

Conquering POTS: School Coping Toolkit

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POTS - What it's NOT!

- ✓ “Not all in your head”
- ✓ “You’re not alone”
- ✓ “It’s not life threatening”

Coping with the illness

- Emotional stages and states vary but there is a common theme
 - Denial
 - Anger
 - Bargaining
 - Depression
 - Acceptance

Support

The Tree of Achievement

'cos it all depends on perspective

I did it!
I climbed a tree!



...Perhaps not quite to
the top...



It was still a tree, and I
climbed it!



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School Plan

- Make a school plan.
- Work out a plan that is best for you and which takes into account how you're feeling and how the school can accommodate your needs.
- Some people may need to have home schooling until they are feeling better, then return to school part time and increase school time depending on how they are doing.
- If possible, do this schooling/teaching outside of the house.

School Plan

- Schedule a meeting with appropriate teachers and advisor/counselor.
- Explain POTS
- Work out a plan that is best for you and which takes into account how you're feeling and how the school can accommodate your needs.

School Plan

- Communicate, Communicate, Communicate and if you can do it without your parents!
- Speak assertively so people understand your feelings and what you need.
- Schedule a meeting with appropriate teachers and advisor/counselor
- Explain POTS
- Be prepared to show documentation from doctors

School Plan

- Work out a plan that is best for you and which takes into account how you're feeling and how the school can accommodate your needs.
- Be careful not to ask for special treatment you do not need
- Can cause resentment from other students
- Never use POTS symptoms as an excuse when it is not the reason for the problem
- Teachers can become impatient & less willing to work with you
- Be prepared to show documentation from doctors

School Plan

- Hire an at-home tutor
- Create a Plan:
 - 504 Plan (High School)
 - Extra time for assignments, exams, & projects
 - More travel time between classes
 - Excused absences for appointments
 - Reduce class load (if you can)
 - Find your best time of the day and try to modify your schedule to get the most of it
 - Contact the Disability Center (College)
 - Assistance with travel time between classes
 - Schedule classes at the best time, not too early with breaks in between

School Plan

- Take time to create a balanced plan
- Work out a plan that is best for you and which takes into account how you're feeling and how the school can accommodate your needs.
- Create a Plan:
 - 504 Plan (High School)
 - Extra time for assignments, exams, & projects
 - More travel time between classes
 - Excused absences for appointments
 - Reduce class load (if you can)
 - Contact the Disability Center (College)
 - Assistance with travel time between classes

Back-to-School

- It's normal to be anxious in the beginning!
- Prepare the basics: Nobody copes well when they are tired or hungry – if you are anxious you may forget to eat, which will make symptoms worse.
- Discuss concerns with someone (parent, friend, coach, etc.)
 - Share worst case scenarios
 - What could you do?
 - Develop strategies for dealing with scenarios that worry you

Back-to-School

- Role play different scenarios with someone; play the part of the student
 - Helps prepare yourself for different situations
- Learn ways to redirect your attention away from worries
- Avoid thinking worst case scenario;
- Discuss concerns with someone (parent, friend, coach, etc.)
- Develop strategies for dealing with scenarios that worry you
- If worst case happened, what could you do?

Back-to-School

- Focusing on the worst case scenario causes us to overlook the fun aspects/situations
- **Modify Expectations:** Would someone who had a brain injury or another form of a medical condition be able to immediately return to their previous life?
- Don't let your thoughts get the best of you and like the Nike slogan says:



Back-to-School

- Develop a timeline – Example Below:
 - 3 weeks before
 - Begin waking up, eating, and going to bed earlier
 - Begin doing normal activities again
 - Develop some coping cards
 - “Physical symptoms are not life threatening”
 - “I can get through this”
 - “The odds of passing out are slim and I know what to do”
 - “I’ve felt worse before and got through something similar”
 - Depending on situation, schedule meetings with school team/teachers
 - Arrange for support upon return
 - Connect with friends who have been in school

