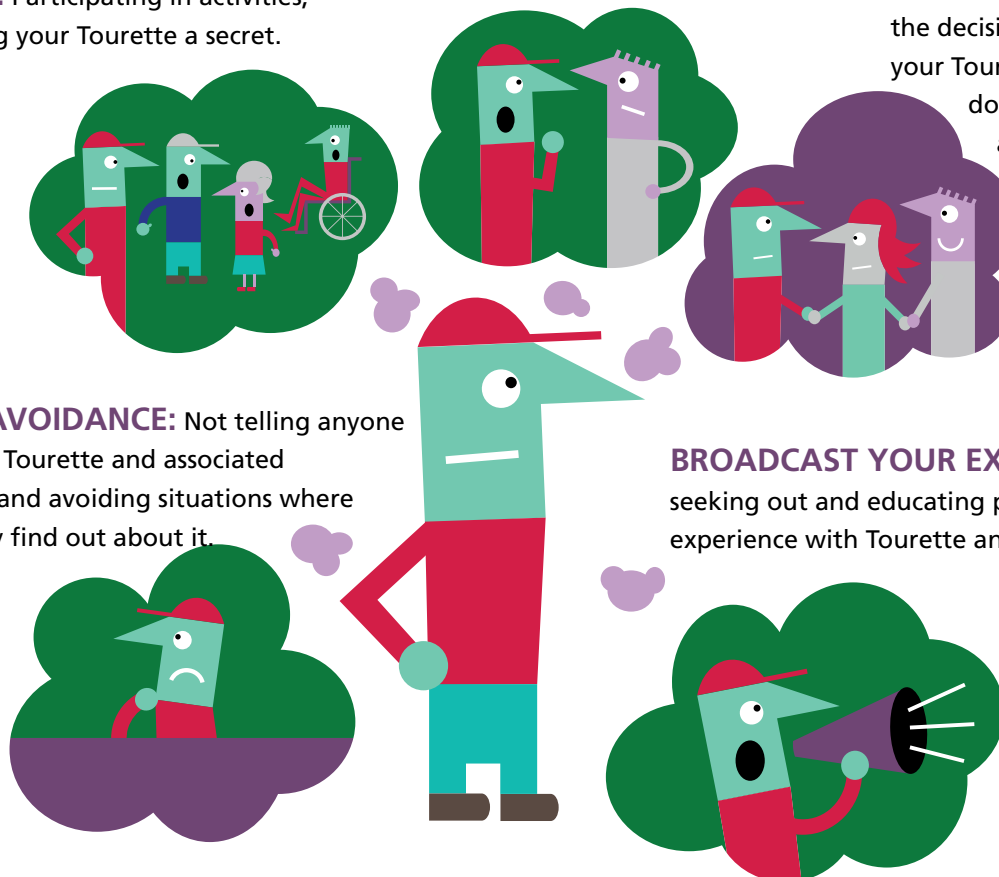




Table 2E: Five Choices of Disclosure Pros and Cons

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.

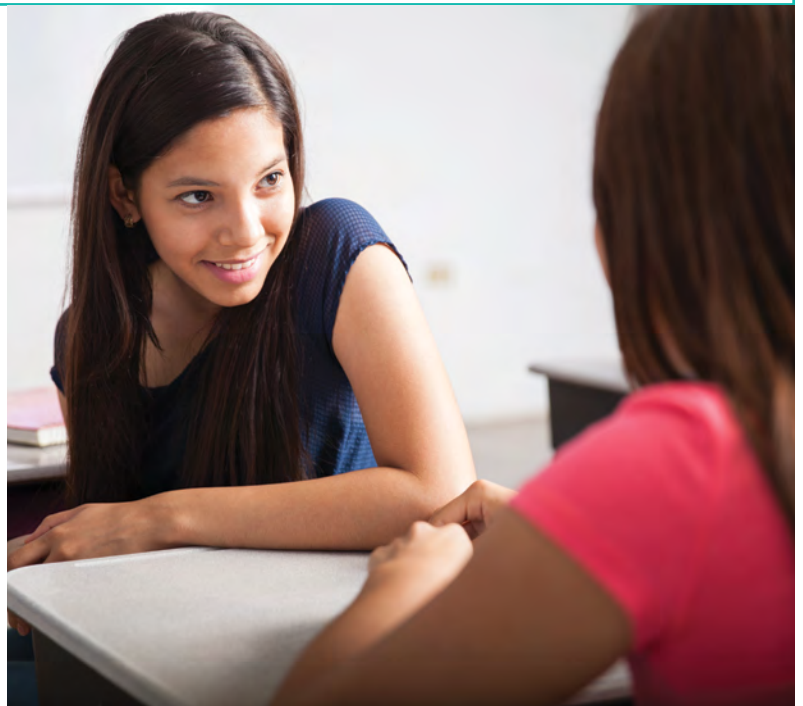
BROADCAST YOUR EXPERIENCE

Pros: You don't have to worry who knows about your 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 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





Optional: Show video **5 Levels of Disclosure** where college-age youth discuss how the different choices of disclosure played out in their experiences. (<https://wisewisconsin.org/lup-to-me/facilitator-resources/>)

To be sure that you have helped the participants to understand the five choices, tell them that they are going to do an activity to “Test the Teacher.”

Draw Table 2F (or the cloud graphic used in worksheet 2.4) on a large white board and have the name of each participant on a 3x5 card and tape the cards, one to each box. When you come to that box ask that participant to comment on the pros or cons for Maggie making one of the five disclosure choices at school. Go in order from Avoidance to Broadcast. Assist the youth to think through each choice of disclosure for Maggie. Each person has the choice of Play, Ask for help from the group, or Pass. (Maggie’s story is in the workbook on [page 4](#))

TABLE 2F: Pros and Cons of the Five Disclosure Choices	
Maggie: _____	
Pros	Cons
Social Avoidance	
Secrecy	
Selective Disclosure	
Open Disclosure	
Broadcast Your Experience	



From the Participant Workbook: (refer back to page 4)

Consider how each of these choices of disclosure might play out for Maggie. We looked at Maggie's story in our last lesson. In case you don't remember, here is a refresher of what she wrote about herself:



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.

