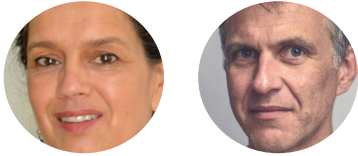


# Dystonia: what it is like, what it is, and how to help people suffering from it



By Alexandra Mazek and Christian Steineder

**D**ystonia is the third most common neurological movement disorder after tremor and Parkinson's disease. Today there are many scientific articles discussing different aspects of dystonia. However, explicit and effective assistance is rare.

In this article we want to provide general application oriented information concerning dystonia. We want to show how A.T. principles can help to deal with and even overcome dystonia. The article is based on our personal experiences. We both suffer from dystonia, and we were greatly helped by the A.T. Today we both work as Alexander Technique teachers. Alexandra has taught the A.T. for 19 years, Christian for three years.

The article is organised into three main parts. Each part is devoted to one of the questions:

- A) What it is like to have dystonia?
- B) What is dystonia?
- C) How to work with people who suffer from dystonia?

## A) What it is like to have dystonia?

We were both affected by dystonia at an early age, 27 and 25. In Christian's case it affected the hand, in Alexandra's, the voice.

### Christian's story

When I was 25 I wanted to handwrite a letter after a long break from writing due to an extensive summer trip. However, I had to realise that I could not write any more. Whatever approach I tried, my hand cramped immediately. Unfortunately this state never improved for the next couple of years, no matter how hard I tried. Being a mathematician, my working devices were pens and paper, so this condition meant not only daily stumbling blocks, but also professional troubles. I was highly ashamed of this problem and therefore understated my troubles to my friends and associates as well as to medical professionals. Even so, the typical reaction was a lack of understanding. Even when I eventually knew that I had a condition called "writer's cramp", there seemed no way out of my situation until I found the Alexander Technique and my teacher – Alexandra.

### Alexandra's story

When I was 27, I suddenly lost my voice after a cold. It sounded like a bad telephone connection: my voice was interrupted when I tried to speak the vowels a, e, u or o. Talking to strangers, ordering coffee from a waitress, and even saying "hello" in passing became very difficult. Eventually I had to give up my job in an international development project. Interestingly, my voice was not always the same; It worked almost normally in some situations, for instance when speaking to a pet, or to close relatives, but of course, the more a situation was perceived by myself as "important" or "a challenge", the worse it got, the decisive factor being fear. Sadness made speaking even worse, whereas being angry gave strength to my troubled voice. When something does not work, one tries harder, and trying harder made it worse. Nobody knew what it was, until years later I found my condition described by an Alexander-Teacher in a STAT newsletter. At last I got a name for my condition.

## B) What is it?

Dystonia is described as a neurological movement disorder. Too many excitatory impulses are sent from nerves to muscles, causing cramps.

There are different types of dystonia. The people who are most likely to contact an Alexander Teacher are those suffering from focal dystonia. Focal dystonia can affect the voice, the neck (torticollis), the lips, eyes (blepharospasmus) and the hand/fingers (writer's cramp).

Dystonia can be triggered by:

- a goal (for example trying to perform well, a desire to appear "normal" when watched by others),
- contact (for example of the fingers with the strings or the keyboard, the lips when getting in contact with an instrument)
- movement (walking, twisting the arm in order to, for example, hit a ball),
- posture (holding an instrument in a certain position),
- pressure (pressing fingers against a drum, or a pencil, for example).

It should be pointed out that dystonia is a highly individual problem: the triggers, the involved muscles, the degree of cramps, the connected psychological patterns - all of these strongly vary from patient to patient. This makes it very difficult to find possible targets for treatment. An approach that has positive effects for one client might be even counterproductive for others.

It used to take years for people with dystonia to be diagnosed. Nowadays the illness is better known, and the chances for a person with dystonia to find his or her way to a neurologist are good. Most likely the doctor will suggest trying botulinum toxin injections if there are relatively few muscles involved. Botulinum toxin immobilises the muscles for some time (three months on average). Antidepressants are often prescribed as well. In any case, the neurologist will dutifully inform the person: "Whatever you try, there is no cure for your condition. You will have to live with it."

We think that there is an alternative outlook based on the principles that:

- a) the brain is changeable,
- b) there is no rigid dichotomy between healthy and ill. We are somewhere in-between at all times, and
- c) A LITTLE BETTER IS BETTER.