Back-to-School

- Develop a timeline – Example Below:
 - 2 weeks before
 - Continue waking up, eating, and going to bed earlier
 - Practice some coping skills
 - Meet up with previous friends/peers
 - Visit the school, preferably during a fun class or school activity
 - Slow return if necessary
 - Attend one activity/class a day
 - Start with those that are least difficulty and uncomfortable
 - Think about when you learned to ride a bike –you worked your way up

Back-to-School

- Develop a timeline – Example Below:
 - 1 weeks before
 - Continue waking up, eating, and going to bed earlier
 - Continue practice coping cards
 - “Physical symptoms are not life threatening”
 - “I can get through this”
 - “The odds of passing out are slim and I know what to do”
 - “I’ve felt worse before and got through something similar”
 - Arrange to attend school with a friend
 - Make arrangements to have someone at school to meet with (preferably daily) to discuss progress

Planning Ahead: Strategies

| Problem | Skills | How do I do it? |
|--|--|---|
| Walking long distance is difficult | Social support Problem-solving Distraction | Get people to support you Take breaks Focus on a tree, walk to that point |
| Lack of motivation | Imagery Coping thoughts Social Support | View self as survivor, music I can do this! Be accountable to someone else |
| Tired a lot | Distraction | Get company Sunlight exposure Get excited about something |
| Getting it all done in a day/time management | Life balance | Plan the day, set realistic goals, balance energy skills Plan breaks Revise Plan Reduce stress |

5 Levels of Relationships - What to share & who to share with

Level 1: Low trust “Just the Facts”

Facts are shared –

The weather is supposed to be good this weekend

Level 2: Another safe territory –usually about what other people have said

“I heard the new English teacher is hard”

Ian told me the team was awful last night”

Level 3: Where connections between people begin. Trust helps you disclose your opinion

“That movie was amazing”

“I think smoking is stupid”

5 Levels of Relationships

Level 4: “I feel statements”

- Emotions and Feelings are shared about factual events
- This is where trust and friendships form
- “I’m so upset about my math grade”
- “I am so embarrassed that my father lost his job”

Level 2: Another safe territory –usually about what other

Thinking Right

- The power that our thoughts have over our mood is crazy!
- You can be hanging out with friends and be miserable because your worries are pulling you a million miles away which gets in the way of you being the true “you”.
- Our mind is constantly thinking about a million different things (upcoming test, upcoming doctor’s appointment, annoying siblings, family members, funny, exciting moments).
- Our mind can start to become automatic and think in threatening manor if we think about negative/sad/scary things all the time.

Thinking Traps

- 2 General Types of Tools

1. Let your anxious thoughts come and go.
2. Challenge your thoughts and come up with more helpful self-talk.

Thinking Traps

Handout Provided w/examples

- All or Nothing Thinking (or Black and White Thinking)
- Catastrophizing
- Overestimating
- Fortune Telling
- Overgeneralizing
- Mind Reading
- Negative Brain Filter

Thinking Traps

You can come up with some helpful coping statements/self-statements for a specific situation.

- These are just symptoms.
- I can do this, I will be OK.
- I am stronger than I think.
- I can handle this.
- I can cope with most things.
- It's not dangerous, and it's just temporarily uncomfortable.
- I don't need to assume the worst.

Thinking Traps

- Either you control your attitude or it controls you.
- For example, if you have to debate a topic in front of your class and are afraid of messing up or of others laughing, write down and repeat specific statements to yourself such as:
- Who cares what others think, they won't be perfect when it's their turn!

Thinking Traps

- I did this in class last year and I can do it again.
- I have time to practice. I can ask for help.
- Hey, I can handle this. I've felt bad before and the feeling doesn't last forever.
- If I mess up, what's the big deal? I will laugh at myself with them and keep going.