Next, 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.



Guide them to complete Worksheet 2.4. (page 16) Ask them to select a setting/group from their life and complete the worksheet listing the pros and cons for them for each choice. If time is limited, suggest that they complete on their own.



Pros and Cons of the Five Choices of Disclosure for Me

Setting: _____



SECRECY
PROS:
CONS:

SELECTIVE DISCLOSURE
PROS:
CONS:

OPEN DISCLOSURE
PROS:
CONS:

SOCIAL AVOIDANCE
PROS:
CONS:

BROADCAST
PROS:
CONS:



Closing of Lesson Two

Summarize what was done in Lesson Two and give a brief preview of Lesson Three. Then guide the youth through a grounding exercise.





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.



Lesson 3. Part 1. Disclosure Decisions Practice Game

LEARNING OBJECTIVE

- Practice considering the choices of disclosure through this interactive card game.

Instructions:

1. Print off enough sets of cards for each group of three **BEFORE** this session. (found on pages 29-34) It would be best to print them on cardstock. You could even have them laminated for repeated use.
2. Break participants into groups of approximately three.
3. Make two card piles. The larger cards have the stories of six different high school students on them. The small cards have different settings and situations in which a person might consider disclosing.
4. One participant draws a large card and another draws a small card.
5. Read the larger story card first aloud to the other people in your group. Then, read the smaller setting/situation card. Discuss as a group what disclosure choice might be most appropriate for that person in that setting or situation, and why. Then, discuss what would be needed in order for that person to feel safe making a choice to be even more open. Participants can draw a few different settings/situation cards for each story.
6. After you've drawn a few settings/situation cards and discussed, have another group member draw a new large story card and one draw the smaller setting card, and repeat the process.

Assemble the youth back into one large group. Each small group will share one example that they discussed, including what disclosure choice they found to be safe/appropriate, why, and what would be needed in order for the person described on the card to move to a more open disclosure choice.

Mary – 16 years old

Mary is 16 years old and has had Tourette for as long as she can remember. She does well in school, is on the honor roll, and is involved in a lot of activities.

Mary is very well-liked by teachers and peers. They all know she has Tourette and accepts her for it. Mary's tics are mild but noticeable and occasionally she yells out phrases.

Mary wants to go on a school trip next summer but the only way she could go was to get a job and earn money. She loves fashion and design and decided that she wanted to work in the mall at a clothing store. She aced the 30-minute interview because she's outgoing, has great references and was able to hide her tics for that short period of time.

Now she's working and concerned that co-workers, her boss, and customers are noticing her tics.

Stuart – 15 years old

Stuart is a sophomore in high school. He's shy, has trouble making friends and doesn't talk in class.

Stuart was diagnosed with Tourette when he was 8. He barks like a dog, hisses like a cat, jerks his head and his arms, and twists his body around. He sits in the back of the class and has permission to stand up if he needs to.

When he feels he has to make noises he tries to leave the class. Either way, the other kids notice him—he's either making noises, ticcing, standing up, or walking out of the room. He has trouble focusing and doesn't participate in class.

Because sitting in class is so hard for him, and he's so ashamed of his tics, he usually tells his mother he has a stomach ache or headache so he won't have to go to school. He won't let his mother tell the teachers what is wrong with him and none of the kids know either. He just wishes he could crawl under a rock and not have to be around anyone again.

Steven – 15 years old

Steven was diagnosed with a reading disorder when he was in 2nd grade. School was always hard for him and he never liked going. When he was 10 he was also diagnosed with Tourette, Bipolar disorder, and ADHD.

At 12, he didn't tic as much (thanks to the medication) but his moods and impulsivity were out of control. He yelled at his teachers and refused to do what they say. Things got so bad that Steven was sent to what they call a "therapeutic school", a school for kids who have trouble functioning in public school.

Steven loves his new school and was able to tell the other students about his TS and the associated disorders. Steven also plays on a neighborhood basketball team. He never tics when he's playing but his tics increase right before the games and also afterward. The other players have started to ask him why he does these "strange things".

Steven feels OK telling them about his Tourette but, not sure he wants them to know about the associated disorders and why he goes to a special school.

Danny – 15 years old

Danny is 15 years old and a freshman in high school. When Danny was 10, he began blinking his eyes and scrunching his nose. His parents took him to a doctor who said it was just a nervous habit.

Over the next five years Danny developed new tics like swinging out his arms, jerking back his head and sometimes yelling out words.

When Danny was in grade school the other students got used to him and didn't tease him. Now that he's in high school he's with a whole new group of students who stare at him, tease him, and call him names. His parents took him to a new doctor, who told him he has Tourette Syndrome. Danny was given medication but the medication makes him tired and it only helps the tics a little. The other kids stare at him and make fun of him.

One of the boys behind him tells him to "stop it" when he shouts out. Danny knows he can't help it but he's still ashamed and embarrassed by his tics. He wants people to understand but is afraid that telling them will make things worse.

Jason - 17 years old

Jason's tics began when he was very young. Through lots of treatments, he has learned to suppress, minimize, or delay many of them, but he is not able to under times of stress or discomfort. As a result, he has developed anxiety.

Over the next year, he has a lot of transitions. He will be finishing his senior year in school at a new high school. He plans to start a part time job. And, he will be applying for college. He knows these next experiences are likely to cause him anxiety and his tics more evident to people. He wants to make a good first impression and does not want his Tourette or anxiety to define him.

Rosa - 12 years old

Rosa has lived with a variety of tics since age 7. Shy by nature, she does not talk much to anyone other than her family. Lately, her family has started to be concerned that Rosa may also have depression. She spends much of her time alone, does not have many friends, and complains at times that people at school bully her. Just this last year, she declined many opportunities to attend groups and clubs at school.

