



WE HAVE GOALS

My Dystonia & I

A PATIENT-TO-PATIENT
GUIDE

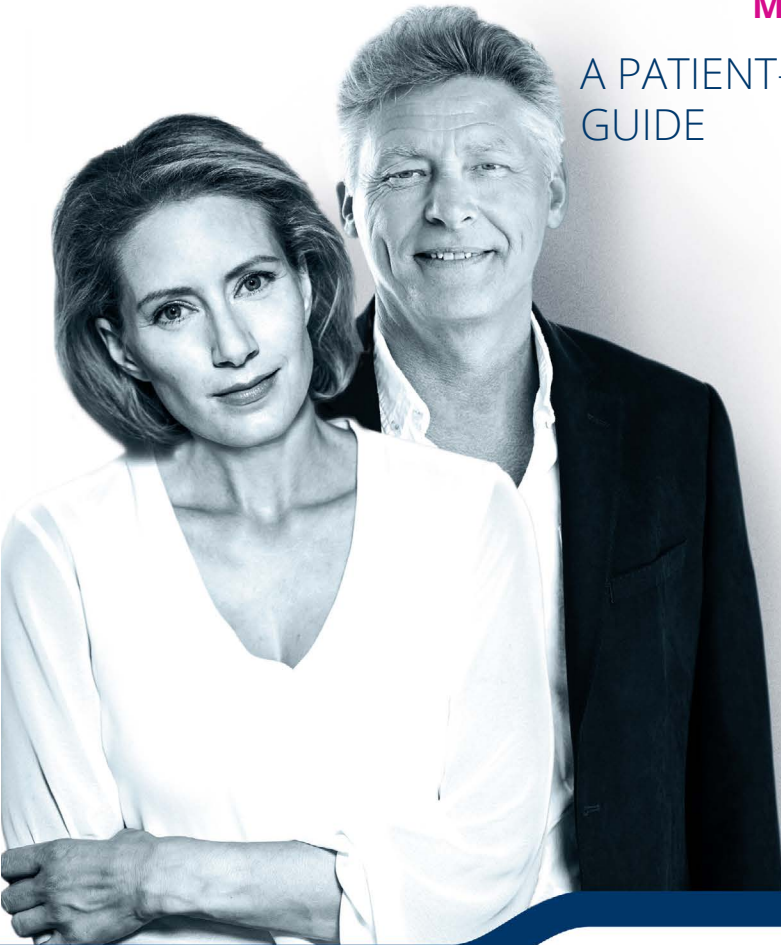


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I AM SYBIL

Managing my Depression

THIS IS HOW I COPE WITH THE PHASES OF DESPAIR

Sybil 43, Office clerk,
living with dystonia for 9 years

This can't go on like this.

I have tried everything, something
must be out there!

An example of my withdrawal: I creep away in the evening



Situation

My thoughts and behaviour

My last injection was already three months ago

I am upset with my progress and envious towards others who are feeling better.

My body tweaks and pulls

I try to ignore it.

I rely on my injections, whether I like it or not.

I feel like I am failing.

I exercise and release my posture daily.

I've tried everything. Even alternative exercises through the internet.

I go back to bed.

I'm fed up!

After the low: now I ask myself the important questions!

What exactly frustrates me?
How do I evaluate my condition?

- I don't want any pity from others.
- I don't feel like going out.
- Nobody notices that I am alone.

At least watching TV without pain -that would be good.

All the things I could do without dystonia!

No one calls me anymore.

How did my **body** react?

- My muscles were pulling more and more. My neck did what it wanted.
- Nothing helped. Not even any of the small "tricks".

What **thoughts** went through my mind?

- Why can't I just live like everyone else?
- I can't think about anything else.
- I am angry and feel helpless.
- Typical me- everything is going wrong!

How did I **act**?

- I cancelled our girl's meeting.
- Then I crept into bed.
- I tried to first find the best sitting position.

This is how I will help myself in the future: I will pay attention to my thoughts, my body and my behaviour.

