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# ALTERNATIVE TREATMENTS TO TREAT CERVICAL DYSTONIA

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APRIL 19, 2016



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59 **Prepared for: Instructor, Bob Megens, Researching and Reporting**

60 **Prepared by: Marleny Sloan - Marleny75@hotmail.com**

61 **Submission Date: April 19, 2016**

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**TRANSMITTAL LETTER**

APRIL 19, 2016

Massage therapist; Stacey Miller

Essential Balance

227 Mitton Street

Sarnia, Ontario

Dear Ms. Miller.

I have completed a report that investigates the current alternative treatments to treat Cervical Dystonia.

The research revealed that three major institutes treat the condition using a natural approach. The patients can do this treatment with a combination of Botox injections or by itself.

I conducted a survey for an online support group which members suffer from the condition in order to find out if they were aware of these institutes that offer the physical rehabilitation program.

I completed an interview for two of the professionals that provide these alternative treatments which led me to the conclusion that for the program to be successful, clients have to commit to it and understand that it is a long process.

Based on these findings, the report recommends that patients should do the following to achieve a better quality of life:

Look for an online support group and family members counseling for them to understand the condition and be a great encouragement for the patient to follow the rehabilitation program with a definite attitude.

Patients should follow the program as prescribed to see positive results

In most of the cases, patients can benefit to complement the rehabilitation treatment with other therapies to address any other physical and psychological issues that accompany this condition.

Is vital to create and organize a daily activity to find a life purpose.

The goal for this is to get some stamina and good energy to reach a good balanced life style.

Thank you for the opportunity to complete this investigation.

You can contact me at: marleny75@hotmail.com if you have any questions about the report.

Sincerely,

Marleny Sloan

## **Executive summary**

For this Report I tried to research the best alternative treatments to treat people who suffer from cervical dystonia. These people can reach out for any of these treatments to help themselves achieve a state of recovery and learn to manage the debilitated symptoms characterized by this condition.

The institutes that offer the best alternative treatments are:

- S. T. R. Recovery Clinic; Abigail Brown Director
- Dr. Farias, Neuroplasticity Training

• L. Cross Training Institute

The Dystonia Medical Foundation of Canada and the Dystonia Organization of UK are an excellent source of information for people who suffer from different types of dystonia. They offer up to date new treatments, medications, and support for patients and family members.

I conducted a survey to an online support group which has 60 members, and 24 of them completed the questionnaire.

I learned from the survey data how individuals who live with cervical dystonia help themselves to find a way to better cope with the condition. Some of them have been very active on researching alternative therapies.

They had tried: Botox as a medical treatment, chiropractors, physiotherapy, massage therapy, stretching, meditation, acupuncture, etc.

Ninety percent of the people are aware of S.T.R. Recovery Clinic whose director is Abigail Brown and 60% of the people know about Dr. Farias neuroplasticity training, but only four people have tried it, and none of the people were aware of L .Cross Institute in Germany.

The interview with the professionals that offer the alternative programs states:

- That people can reach improvement in the condition and control symptoms when they are consistent with the program and follow the recommendations.

- They can complement the treatment with botulinum toxin injection. It is crucial to address other issues for the treatment to be successful.

- These programs work in conjunction with different physicians; they can assist patients where dystonia has affected other parts of the body.

- Family and psychological support are fundamental to achieve an optimal quality of life.

## **Conclusions**

Based on the information provided from these professionals in treating cervical dystonia with alternative treatments we can conclude the following:

the effectiveness of these approaches and that they are free of side effects and positive results by managing the symptoms of cervical dystonia and obtain, maintain a high quality of life, with Botox as a complementary treatment or without it.

149 Dr. Farias learned that damage to the cerebellum and frontal lobe were some of the causes of developing the  
150 condition. He uses Neuroplasticity to heal these areas of the brain by applying these therapies:

151 Neurostimulation, Neuromodulation, Neurorelaxation and Neurodifferentiation.

152

153 L. Cross therapy uses a unique device called Acromipelvimeter for constant review of statics and pelvis  
154 alignment. The patient has to perform the exercises in front of a mirror so he/she can be aware and maintain  
155 proper alignment of the head and neck.

156 Patients interested in this rehabilitation program need two weeks to learn the rehabilitation exercise which  
157 takes around 45 minutes.

158

159 S.T.R. Recovery Clinic: Abigail Brown, director

160 Patients can take this course directly in the clinic or as a long distance program. The Director provides a  
161 manual which contains all the training exercises printed and a DVD to guide the patient to perform the  
162 exercises correctly. She offers a DVD that shows specific Cervical Dystonia massage for patients, water, and  
163 gym activities.

164 The manual contains the recommendations and support to go through the program successfully and achieve  
165 recovery.

166 Based upon literature found on the Internet and periodical databases we conclude that Botulin toxin is the  
167 primary treatment for cervical dystonia but when Botox injections stop working, patients can benefit from  
168 alternative therapies to manage the symptoms of cervical dystonia and be able to function and perform basic  
169 tasks. (stated as see appendix B)

170 The goal of physical therapy is to increase and preserve range of motion, strengthen weakened muscles and  
171 stretching exercises to elongate them.