Rosa also feels like she embarrasses her family. They avoid attending a lot of social situations and she thinks it is her fault. The last time they attended a movie, they were asked to leave when other moviegoers complained about Rosa's verbal tics. She feels different and like a burden to her family. And, she knows her mom also feels guilty and like Rosa's tics are somehow her fault.

Rosa is tired of all the energy it takes to avoid people, put on a brave front when bullied, and live with Tourette. Recently, she has considered opening up to a school counselor, but she is embarrassed about what she will think of her.

Locker room after practice — someone drops their medication and _____ notices it is the same medication he/she takes. The person looks really embarrassed and afraid that _____ saw the medication.

Facebook — someone from school posts that they hate taking their medications because of how it makes them feel. _____ considers responding

Tourette Camp

Hanging out with a friend one-on-one

Support group led by the school social worker — first time meeting with them

Audition for a role in a play where the character contemplates suicide

Instagram/Tumblr — someone posts stigmatizing words under a picture. _____ considers responding.

A party with people from school

Gay-Straight Alliance meeting
— discussion on the idea
of “coming out” in all
aspects of our lives

Choir/band practice

Talking with a teacher after class
to get extra help with homework

Job interview

Facebook — contemplating
posting a status about
experiences with
Tourette

Art club — Someone mentions
how art is the only thing
that gives them relief
from anxiety

Hanging out with a small group
of friends in the lunchroom
at school

Interview for college admission

TV interview

Psychology class — The class is discussing mental health diagnoses and terminology

Family reunion talking to cousin who recently got out of psychiatric hospital

Grandparent asks you how you have been



Lesson 3. Part 2. To Whom Might You Disclose?

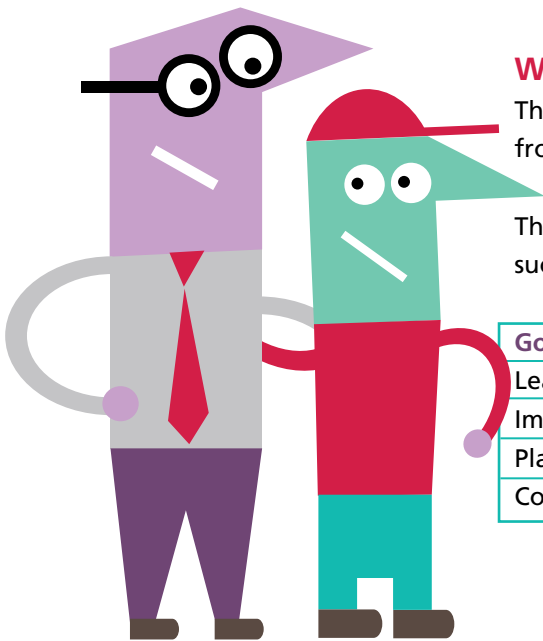
LEARNING OBJECTIVES

- Learn how to identify a good person to whom youth might disclose.
- Understand the procedure for “testing out” the person before disclosing.



Review the first section of this part in the Participant Workbook.

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



1. Ask the group if they can think of a few other examples of these relationships.
2. Then, discuss how telling people might help you to get what you need in that relationship.
3. Now ask the group, “If your goal in disclosing is to get support and understanding, what would you want that person to be like?” Brainstorm as a group and list on flip chart. Some ideas to get your brainstorming started are:

- Kind
- Good listener
- Empathetic (tries to understand what it is like to have my experience)
- Loyal
- Helpful
- Open-minded
- Trustworthy

After the list is complete, lead group in discussion of how do we tell if someone can be trusted. After some ideas, point out that we cannot be sure and at some point we have to trust ourselves to make good decisions about people and to be prepared if it we don't get the response we expected.



Testing a Person for Disclosure

One way to test a person for disclosure is to bring up something from a movie, TV show, or other form of media and to ask what the other person thinks of it.

We are going to demonstrate how that might go and ask you to be the judge for whether the reaction the person gives makes that person someone to whom you would disclose.

We will walk through several scenarios of testing a person for disclosure together as a group. Based on your assessment of how the test disclosure went, hold up the appropriate hand signal: thumbs up = Yes, thumbs sideways = Maybe, thumbs down = No.



YES



MAYBE



NO

YES: *You believe the person is safe to disclose to. They exhibit positive characteristics, such as empathy and trustworthiness, and after testing for disclosure, their response implies that they are likely to respond positively if you were to disclose to them.*

MAYBE: *You believe you should proceed with caution. You may need to gather more information, get to know the person a little better, and perhaps test them further. This may not be the best person to disclose to if you are seeking emotional support or understanding, but it may be worth it for you to try if their knowing is important to you being able to accomplish a function in your life. Still, proceed with caution.*

STOP: *You believe this person is unsafe to disclose to. They hold stigmatizing attitudes that, at least at this time, seem inflexible. They exhibit strong signs that they may not be a supportive or understanding person, and may even be likely to try to hurt you with the information you've shared. Avoid disclosing to this person. Instead, find a more suitable person who will be able to support and help you.*

Go through a few examples of ways to test a person for disclosure and a few possible outcomes.

After each test response, ask participants to hold up the hand signal that identifies what they think the person should do with regards to disclosing. Briefly discuss agreements and variety in the responses. All perspectives count and can help others to think through their decision.

One facilitator reads the question and the other gives a response.

Example One:

"I have been hearing lots of actors and musicians talk about their mental health challenges or addictions lately. What do you think about people just coming out with such information?"

Possible Responses: (remind youth to hold up their hand signal for each response)

- *"Crazy people living a crazy life. What did they expect?!"*
- *"It takes a lot of guts to open up about those things when every move they make is documented by photos and social media."*
- *"I don't know what to think. Sometimes it seems pretty cool that they are open and other times it seems like they are just trying to give excuses for their really bad choices."*
- *"My cousin has bipolar and I know that she feels pretty alone, like no one else deals with the things she does. I hope it helps her to hear that others face it too."*

Example Two:

"Did you see that TV show about the person with really bad OCD where they couldn't even go to school and had to be hospitalized? What did you think of it?"

