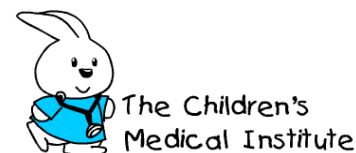




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the turner support group (TSG) newsletter



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## Big Things in Small Packages

A personal account of growing up with Turner Syndrome

These are snippets from the journal of a woman with Turner Syndrome. All excerpts are printed with her permission.

For more insights into her thoughts and experiences, visit <http://www.cnwl.igs.net/~poirier/>

"My name is Shirley Poirier. My story is not unlike any other in the sense that I probably make it out to be more than what it really is. The emotions involved in writing it are more intense than its purpose. The nature of the story is my struggle, or would be struggle to overcome my self imposed fears and reservations that I cling to."

### Never mind the weather, here we are together

Picnic at the Singapore Botanic Gardens

**Missed out on our last TSG event? You surely missed out on lots of fun! Find out more below.**

Weather forecast for that morning: "Rain in the Central district." Associate Professor Loke Kah Yin chuckled and said with all the optimism that he could muster: "Don't believe the weather forecast!"

So the picnic for our Turner Support Group went on as planned on the morning of June 23 at the Botanic Gardens. The weather was more than we could have asked for. Although it rained a little, it was only for a short while - which was a good thing because it lowered the

temperature.

The good turnout that day speaks volumes for the objectives of the support group, which are to bring members together to share problems and solutions, and to get to know each other better. Although the group meets twice a year, members and their families have come to know each other over the last few sessions and only have to catch up from where they left off. New members are warmly welcomed into the group and so our circle expands.

It was fun and games for all of two hours, which had everyone participating. One of the highlights for the younger

kids must be feeding the black swans with bread which we had brought for that purpose. After the picnic, a number of us with time to spare, visited the Orchid Garden. As usual, members each went home with a goodie bag with souvenirs to remind them of a morning well spent in the company of family and friends.

- Gloria Chan

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"I guess it would be best for me to start at the beginning. I was born in a small town in Eastern Ontario by a seemingly middle class couple. I had a toy filled nursery, a sister, and Turner Syndrome. I was born on November 11, 1970 at 8:29 P.M. I weighed 5 pounds and 3 ounces. I was diagnosed at birth, and not given a very promising prognosis. My parents were told that I might not walk, and would more than likely be 'retarded'. Thankfully my parents stayed strong, and envisioned the best scenario instead of listening to the one they were given. I wonder sometimes what might have happened if my Mom found out early enough to have an abortion. Would the Doctor have recommended it?"

"My Mom confessed to me once that for a very long time she kept wondering what she did to deserve everything she had to go through with me. She said it took her years to realize it wasn't her fault, Dad's, or mine. An important point to make about Turner's is that neither the Father or Mother can be blamed for a T.S. birth. The loss or mutation of the X chromosome is just a random happening with the sex cells during conception, nothing more."

"It's difficult to describe what I went through during puberty. I believe I went through it without really knowing it. It sounds sad now, but I never had the normal concerns about becoming a woman, because I never thought I would become one. I struggle with that everyday. I think when a teenage girl realizes that her body can create another human being, something happens. I think it might instill the idea of responsibility and maturity. That wasn't there for me, because right from becoming a teenager I knew that I couldn't conceive a child. I'm sure there is more to being a woman than just being able to have a baby, but one has to admit it is a major part."

Visit our website at <http://www.med.nus.edu.sg/paed/tsgweb/history.html>

"I believe there's an internal battle that takes place inside everyone. Respect, accomplishments, and intellect are all things we humans crave, and sometimes even demand. For some people, this task is easily completed, but for others it's never attained. I guess that's the chip I lug around on my shoulders. I can't recall a time where I haven't felt that I didn't need to prove myself. Wanting to be seen as someone with something to offer is common, but because of my stature (or lack of it), I feel like I've had to surpass expectations in order to believe I'm capable. Growing up I went by the assumption that no one expected anything from me. I don't know when it happened, but the self pity went away, and I found that my limitations are self imposed. I discovered I didn't want those limitations anymore. I allowed myself to grow up, and become a woman - hear me roar!"

"Sometimes I get a little overwhelmed. I think about my possible career choices, all the decisions I never considered making are right in front of me now. When I realized that I was handling the high school experience, it opened doors for me. I was suddenly seeing myself as a smart and capable person. I could think about Colleges, and I did. I have a diploma in social services (behavioral sciences). I'm working on a diploma in Accounting. I knew I could have a career, and even romantic involvements. I can take care of myself, and make intelligent choices for myself. I deserve to live my life for me, and the things that are important to me, namely my husband, family, and happiness."