Thoughts: small goals, and do not compare!

- Botulinum toxin does not solve my problems- it offers possibilities!
- I will control my thoughts and do what I have planned.
- I will not compare myself to others- that triggers negative thoughts.
- Being alone can also be nice.
- Sad thoughts are normal- but I shouldn't have them too often.

Body: ups and downs are normal!

- I know that my botulinum toxin always needs to be re-injected.
- I will go to treatment regularly - this way I don't always have to think about it.
- Botulinum toxin doesn't cure the disease, it improves the symptoms.

Behaviour: activities block negative thoughts!

- I will plan my evenings and weekends to be active.
- I will pay attention to the nice things in daily life.
- I will schedule the best intervals for my botulinum toxin treatment and stick to them- always.
- If it helps, I will seek support from a psychotherapist and self-aid groups.
- I won't blur out symptoms and negative feelings with alcohol.

My notes:



I AM THOMAS

Finding Satisfaction?

THIS IS HOW I CONQUER THE DAILY UPS AND DOWNS!

Thomas 52, logistics coordinator,
living with dystonia for 14 years

My path is retirement, not this disease!

My life is good, but with dystonia
I have become tired more often.

An example of dissatisfaction: Weekly grocery shopping



Situation	My thoughts and behaviour
Late afternoon grocery shopping	<i>Why is it so bad again today?</i>
It's painful when I take groceries off of the shelf	<i>I am frustrated and want this to stop!</i>
I always pay attention that no one is watching	<i>It was much better yesterday! I can't take it.</i>
I made it, but it was hell!	<i>This will not go away. I'll need to get used to it.</i>

More often dissatisfied: now I ask myself the important questions!

What exactly frustrated me? How do I evaluate my condition?

- This is getting worse compared to yesterday.
- It's embarrassing in public.
- It was just harmless grocery shopping.

Is this possibly the beginning of the end?

My "wobble head" continues to happen.

I am angry about my limitations.

How did my **body** react?

- The pulling became stronger. My neck did what it wanted.
- The sensory trick with my hand did not work.

What **thoughts** went through my mind?

- I believed that strangers thought I was crazy.
- I dramatized it more and more.
- Nothing was working!

How did I **act**?

- I turned myself so that hopefully no one could see it.
- I only concentrated on the dystonia - and forgot half of my groceries.
- I didn't want to ask for help for the high shelves.
- I wanted to go home as soon as possible.

This is how I will help myself in the future: I will pay attention to my thoughts, my body and my behaviour.

Thoughts: express them and don't compare!

- I will try to free myself from shame.
- I will not compare myself with healthy people or the ideal situation.
- I will mentally prepare myself to be able to explain in short order, even to strangers.

Body: take care of yourself on your own!

- It is important that I get enough sleep.
- Regular treatment of my symptoms and a good pain management plan will help me cope better.
- I will not go constantly from doctor to doctor - this just adds stress.

Behaviour: stay positive and realistic!

- I will judge my symptoms according to a regular measurement, e.g. school grades.
- I will prepare 2-3 short, understandable sentences to explain my symptoms; and adjust them to my situation.
- To better control the dystonic ups and downs, I may eventually make use of professional help in the form of behaviour therapy.

My notes:



I AM CAROLINE

Career Challenges:

THIS IS HOW I MANAGE MY STRESSFUL JOB LIFE

Caroline 38, web designer,
living with dystonia for 6 years

The more important the situation,
the more the cramps increase.

When I need to sit still it's especially bad.

An example from my job: The meeting with my boss



Situation	My thoughts and behaviour
It's 9 o'clock in the morning and I am sitting in front of my boss	<i>I am totally tense, and I hope she doesn't notice anything</i>
It's really important: it's a difficult project and I am a specialist in this area	<i>I see her glance. But she pretends it's nothing.</i>
I am not getting to the point.	<i>I am distracted. I notice that the symptoms are also getting worse. Then I panic even more.</i>
We agree that the project "still has some time" and that I will revise the concept again.	<i>I would prefer to avoid this situation-or just sink into the ground. In a nutshell it really went bad.</i>

After the meeting: now I ask myself the important questions!