Some possible responses: (hold up your selected card for each response)

- *"I didn't realize OCD could be that serious. I guess I don't really understand too much about it."*
- *"You know, sometimes I think I might have a little bit of OCD!"*
- *"My mom has OCD, and she had to go to a therapist for a while. It was kind of weird at homethen but she is doing really well now."*
- *"I think it's pretty stupid that someone would go to a hospital for their OCD. They just need to get a life. People are too obsessed with getting treatment for every little thing these days."*

Before the next session, youth can practice this in their own lives, and see how it goes. Suggest that they find a person to whom they might want to disclose, and practice some of these techniques in "testing" them for disclosure. Worksheet 3.1. ([page 18](#)) is a tool that they can use to help think through how they would test someone out.



Testing Someone for Disclosure

News story, TV show, or movie that addresses Tourette and associated challenges

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.



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.

Was there anything else to note about their response? If so, please write it here.



Lesson 3. Part 3. How Might Others React to Your Disclosure?

LEARNING OBJECTIVES

- Explore the different ways people may react to someone's disclosure.
- Consider how youth might feel about the different reactions and practice how to respond.

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

Understanding
Caring Support
Assistance
Sincere Interest

Hurtful

Disrespect
Denial
Punishment
Fear/Avoidance
Blame

Ask the youth to give two examples of what each negative reaction may sound like. **Write the actual quotes on a flip chart or white board for use in the following activity.**

Respond to Reactions Activity

PRIOR to this activity, be sure to discuss from the participant workbook: (page 19)



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.

The relationship cards for this activity are found just after the direction in this manual. Print off and cut out the necessary number of sets ahead of time. Laminate and keep them for future use!

DISPLAY THE LIST OF PROS FOR DISCLOSURE AND CONS FOR NOT DISCLOSING FROM LESSON 2. INCLUDING YOUR REASON FOR CHOOSING TO DISCLOSE IS GREAT CONTENT FOR YOUR RESPONSE.



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.



**Facilitator
Note**

Instructions:

1. Break into groups of approximately three. Number yourselves 1, 2 and 3.
2. #1 selects a relationship card and reads it to the group. #2 reads a possible hurtful reaction brainstormed by the large group to group member #1, acting as if #2 is the person on the card reacting to #1's disclosure. #1 shares how they would respond if they were trying to give a calm and confident response to the hurtful reaction to their sharing. They can ask #3 for assistance in coming up with a response that seems confident and honest.
3. Example:
Person #1 selects the relationship card "teacher"
Person #2 selects a reaction to disclosure from the brainstormed list: "I hope you do not expect me to treat you any differently than anyone else!" and reads it to person #1 as if they are #1's teacher and #1 had just disclosed their Tourette and associated challenges.

#1 thinks of a response to the teacher that is calm and confident such as: "I told you about how I get really anxious in small groups because I thought you could help me think of what to do so I can keep my grades up."

HINT! USE THE REASONS FOR DISCLOSURE LIST FROM LESSON TWO.

4. Repeat the process with #2 selecting the card and #3 choosing a reaction to say to #2 so #2 can practice giving a calm and confident response. Then have #3 select a card and #1 choose a reaction to say to #3 so #3 can practice a calm and confident response. Select new relationships and reaction quotes for each practice round.

Parent

Grandparent

Older Sibling

Best Friend

Younger Sibling

Coach or Youth Leader

Teacher

People You Eat Lunch
With At School



How will disclosure affect the people in your own life?

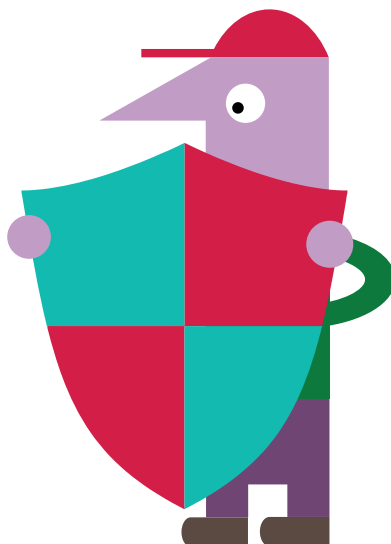
Close this section by saying: “Now that you’ve had a chance to place yourself in another’s shoes as you consider the impact of disclosure, think about how disclosure will affect the people in your own life? Think about the people in your own life who you value your relationship with, and whose feelings and opinions matters to you. Then consider these questions:

1. In what ways might my disclosure affect the important people in my life? Would the setting in which I disclose affect how they feel about it? For example, would my mom feel differently about me telling my best friend vs. posting on Facebook?
2. Whose opinions will I value the most if I want to get insight about whether I should disclose in the various settings of my life? For example, will I weigh my sister’s opinions about my disclosure more heavily than the opinions of my coach?

Reiterate with the youth the following from their Workbook:

Protections Against Unwanted Disclosure

In making decisions about disclosing your experiences with Tourette, 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.





Closing of Lesson Three

Summarize what was done in Lesson Three and explain what will happen in Lesson Four.

Ask the youth to read pages 22-23 and draft their story using pages 25-26 before the next time you meet together. You will want to copy these pages for them to take with them if you are keeping their workbooks.