"Rob and I celebrated our fifth anniversary on August 27th, 1998. There was some cosmic happening that occurred when we met. I almost instantly trusted him. I could tell him about the Syndrome, and knew that he wouldn't run away. Ten years ago, I don't think I was imagining this. It's something I never thought about... We joke and say that the only reason we're perfectly matched is because no one else would have us. It hasn't always been easy. We have our little tiffs like all couples. We are dealing with something a little different though because of me having T.S. We know that we are going to see each other through any situation. Rob & I feel we give to each other something that would otherwise be missing... I can share anything without the fear of losing him. It's ironic in a way. It's because of his influence in my life, that I've become independent and self respectful. I love him dearly, but I know I would be all right on my own. I think it's important for women with T.S. to know they fulfill their own needs. You don't need someone else to validate your importance. Rob supports me in my endeavors, but I know it's my own desire that will motivate me to achieving my dreams."

"If there is one last thing I get to ever say about what I have written, it is a favor I need to ask any parent or guardian of a girl with Turner's Syndrome. Please don't hide them. Let them learn and experience life. They can achieve as much, or even more than anyone else. Give them the opportunities to shine, and they will. Thank you for reading, and I hope you have enjoyed it. I certainly have enjoyed writing it. From the bottom of my heart, I thank you."

## Psyche Quiz

# Road to your secret self...

### How to do it:

- ✓ **Get ready everything you need – pen, coloured pencils and a piece of paper**
- ✓ **Read through the questions one by one, jotting down your answer or drawing out your response**
- ✓ **Once you've finished, turn the page to see what your answers mean.**

### First of all, imagine you're walking along a road...

1. Describe the condition of the road in as much details as you can.
2. What colour is the road?

### You carry on walking until you come to a river...

3. How clean is the water?
4. How fast is the current?
5. What, if anything, is in the water?

### Hmmm, you need to get to the other side of the river...

6. How do you cross it?

### Phew, you've made it to the other side of the river and are just standing there looking around when you suddenly spot a house...

7. What is the colour of the house?
8. Describe the condition of the house.
9. Does anyone live

there? If so, who?

### You carry on walking and spot a key lying on the road...

10. Describe the condition of the key.
11. What do you do with the key – pick it up or leave it on the ground?

### You continue down the path until you come to something that blocks your way...

12. What is it?
13. What's beyond the obstacle?

### Now turn the page to discover your secret self...



## Get rid of clutter

- Gloria Chan

Have you been telling yourself "I'll clean up my room this weekend" but never got round to doing it?

With the new year just round the corner, get it done this Sunday! The reward is a nice, clean room with everything in its place.

Looking at the state of your room, you probably don't know where to start. Don't panic. Tackle one thing at a time.

Start with your wardrobe, then the drawers, the bookshelf and your writing table. Ever pulled out everything from the cupboard and drawers, and then wondered what to keep or what to throw? It all depends on their sentimental value or whether you have any use for them.

With clothes, the rule of thumb is if you've not worn it in the last one year, you can safely give it away and not miss it.

You would want to keep those knick-knacks and birthday cards you received from your friends. Put them all together in a box and you can go through them and recall all those happy memories on a day when you're feeling down.

Put aside all the photos you've taken during the year and slot them into albums another day. Go through all the old books and magazines. Those books that you don't want, give them away or try selling them to a second-hand bookstore. Tear out articles you want from magazines and place them in folders.

You'll be surprised, spring-cleaning can be very therapeutic. You find yourself coming across items which you thought you had lost for good.

Slowly and steadily, get rid of clutter. At the end of it all, take a long leisurely shower and then jump into bed, and enjoy the feel of a nice, clean room!

## What your answers reveal about you...

You've reached the end of your road so take your answers, read on and discover all about that psyche of yours...

### **The road (Q1 & 2)**

**The way you described your road symbolises the way you see your life at the moment.**

If the path was smooth and freshly tarred, you feel your life is pretty easy and smooth. However, if it was bumpy and riddled with potholes, then you've probably been having a rough time lately.

**Now match the colour you picked for your road. The adjectives indicate how you secretly perceive yourself:**

White: innocent or sheltered  
Black/blue: sad  
Orange/green: confident  
Transparent/shiny: spiritual  
Yellow: carefree  
Grey: confused  
Red: super-excited  
Brown: unappreciated  
Purple: unique of original  
Pink: old fashioned  
Gold: money-oriented

### **The river (Q3, 4, 5 & 6)**

**The way you saw the water represents intimacy or your ability to get close to others.**

The cleaner the river was, the more trusting you are. The murkier it was, the harder it is for you to open up. The faster the river's current was, the quicker you are to leap into a relationship.