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Let us illustrate in particular the last point: I, Christian, experienced dystonia as a highly irrational condition. My hand worked without any problems in almost all situations – I could eat with a fork, I could even “write” with pens with caps on – but it cramped in an inexplicable way as soon as I was trying to use the pen to actually bring my thoughts to paper. Due to this on-off state, I was tempted to do everything I could to understand and eliminate the whole problem at once. I thought since there is one very specific situation which causes my troubles (writing), I only need to understand what is going on, and then I will be able to remedy my problem immediately.

However, a movement is a combination of many ingredients: it has to be coordinated in time (too early vs. too late), in pressure (too soft vs. too hard), and in size (too big vs. too small). To perform a movement, all these parameters must be applied with a more or less suitable equilibrium. But in my dystonic pattern, several parameters were askew. Changing even the smallest of any of my miscalibrated parameters towards the desired equilibrium meant a step towards dissolving my dystonic pattern, even if I did not understand the progress immediately. That is, in short: (Only just) a little better is (already a lot) better.

### C) How to work with people suffering from dystonia?

The rest of the article is devoted to practical information. First, we will try to describe the feelings that are most likely to accompany the condition and practical problems which arise out of it. Then we come to the central point of this article, the presentation of a toolkit. We will discuss:

- crucial symptoms of the illness in light of the key principles of the AT,
- how and why the A.T. approach can help, and
- which adjustments to our usual A.T. work are necessary.

#### First encounter

Unlike a person with spastic movements due to a birth trauma, the client with dystonia has lived a perfectly normal life before disaster struck without any obvious reason. Most likely, they’ll feel deeply ashamed of not being “normal” and being unable to live up to their ambitious standards. On top of this, they may have lost their job already or are afraid of losing it. In this situation, they try as hard as they can. Eventually however, if no help is in sight, a person might lose hope and withdraw.

For the teacher it presents a difficult situation. Here is someone in desperate need of your help, and you might start end-gaining because you want to help them. For example the client with a torticollis, whose head is pulled into an awkward direction with great force. The wish to take the weight of the client’s head may be very strong, and yet it is important to stick to principle and not to work directly for an immediate relief.

Things to tell clients with dystonia are:

- that a long path lies ahead,
- that on this path, every little bit of progress is an improvement, (a little better is better),
- that setbacks are part of the journey to recovery, and the only thing that matters is that there is progress in the long run.

The teacher should be prepared for the setbacks as well and help the client to

1) discover reasons for those setbacks. This is very important because it will help to demystify the condition. Lack of sleep, quarrelling with a family member, an unusually long exercise, or just preparing for a weekend holiday, these are just a few examples for incidents that increase stress, and increased stress will often bring about a deterioration. Asking the client if something special happened (e.g. if they did something unusual) and linking those incidents up with the setback helps a lot too.

2) meet the setbacks with an optimistic attitude and a renewed enthusiasm in the process of getting better.

Even if there is no “rational” reason to be found for a setback, this might be due to our lack of understanding of how the brain works, and how it controls movements.

#### Excitability

People with dystonia suffer from the same problems and misconceptions as other clients: faulty sensory appreciation, need for tension, wrong body maps... just in an amplified form. Whatever process causes the dystonia (scientists presume it lies in the basal ganglia), the fact number one to take into consideration is that a person with dystonia is highly excitable.

The excitability was there long before symptoms of dystonia appeared. It means that for this person, so much positive experience is linked to excitation: for instance, for them feeling happy means feeling excited, being creative, feeling motivated, fun. You might say that dystonia is an addiction to muscle tension and excitement.

So, from an A.T. perspective, the first step would be to facilitate movement without excessive tension. The clients will eventually experience moments of wellbeing without so much excitation and will then have more choice on their journey. Alexandra: “The gentleness of the Alexander touch and the wholeness that I experienced opened my view to another possibility of being. Rather than jumping into the lake with a pounding heart, it is like gliding over its frozen surface, while the heart expands quietly to take in the whole big picture.”

#### End-gaining

We mentioned that the person who is unable to do things that used to be natural will try harder. As A.T. teachers, we know that dysfunctional tension results from feeling a need for tension.

Typically the patient will go through the following phases:

- a) feel the need for tension and be unable to control it,
- b) with help from the teacher the need for tension will be felt, but the client becomes able to control it,
- c) eventually the need for tension will cease.