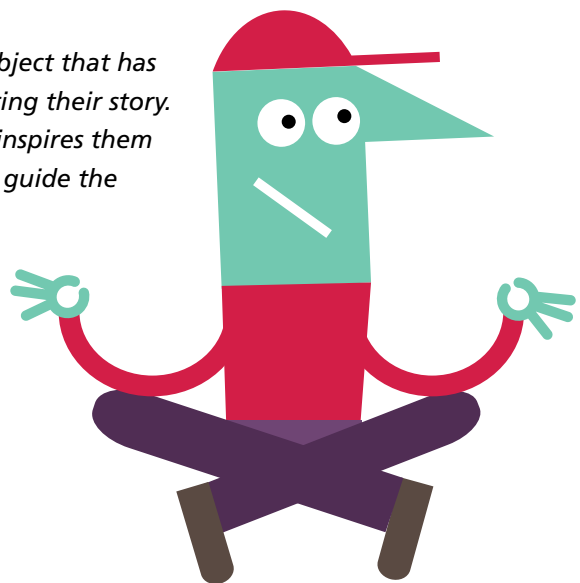
Point out that Shoshi's story can be viewed on the website, rogersinhealth.org. Go to the Stories of Recovery Page and scroll down to Tourette Syndrome.

Make it very clear that the youth will not be forced to share their stories in Lesson Four. They will draft their stories for themselves. If they choose to share with the group, that will happen during the next session. Clarify that there will be a time limit on each person's story time. For instance, if there are 8 in a group and you leave 15 minutes for introductory activities and 10 minutes to close the session, that would leave 35 minutes in a one-hour session for all to tell their story, or 4 minutes per person with very brief feedback. Strongly suggest that they practice beforehand so they are able to get to their strengths and accomplishments! Tell them that you will stop them halfway through to ask that they move on to the parts of their story that highlight their wisdom and accomplishments.

Please, also, remind the youth of the discussion regarding language that was discussed at the beginning, during the **Setting the Tone** section.

"Your story is a chance to share how you identify. Carefully think about the words and labels you will use to describe your experiences with Tourette. What words feel and sound right to you? Sharing your story may also be an opportunity to try using new words to describe your experiences."

Tell youth that they can bring a picture or small object that has meaning to them if they want to use it when sharing their story. They can also take a photo during the week that inspires them to talk about their strengths and resilience. Then, guide the youth through a grounding exercise.





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 associated challenges and steps you are taking in recovery. 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

LEARNING OBJECTIVES

- Consider different ways for youth to tell their story.
- Review an example of one person's story. (or view the video)
- Discuss what words each will feel comfortable using to name their Tourette and associated challenges.
- Use the provided guide to assist youth in telling their 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.





Talk briefly about the different ways depicted in the graphic.

- **Write a letter**

This is a good way of selectively disclosing to a person you trust in a one-on-one setting. This is especially good for a person who is good with the written word, but struggles more to express things in conversation. Rather than sending it, you may want to have a face-to-face conversation and ask the person to read it while you are together, so you can discuss it with them. Writing it ahead of time allows you to lay out all your thoughts clearly so you don't forget what you want to say.

- **Write a poem, spoken word piece, or song/rap.**

You may have a talent in this area. This is a great way to share your story with an audience, or just with a couple people.

- **Give a speech to a group.**

If you have decided you're ready for broadcast disclosure, you'll have the opportunity to put together and practice delivering a speech. Always practice telling your story and preparing for unexpected reactions with someone first.

- **Create art, collage or scrapbook**

You can share this with your loved ones and explain what it means to you, or just keep it for yourself as a record of your recovery. If you've chosen to share on the broadcast level, you might show your work at an art exhibit and write about your recovery in your artist statement.

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.



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.



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?

Shoshi'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.



BEFORE MOVING TO WORKSHEET 4.1 – Lead youth to brainstorm words that people use to refer to their Tourette and associated challenges. Discuss pros and cons of different words and encourage youth to select the language that feels right for them. Guide them to choose the language that honors their challenges and their strengths. Ask which words might have the strongest chance of increasing inclusion and solidarity for those with Tourette and associated challenges.

Facilitator
Note

Worksheet 4.1 (pp 24-25) 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.



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 symptom management.

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.



I want to end with these two key points:

1. I, like all people with Tourette, 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 (page 26)* 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.

When you facilitate the sharing of stories, set up the following guidelines for the experience:

1. In order for all to have the option to practice sharing their story if they would like to, set a time limit and let participants know how you will help them to know when there is one minute left.
2. Anyone can pass.
3. When participants are sharing their story they can read directly from their guide or speak without notes.
4. After someone tells their story, we will allow for three positive feedback statements and then will move on to the next person who wants to tell their story. Or, each person can write an anonymous positive statement on a card and then give it to the person sharing their story.
5. No one will ask questions or make suggestions to participants after telling their story.
6. Remind youth that this is an opportunity to practice telling their story out loud and seeing how it feels to do so.

Facilitator
Note



Quality of Experience (page 26)

Use the following 7-point scales to rate the quality of your experience telling your story about 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.





Closing of Lesson Four

You may need to use time in Lesson Five to complete the story sharing, but do your best to allow all participants the chance to tell their story during the time provided to cover Lesson Four, as the youth may have prepared for this opportunity and could experience anxiety having to wait to tell their stories until the following session.

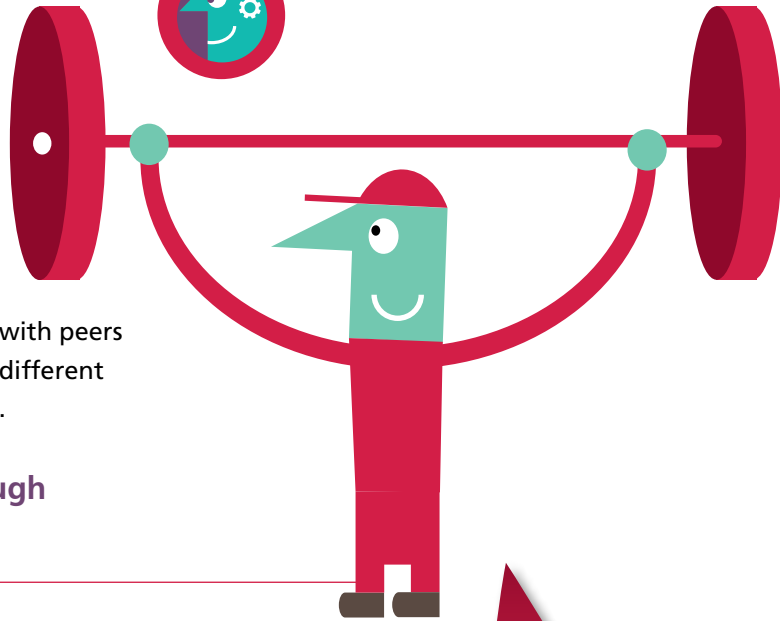
It is especially important to end this lesson with a grounding exercise. Use the simple exercise from Lesson One with some different comments. Ask youth to sit with both feet on the floor, backs straight but relaxed and away from the back of the chair and eyes either closed or softly open, palms on their knees. If eyes are open, it is helpful to focus on one object such as a spot on the floor 6-10 feet in front of you.