If the water was clear or inhabited by harmless creatures, you have mostly had good and happy relationships with others.

If there was something in the water that could have bitten you, then that's a good chance you've been hurt by someone you trusted. Twigs, leaves or branches floating in the river also signify hurting feelings.

### **Crossing the river:**

**How you got to the other side reveals loads about how ready you are to fall in love. The closer you allowed yourself to get into the water, the more trusting you are in a relationship. If you...**

Swam across: you're ready to fall in love because you are happy and comfortable with the way you are.

Stepped on stones or took a boat: you're slow to open your heart

Walked along a fallen rock: you are scared of love but you've also been known to lose your balance and fall in completely!  
Crossed a bridge: you tend to shy away from intimacy wherever possible.

### **The house (Q7, 8 & 9)**

**The way you saw this house symbolises your emotional support system – your parents, family, friends or anyone else who you lean on.**

If the house was in good condition, you probably get lots of affection and encouragement. If it was run down, you probably need a little more attention than you're getting. The person whom you pictured in the house signifies how solid your self-esteem is. If you live in it, you have a good self-image, but if it's somebody else's home, then you don't yet believe you deserve to get everything you want. If the house is empty, this could mean you have trouble bonding with people, especially your parents. The colour of the house symbolises what your family life is like - check the colour list under The Road to discover what the colour of your house truly means.

### **The key (Q10 & 11)**

**The condition of the key represents your outlook on life.**

Optimists see shiny, functional keys, pessimists see tarnished or rusty keys. If you picked up the key, then you're confident in your problem solving-abilities. If you left it on the road, then you're not always sure of yourself when it comes to making decisions.

### **The obstacle (Q12 & 13)**

**The obstacle is the last part of your road trip and represents the stuff that's stopping you from achieving ultimate happiness – this could be a person, a situation or a feeling, and it may be a current problem or something from your past that is still bugging you. Here are the most common ones and what they mean...**

A wall or fence: you keep your feelings to yourself.

A small rock: there's tension in your life but you'll be able to sort it out quickly.

A boulder: there's an important issue that you need to deal with, because it's stopping you from moving on.

An unfriendly animal: something (or someone) is frightening or intimidating you and you're trying to steer clear of whatever it is.

A fallen tree: emotional pain about things that happened in the past might be making it tricky for you to get on with your life.

What you envisaged beyond the roadblock represents how you imagine your life will be in the future. If you saw something bleak, this suggests you think life is going to be hard, and if the view beyond was misty, then your future's not yet clear. If however, you saw beautiful scenery or sunshine, you're looking forward to whatever the future holds.

For more info, check out

[www.roadmind.com](http://www.roadmind.com)

- Printed with permission from "Sugar"

## Q & A

**Recently, I have improved my ability to concentrate along with a strategy...**

- Work on developing positive attitudes towards the work.
- Do not let yourself daydream. Rid yourself of the daydreaming habit by noting down the times when you catch yourself daydreaming. Try to extend the amount of time you concentrate and catch yourself at the beginning of daydreaming rather than letting it go on.
- Make sure you get enough rest. Stop working when you get too tired to concentrate well. Take a break to get some exercise. Some people can take a ten-minute nap and then get back to work refreshed.
- Set aside a place only for study, for eg. a quiet room with good lighting.
- Strengthen your ability to concentrate by selecting a symbol or object related to study, for e.g. choosing an attire that you're most comfortable studying in.
- Set a specific amount of time to complete an assignment and keep to the target.
- Warm up to subjects before class or doing an assignment. Start with a review instead of beginning new work cold.
- To concentrate during class, find ways to be actively involved in your learning for e.g. participate in discussions or take notes in class.

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## Did U know?

- \* The word pullup, racecar and kayak are the same whether they are read left to right or right to left.
- \* One type of deep-sea squid is born with both eyes the same size. As it gets older, though, its right eye grows up to four times bigger than its left eye. Some scientists think the squid uses its large eye to see in deep water and the smaller eye to see in shallow water.
- \* Did you know that the can opener was invented 48 years after cans were introduced? Cans were opened with a hammer and chisel before the advent of can openers.
- \* The names of the continents all end with the same letter with which they start.
- \* TYPEWRITER is the longest word that can be made using the letters on only one row of the keyboard.

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