What triggered the stress? Which thoughts did I have?

- Requirements
e.g. sitting still.
- Meaning of the situation.
- My boss' reaction.

*Don't wobble!
Don't even cramp!*

*It's important.
Can't fail now!*

*Did she look at me
awkwardly?*

How did my **body** react?

- The first signs of my tension are slowly building up.
- It became harder and harder to cover-up the tension.
- As the tension increased - the symptoms did as well.
- I didn't sleep very well the night before.

What **thoughts** went through my mind?

- If this continues then I can forget about my job!
- Oh my gosh, my existence!
- I have always managed everything before!

How did I **act**?

- I was panicking and nervous.
- I became jittery and was distracted.
- I disconnected early on.

This is how I will help myself in the future: I will pay attention to my thoughts, my body and my behaviour.

Thoughts: end the negative spiral!

- I will concentrate on the task and not search for critical signs.
- I will actively pay attention to what went right.
- I know that I can control critical situations.

Body: block the acute increase of symptoms!

- I will pause for a moment.
- I will relax and concentrate on certain body sections.
- I will make a plan to counteract the symptoms.

**Behaviour : don't avoid critical situations-
speak openly about them!**

- I will not avoid or shorten important situations.
- I will not jump into the situation, but I plan beforehand.
- I will actively manage the situation (eye contact, clear voice, etc.).
- I will address the situation myself (in 2-3 short sentences).
- I will keep it short and comprehensive (simple language, no technical terms).

My notes:



I AM ROGER

Expectations and anxiety about the future:

THIS IS HOW I FACE MY FEARS

Roger 49, travel agent,
living with dystonia for 8 months

I will prevail over this disease.

An example of my fear: a friend's birthday



Situation

My thoughts and behaviour

Engaged in conversation - the symptoms were almost gone.

One of my friends noticed and now thinks I am crazy- but doesn't say anything of course

I actually wanted to introduce my new partner to my friend

I prefer not to, instead I try to ignore the symptoms

I am constantly given good advice and suggested "great therapies"

I don't want to constantly talk about my dystonia. I am more than my disease!

The day after: now I ask myself the important questions!

What exactly am I afraid of?
What does my future look like?

- I am only surrounded by healthy people.
- Everyone has so much “understanding”.
- Everyone recommends something different to me.

I don't want to constantly speak about my disease.

I just feel like I don't belong.

They should just leave me alone!

How did my **body** react?

- It betrays me - once more.
- Initially it was o.k., but then it got worse.

What thoughts went through my **mind**?

- This can not go on like this!
- I am constantly thinking about my future as an ill person.
- There has to be something, I can't stand it anymore!

How did I **behave**?

- In the beginning I tried to stand in a way that no one would see.
- In the end I only concentrated on the dystonia.
- Finally, I just left- why did I even attend?

This is how I will help myself in the future: I will pay attention to my thoughts, my body and my behaviour.

Thoughts: capture the anxiety about the future!

- I will concentrate on the present.
- I am always mindful that the effect of botulinum toxin diminishes in between treatments.
- I am aware that my symptoms increase when being stressed or sad.

Body: poor expectations trigger stress!

- The dystonia is visible, but I can control the daily fluctuations.
- As my problem is physical, I can point it out myself.
- I know that a few treatments are necessary until a good result is achieved.

Behaviour: only give the dystonia what it needs-but not more!

- I will talk with my doctor about my treatment options with botulinum toxin.
- I am in charge, not the dystonia.
- I will take care of my mental health:
I will look for support when I need it.
- I will not leave uncomfortable situations.



In cooperation with: Institut für Psychologie, Martin-Luther-Universität,
Halle-Wittenberg, Prof. Dr. Bernd Leprow

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MTE-157