Letting your thoughts come and go

- "Hmmm, that was a random weird thought that just popped up in my head!"
- "Huh, no wonder my heart is racing more than usual, if that is what my brain is imagining. It's just a thought and I can let it go."
(Example of how to make sure our thoughts are not making our POTS symptoms worse).
- Be curious about your thoughts, without getting caught up in them. It's like standing outside and watching cars pass by.

Coping with Symptoms

Challenge your stinkin' thinkin'

- Is what you are telling yourself really balanced, fair, and realistic?
- To find out, ask yourself the following questions?
 - Have I been in this type of situation in before? What happened in the past?
 - What would my best friend tell me in this situation?
 - What would I tell a friend in this situation?
 - Is there anything positive I am discounting or not remembering?
 - In one month, how much will this really matter?

Coping with Symptoms

Challenge your stinkin' thinkin'

- How much of this is outside of my control?
- Am I blaming myself for something that is not 100% of my control?
- What's the worst thing that could happen? If the worst thing DID happen, what could I do to handle it?
- Are there any other possible explanations?
- Is this a hassle or horror?

Challenge your stinkin' thinkin'

| AUTOMATIC ANXIOUS THOUGHTS | CHALLENGE THAT SNEAKY THOUGHT? |
|---|---|
| “Everyone is looking at me – they think I’m weird or something.” | I have no idea what they are thinking. They would probably look at anyone new who walks in the room.” |
| “They never called me to invite me to the party” | Just because I didn’t get invited to this party does not mean I will not be able to develop friendships with them or others. I just need more time to get to know them. |
| “What if I feel like I can not concentrate in class or feel like I am going to faint” | I may get a little anxious about this but I have been in similar situations in the past. I can tell the teacher I need to leave the classroom and always ask a friend or the teacher what I missed. |

Coping with Symptoms

- Distraction Techniques: Goal – Redirect your attention away from your symptoms. Keep your mind busy so you have less time and mental energy to focus on the pain.

Distraction Techniques

Count how many people around you have same colored socks, shoes, etc

Count colors in your environment

See how many people you can get to smile at you

Count bricks in wall or squares in carpet

Close your eyes & just listen. See if you can identify at least 10 sounds in the environment

Have a conversation with someone about something you enjoy

Play with a pet. Focus on how their fur feels

Accepting the Present Reality

- Acceptance:
 - Does not mean giving up!
 - Turns suffering you can't cope with into pain you can cope with.
 - Is the opposite of “why me?” And “things should not be the way they are.”
 - Life can be worth living, even when there is pain.

Accepting the Present Reality

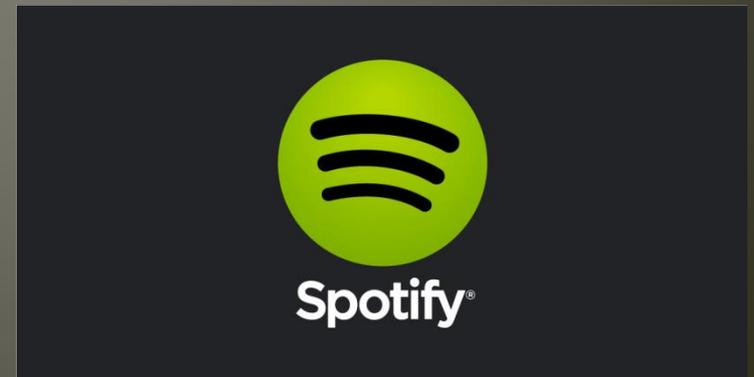
- *Acceptance is a choice.* It is coming to a “fork in the road.” You may have to turn down the road of acceptance to help you improve your functioning.
- 1. Fight “suffering from the symptoms”.
- 2. Fight the “symptoms to get your life back”.

Coping with Brain Fog

- Schedule “thinking activities” before “standing activities.”
- For example taking two part exams in school with a standing part and a seated part, I would request that I always take the seated part first and the standing part second so as not to have the brain fog following the standing affect the seated portion.

Music & Pain

An hour a day keeps the doctor away!



Thank you!

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