In a calm and soothing voice:

- *“Relax your minds and bodies. Take a deep breath by expanding your belly or abdomen, bringing air in through the nose and out through the mouth. Quiet your minds by simply noticing when thoughts come into your mind and allow them to leave without attention to them.*
- *We are going to use some of our senses to experience our present surroundings. I will give directions aloud, but you will keep your responses to yourself. As we complete this activity, remember to keep breathing fully into your abdomen.*
- *To start, take another full breath and identify one thing you can see/saw in this space. Say the name of that thing in your head. Next, what is one thing you could touch or feel? How would it feel? What is one thing you can hear? Where is the noise coming from? What is a smell that makes you feel relaxed such as a fresh rain, chocolate or a flowering tree. Imagine breathing in that smell as you sit there. And lastly, what is one thing you would like to taste the next time you eat? Imagine the texture and flavor of that food item.*
- *Take another full breath and allow stillness to come over us.*
- *You have experienced the courage and strength of your peers as stories were shared and heard. Allow a sense of gratitude for each other and for yourself to settle into your mind and heart.*
- *Your peers have committed to keep what you have said confidential. I am grateful for your respect for each other.*
- *Remember that the goal of the program is to increase your confidence in your ability to make helpful decisions about if and how you share your story in the future. If you are feeling uncomfortable with the thought of sharing your story in the near future, it is OK. The goal is not for everyone to talk about themselves to others but to be in control of their story and what, when and to whom to share it.*
- *Wish them all a good week (or whatever time frame before you see them again) and remind them of the people they can connect with in the meantime if they would like to talk about anything that came up for them during the lesson.*



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.

Lesson 5. Part 1. Up to Me through SOLIDARITY and Peer Support

LEARNING OBJECTIVES

- Identify that solidarity with peers may make disclosure easier.
- Explore many types and characteristics of peer services.

You may wish to plan something special for the group to do together to close this last lesson. (Art, movement, music, refreshments, positive affirmations for peers, etc.)

Lead icebreaker, review goals and then complete any story sharing that was not completed in Lesson Four.

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 and associated challenges 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 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.



Facilitator
Note

On Worksheet 5.1 ([page 29](#)) ask participants to list all the peer programs and sources of adult support they can think of. After doing so, have the group generate a master list.



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		
2		
3		
4		
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		
2		
3		
4		
5		

Lesson 5 Part 2. Putting it All Together



Facilitator
Note

LEARNING OBJECTIVES

- Summarize insights from the worksheets provided in this workbook.
- Decide how you would like to move forward with the issue of disclosure.

We end the program with a pause for insight and direction. In Worksheet 5.2, questions are provided so that participants can summarize insights and decide on future directions.

Either ask the youth to individually reflect on the Up to Me experience using Worksheet 5.2 (pp 30-31) and then lead a discussion with the whole group or simply let the worksheet guide the discussion without first completing it. Ask the youth to discuss one or two decisions that they have made about disclosure and going forward from this program.



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*)



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?



Closing of Lesson Five and Up to Me Program Series

End the series with a grounding activity and any other fun activity that you have planned for your group. Be sure to reiterate the goals of this program and that there are safe adults in the school and community who seek to offer ongoing support. If you are having a booster session, remind the group of the booster session date and location.





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 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 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.

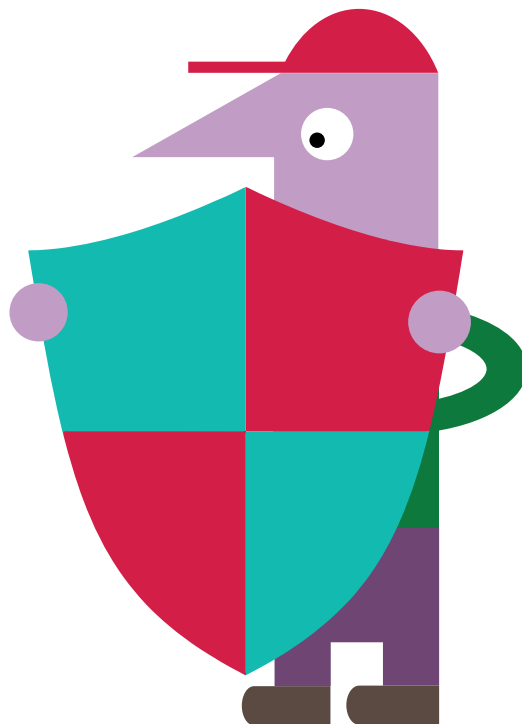
Contact the ACLU, or ask for help from another trusted adult if you are unsure of how to do research about the laws in your state.

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 Tourette and associated challenges. .





BOOSTER

Complete the booster session with youth participants one month after completion of session five of the Up to Me program. Use the Booster as a check-in with the youth.

This session may be facilitated as an open discussion or by using the worksheets provided. If the group members are most comfortable with structured activities, the worksheets will help the group to open up and reflect on their experiences, learnings, and choices moving forward. **Print the worksheets from this manual to give to the participants — the worksheets are NOT in the workbook.** Some may be used simply to guide facilitation of the check-in.