This is what happens with all pupils, but the individual with dystonia feels this need for tension to a greater degree.

A second aspect of end-gaining which usually affects a patient with dystonia is an extreme over-focus – the place of trouble is like a black hole which entirely attracts the patient’s attention. As soon as the dystonic movement is to be performed, the awareness narrows down just to this movement.

For instance, when I, Christian, had to write something, I totally forgot what I wanted to write; the writing itself was the only thing I could think of. When I, Alexandra, speak, and the focus shifts from “Me, Speaking!!!” to the content, my voice usually improves.

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Both aspects mentioned here can be addressed by the A.T. teacher. Using suitable procedures and (micro) movements, the A.T. teacher can help the client to gradually (a little better is better) experience the possibility of performing the movement without the tension and the over-focus. It is important for these challenges to be small but interesting, in order to distract the client from his/her habits (e.g. draw attention to the alternation of tongue pressure against the hard palate and release while doing tatata, to distract from listening how it sounds). Eventually new pathways are created to perform the problematic movement. Of course this process is strongly connected with inhibition – we will discuss this below.

Imagine someone who is constantly encountering situations where they fail. The fear of being wrong becomes a constant companion to such a person. The person often feels extremely ashamed if she/he is not able to perform a movement correctly or speak correctly. If we explain to the client how the will to do the right thing has been linked in the brain to the wrong movement, it will then be easier to convince them of the necessity of making mistakes and of feeling wrong. It will help them to be more willingly wrong. For example: one of my, Alexandra's, clients experienced an improvement in her speaking when I asked her to be more sloppy. She realised that the demand for being "correct" "proper", "precise" had hampered her.

#### Unreliable sensory appreciation: Faulty motor maps

Learning to distinguish between what happens and what we think is happening is as essential for people with dystonia as it is for others. It is important to discover the strange sensations that often lead to the exaggerated muscle tension which often precede the dystonic pattern. For example, the guitar strings suddenly feel too hard and tension is increased, or a tabla player who used too much force because he perceived the skin of the drum as slippery. In people suffering from torticollis, who experience uncontrollable twists of the head, the perception of the internal axis is completely distorted, and the turning of the head is related to a twist of the whole body which the client is not aware of.

#### Recognition of the force of habit

Dystonia sufferers tend to think that whatever happens is due to a dystonic pattern. We can assist them to learn to distinguish between:

- the actual muscle cramps,
- bad habits, and
- compensatory movements.

The teacher should be aware that the focal dystonia affects only one or very few muscles, and all the other tensions respond to our procedures normally.

Let us take the example of a client who could hardly walk because of a dystonia affecting the back muscles. She had a tendency to turn her head to the right and therefore always looked left with her eyes, and there was the neck sagging forward, accompanied by an extraordinary downward pull of the shoulders and a strange walking pattern. And, yes, there were cramps in the back. The journey for both the client and the teacher starts with understanding that most of the unwanted movement patterns respond to conscious guidance and can eventually be controlled. It is of paramount

importance not to focus on the dystonic muscles but to attack the dystonic pattern in inverse order. That is, one should filter out compensations and start working on them to give the pupil – in the best case – the possibility to experience ease when releasing the muscles responsible for these compensations.

#### Non-doing; inhibition

"Neurons that fire together wire together. When they fire separately, they disconnect. Unused connections are weakened and lost." Being moved without having the responsibility of doing the movement affected by the dystonia correctly, has a very healing affect. Christian: My teacher, Alexandra, moved my arm and even wrote with it while I was inhibiting. This experience was the first positive encounter with writing that I had had for years. To experience such moments of success when inhibiting/doing less is even more noticeable given the excitability of dystonic clients.

When the client becomes able to postpone a response – at first once, and then more and more often, it shows, as Joachim Farias, a therapist specialised in dystonia, writes, "that recovery of control process is being established".

To get a person to calm down is progress, even if nothing else appears to change.

So far so good – we have achieved some results, and our client has calmed down. Is that all the A.T. can do? Not if we are ready to make some adjustments to our usual A.T. practice in order to respond to the special needs of someone with dystonia.

#### Adjustments to consider

No standard directions for the dystonia client.