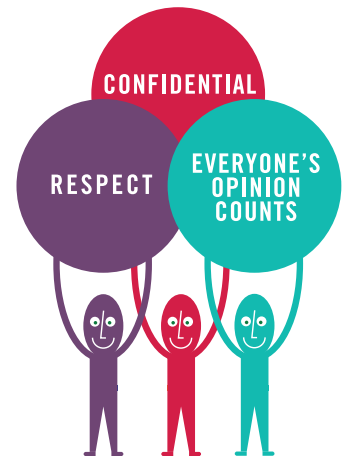
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As in all lessons in this program, begin the booster session with an icebreaker that will help everyone in the group reconnect.

Restate the overall purpose of the Up to Me program:

“Our goal was to consider the choices that we have when it comes to disclosing our experiences with Tourette and associated challenges to others. And, to work together to learn helpful ways to disclose most effectively to protect ourselves against hurtful responses from others, should we decide to disclose. Remind group of the **group guidelines**:

- Confidentiality (describe mandated reporting exceptions of harm to self or others and abuse),
- Everyone’s opinion counts, and
- We respect each other.



End this lesson with a “grounding experience” that gives youth the opportunity to:

- Relax their minds and bodies,
- Be reminded that what was said during the lesson is confidential, and
- Review the goal of the program to increase their confidence in their ability to make helpful decisions about if and how their story is shared.

Part 1: Your Disclosure Experience

PART 1 OVERVIEW

Disclosing is the right decision for some people, but not for everyone. This section is designed to review your decisions about disclosure since completing the Up to Me program about one month ago. We approach this follow-up in two parts:

We review previous intentions to disclose your Tourette and associated challenges, including to whom, when, and where you decided to disclose as well as what you expected from the disclosure.

We discuss whether you disclosed and help you evaluate how the experience went and how it may affect future disclosures.

Did You Intend to Disclose?

One month ago, we identified people that might be suitable for disclosure. The two main types of relationships included: functional (e.g., psychiatrist or teacher) and supportive/empathetic (e.g., someone who is trustworthy and understanding). Use Worksheet 1.1 to review intentions you had for disclosure after you completed the program.

After participants complete Worksheet 1.1, ask them to pair up to discuss the intentions to disclose (or not) that they had after completing the Up to Me program about one month ago. A whole group conversation is a good choice too.



Intension to Disclose – Who? When? Where? What?

When you completed the Up to Me baseline program about one month ago, did you intend to disclose?

- Yes No

If yes, please fill out this table.

<p><i>Who did you decide to disclose to?</i></p>
<p><i>When did you plan on disclosing?</i></p>
<p><i>Where did you plan on disclosing?</i></p>
<p><i>What did you expect from the disclosure?</i></p>

If no, why did you decide against it?

How Did Disclosure Go?

*During the baseline program, we learned how to evaluate a specific instance of disclosure. Worksheet 1.2 is the same one you completed before. It lays out steps to assess whether interactions in which you disclosed to others were positive or negative. You may have disclosed. If so, discuss how it went here. If not, we can still learn from others. Fill in the worksheet **AS IF** you did disclose with a real person in a real setting.*

Explain to participants: First indicate to whom you disclosed, the date the conversation took place, and the location. This will help track successful or unsuccessful elements of disclosure, and may help you to alter your strategy the next time you decide to disclose. Second, consider what your goals were for disclosing to this person and note what you said to the person; remember to be specific! Next, write down how the person reacted to your disclosure. It might also be important for you to note the tone of their voice and their body language, especially if it does not seem to match their verbal content. Finally, rate how satisfied you were with the conversation and how positive you thought it was on the seven-point scale provided. Add up the two ratings into a total score. Totals greater than 10 suggest that the experience was a success and worth doing again. Totals less than 6 mean that it did not go so well and you might want to further evaluate what happened. Scores in between 6 and 10 mean that more information may be needed before going forward.



Did You Disclose? How Did it Go?

Please fill out this page about a disclosure from the past month.

Name of the person to whom you disclosed: _____

Date of disclosure: _____ Place of disclosure: _____

Your Goal(s)

What You Said

Person's Reaction



_____ How satisfied were you with the conversation?

not at all
satisfied

neither

very
satisfied

1	2	3	4	5	6	7
---	---	---	---	---	---	---

_____ How positive was the conversation?

not at all
positive

neither

very
positive

1	2	3	4	5	6	7
---	---	---	---	---	---	---



MORE THAN 10: Good experience; worth doing again.
LESS THAN 6: Not so good; what went wrong?
BETWEEN 6 AND 10: Need more information for the future.

Has your experience changed your mind about whether or not you will disclose in the future?

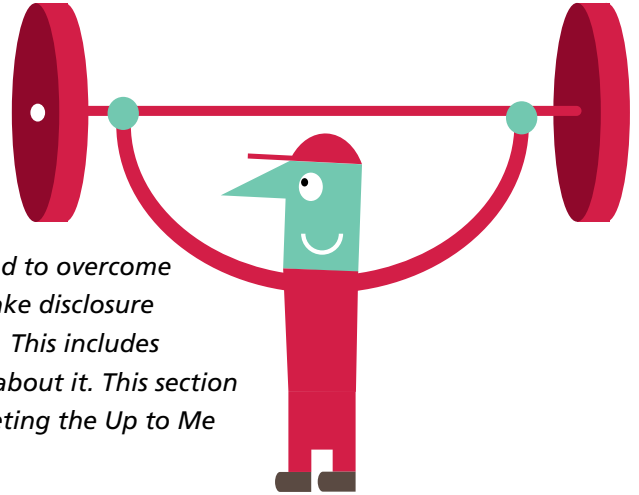
- Yes No

How has it changed?

Part 2: Peer Support Programs

PART 2 OVERVIEW

Some people find it helpful to seek a peer support group to share experiences and struggles of Tourette and associated challenges and to overcome the fear of disclosure. As a reminder, peer support services, may make disclosure easier because a person is joining together with others for support. This includes those who have already disclosed and those who are still thinking about it. This section assesses your experiences with peer support programs since completing the Up to Me baseline program.



Learning Objectives:

- Discuss the meaning of peer support and identify pros and cons of peer support programs
- Rate the quality of your peer support experience.

Did You Pursue Any Peer Support Programs?

One month ago, everyone in the group brainstormed a list of peer support programs they might attend. Worksheet 2.1 will help you to evaluate any peer support experience you may have had since completing the baseline program.

Instruct participants to evaluate their peer support experiences using Worksheet 2.1. Ask participants if anyone would like to share their experience with the group.

Lead a discussion using similar questions as those on Worksheet 2.1 on experiences of reaching out for adult support.

Worksheet 2.1



Since completing the Up to Me baseline program, did you attend a peer support program?

Yes No

If yes, what was the program called?

When and where was the meeting?

How did it go?

Will you return? Why or why not?

Would you recommend it to others? Why or why not?

Part 3: What Has Changed?

PART 3 OVERVIEW

Experiences since completing the Up to Me baseline program may have reshaped your thoughts about disclosure. In this section we:

Learning Objectives:

- *Reassess the pros and cons for disclosure, and compare them to what you brainstormed one month ago.*
- *Evaluate what worked and did not work when telling your story, and decide how you might change the story.*

Revisiting the Pros and Cons of Disclosure

In Worksheet 3.1 we provide you a table to list the short-term and long-term pros and cons to disclosing that you can think of now. Note that we do NOT want you to list only the new pros and cons that you have. Rather, we want you to include EVERYTHING that you can think of, even if you remember that you included it before. As a reminder, pros represent why you would disclose, or what you expect to happen that is positive as a result of disclosing to others. Cons are why you wouldn't do it, or the negatives or harm that could result from disclosing.

Post and review the group's master list of Pros and Cons /Reasons for Disclosure that they completed in Lesson two. Ask participants to circle those items on their worksheet that are the same as the master list. When they are finished, discuss the following questions:

- 1. Were there new items on your worksheet?*
- 2. Did you star any of the NEW ITEMS as especially important? If so, which ones?*



Revisiting the Pros and Cons for Disclosing My Tourette and associated challenges

Setting: _____ To Whom: _____

Since completing the Up to Me baseline program:

- I have decided to disclose my Tourette and associated challenges.
- I have decided NOT to disclose my Tourette and associated challenges.
- I have decided to put off my decision.

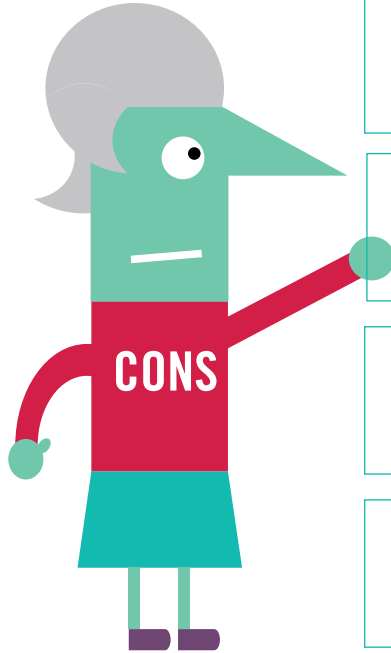
Please use the blocks below to list the pros and cons of disclosure that you have now, about one month after completing the Up to me baseline program.

Just like before, don't censor any ideas. Write them all down.

Put a star (*) next to pros and cons that are especially important.

Make sure to specify the setting and audience to which each pro and con applies (e.g., work, family, etc.), if more than one is included.





How Will You Tell Your Story Now?

One month ago, you were provided with a template on how you might share your disclosure story. It included the following parts:

1. Your name and what you call your Tourette and associated challenges;
2. 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;
3. Ways in which your Tourette and associated challenges emerged, and the age that this occurred;
4. Examples of struggles;
5. How you found what works for you and then, what works and doesn't work;
6. Your achievements and accomplishments despite/because of your challenges;
7. The purpose of your story and struggles with stigma;
8. And the moral of your story:



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

Worksheet 3.2 will help you re-think what you include in your story when you share it with others. It has two parts. **Section I** should only be completed if you have already disclosed. This will give you the opportunity to reflect on parts of your story that did and did not work. **Section II** will then ask you to determine whether there are things that you would like to add or delete in your story. If you have not yet disclosed, you should only complete **Section II**.

The last part of the worksheet will ask you to explain whether or not your goal in disclosing has changed as a result of rewriting your story. Once you have finished, Worksheet 3.3 serves as a fresh copy of the story template so that you can apply any changes that you decided to make in Worksheet 3.2



How Has Your Story Changed?

SECTION I. If you disclosed, please use the table below to list the items that worked or did not work when you were sharing your story. **If you have not yet disclosed, please move on to section II of this worksheet.**

<i>What Worked</i>	<i>What Did Not Work</i>

SECTION II. Please use the table below to list any items that you wish to add to your story (including items that may have been previously crossed out). Also, please write down any items that you wish to take out of your story

<i>Add to My Story</i>	<i>Take Out of My Story</i>

Has your GOAL in disclosing changed as a result of rewriting your story? Please explain.



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 you have struggled 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 symptom management.

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 society. (known as 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.

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.*





Booster Parts 1-3 Conclusion

Facilitate a final discussion about disclosure with the group.

- *Ask participants if they have any questions, comments, or concerns.*
- *Thank participants for contributing to the booster.*
- *Allow participants to voice any final thoughts and fears and discuss the possibilities about disclosure in the future*
- *Remind participants of contact information in case they feel distressed*
- *Celebrate Empowerment!*

End the Booster Session with a grounding activity and any other fun activity that you have planned for your group. Be sure to reiterate the goals of this program and that there are safe adults who seek to offer ongoing support.