Ideally, directions in spoken word are linked up with the experience. Even if we achieve this link, the client with dystonia may need a lot more repetitions than usual, in order to understand how to direct for themselves. No direction may be better than wrong direction and overdoing. Take for example "widening between the shoulders": if a person turns her head to one side, more widening between the shoulders will most likely result in a greater amplitude of a twist. This is not a problem, but it has to be understood by the teacher, and the teacher needs to consider when the pupil is able to understand the complex, three dimensional impact of the direction.

The direction must be firmly linked with an experience, as F. M. Alexander mentioned. (From *Constructive Conscious Control*: "...such a technique involves correct manipulation on the part of the teacher in the matter of giving the pupil correct experiences in sensory appreciation, in the spheres of re-education, readjustment and co-ordination.").

#### New pathways: The need for planned training

The right thing might not do itself, even if you stop the wrong, because it has to be learned from scratch. It takes more than inhibition and direction to create a new pathway in the brain of a person with totally confused motor maps: There is a need for planned training, for example

- different grips,
- carefully measured degrees of pressure applied to the strings, the keyboard, etc.,
- skilful assessment of components of movements, taken in small steps and practiced as such.
- To restore the voice, planned training can include

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simple sounds like humming, sssss and fffff (forget the whispered ah, it is much too difficult a procedure for a dystonic voice, at least for a long time);

- awareness of different positions and pressures of the tongue in different consonants;
- directing and diverting the clients' attention away from listening to herself and anticipating the wrong and troubled voice.

Recent findings of neuroscientists in the rehabilitation of stroke patients show that the brain needs considerable time and many repetitions to generate pathways for movements where they have been lost.

There are specialists who work with clients with dystonia, like Joaquim Farias in Canada and others. They are good at designing rehabilitation exercises that might be a necessary addition to the Alexander work. Since the client will then have to take long trips to meet those specialists, the Alexander-Teacher at home will be of invaluable help to the client to practice and monitor the daily exercise routines.

Neuroscientists tell us that brain training is slow, chaotic, and unpredictable. If there is no visible progress, it does not mean that nothing is happening.

### Unity

Dystonia exemplifies the fact of psycho-physical unity: the inability to stop is apparent in thought, emotions and muscle movements. Healing is required in all these areas. For me, Alexandra, a meditation practice that focuses on the heart ("heartfulness" meditation), helps me to become connected to my inner being and to calm my thinking.

It is a fact that hormones regulate processes during a phase of neurological change, and depression hinders many recuperation processes (serotonin and noradrenalin inhibit acetylcholine which is excitatory for muscles, for example). Thus it is important that the client finds the optimism and positive outlook to facilitate change. Working with a depressed client without addressing this particular problem may be daunting and eventually frustrating (for the teacher and the pupil).

### Be happy

I, Alexandra, remember that from the very beginning, when I realised that I had come across a serious problem in my life, I felt "this has a purpose". That feeling gave me great courage.

I, Christian, remember that I always saw dystonia as a challenge. Even if there were many moments of frustration, the curiosity to understand "what is going on with me" always maintained the upper hand. I also realised that even if dystonia limits my life on one hand – literally! - it gives me the chance to grow.

How can a person find the confidence that, eventually, all these troubles are for my own good? In his famous book *Flow: The Psychology of Optimal Experience* Mihaly

Csikszentmihalyi writes that a person can feel happy or unhappy, independent of what is going on outside if he/she changes the content of his/her consciousness. Joachim Farias compiled a reading list for one of my clients when she went to see him. One book on the list was *The Brain that Changes Itself* by Norman Doidge, another one was *Superbrain* by Deepak Chopra. Reading those books definitely helped my client to keep her optimism on the long journey towards her recovery. Another client found great comfort in singing and yodelling. And we, as their teachers, can radiate our confidence in a happy ending...

The fairy tale of Iron Henry comes to my mind. Iron Henry must bind his heart with three iron bands to prevent it bursting from the sorrow and concern he has for his master, the prince, who has been cursed. When his master is saved and restored, Iron Henry is so relieved and happy that the iron bands around his heart break and snap off with his great joy.

And when they had gone a part of the way, the prince heard a sound at the back of the carriage, as if something had broken, and he turned round and cried:

"Henry, the wheel must be breaking!"

"The wheel does not break,

"'Tis the band round my heart

That to lessen its ache,

When I grieved for your sake,

I bound round my heart."

Again, and yet once again there was the same sound, and the prince thought it must be the wheel breaking, but it was the breaking of the other bands from faithful Henry's heart, because it was now so relieved and happy."