172

### 173 ***Recommendations***

174 Based on the information obtained from the institutes that treat cervical dystonia and from the experiences of  
175 patients that have successfully managed the symptoms from Cervical Dystonia, we can recommend the  
176 following:

- 177 1. To be successful in recovering from the symptoms of cervical dystonia patients have to adopt a  
178 significant commitment towards the training exercises, and be aware of postural habits patterns.
- 179 2. Patients have to understand that it is a long process and a lifetime commitment to manage the  
180 symptoms and achieve a productive and better quality of life.

- 181 3. The patient should keep a positive attitude to be able to continue the program.
- 182 4. The rehabilitation training can be a treatment combined with botulinum toxin or without it.
- 183 5. Understanding that people who do not use Botox injections, in most of the cases, can achieve faster  
184 recovery.
- 185 6. It is vital for the patient to address any personality issues, behaviors, thoughts, emotions, anxiety,  
186 depression and stress levels to have good mental health, so the body and mind will work in harmony.
- 187 7. People who suffer from the condition should look for support for himself/herself and family members  
188 to understand and learn more about the condition.
- 189 8. It is beneficial and healthy to find an enjoyable activity and have an organized daily routine which can  
190 bring happiness and purpose to their lives.

191 Some of these therapies have been found helpful besides The Rehabilitation exercises:

- 192 • Cognitive behavioral therapy
- 193 • Pain management program
- 194 • Different types of meditation, especially ones that can balance mind and body connection.
- 195 • Stress management
- 196 • Biofeedback

197 9. Daily activities to enhance body movements and energy:

198 Lower stress exercises: such as water exercises, swimming, walking, some yoga postures, low impact aerobics,  
199 stationary bike riding, dance classes, and some coordination exercise (stated as see appendix B

200 In the early stage of the condition, once it is diagnosed , if it is possible , people should start doing some  
201 physical rehabilitation to avoid using Botox injections to soon and start learning how to manage the  
202 symptoms of Cervical dystonia, before they progress to the point that it is difficult to accomplish the  
203 rehabilitation exercises.



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    Figure 2-----3

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**INTRODUCTION**

The investigation is about Treating Cervical Dystonia with alternative methods.

Cervical Dystonia is a neurological movement disorder. It is most commonly treated medically using oral medications, Botox injections to paralyze the muscle or with surgery. There is no cure, but people can learn to manage the symptoms. Some can recover or go into remission.

242 I am interested in this topic because I have been living with the condition for five years. Current medical  
243 treatments are not enough to treat and manage the symptoms of the disease, so there is no hope for people  
244 that have to live with the painful and psychological symptoms when these treatments do not work  
245 successfully.

246

### 247 ***Objective and scope of the investigation***

248 The purpose of the study is to research the alternative methods available to treat Cervical Dystonia and find  
249 the persons or facilities that have the expertise to provide the service to treat this type of disorder.

250

### 251 ***Rationale/Benefits***

252 It is important to research and evaluate alternative treatments that will help people cope and live a better  
253 quality of life by managing the symptoms when medical treatments like Botox, or medications have not  
254 worked. There is a lack of awareness of the condition because it is very rare and difficult to diagnose because  
255 symptoms are very variable in different people making it hard to diagnose.

256

### 257 ***Methodology***

- 258 1. I will begin my investigation of the alternative treatments to treat Cervical Dystonia by going to the  
259 Dystonia Medical Research Foundation of Canada, and The Dystonia Medical Foundation.
- 260 2. I want to learn the early symptoms of the disease and the various causes. It is critical to recognize  
261 these signs to see if there is any advantage in implementing alternative treatments before the  
262 condition gets worse, because once the Cervical Dystonia progresses, a person experiences many  
263 adverse physical changes and in most cases, chronic pain.
- 264 3. I will then investigate the psychological aspects of Cervical Dystonia, how it has changed the lives of  
265 people affected and locate resources for counseling patients and family members. I will use periodical  
266 databases and the Internet.
- 267 4. The reason for looking into this essential points is that a big part of the struggle for the Cervical  
268 Dystonia sufferer is to be correctly diagnosed by medical practitioners because it is rare and there is a  
269 lack of understanding.
- 270 5. Once I research the most effective alternative treatments to treat the condition, I will present them to  
271 the online support group, evaluate them, and have the group identify those which have proven most  
272 successful. People will learn and understand more about these treatments and their efficacy to decide  
273 which alternative treatment is worth trying and continue using to achieve/maintain their recovery.
- 274 6. I have three significant resources to research these therapies which are as follows:

- The Spasmodic Torticollis Recovery Clinic. Santa Fe, New Mexico.
  - Neuroplasticity Training. Dr. Farias. Toronto, Ontario.
  - Physical Treatment and Training Institute. L. Cross. Germany, B
7. I will be using the Internet and periodical databases
  8. I will create a questionnaire for 60 people who belong to the online support group.
  9. I will conduct a survey through a Facebook page that the group has created, and then I will collect and analyze data.
  10. I will address their concerns using alternative therapies, specifically one which utilized stretching and exercises targeted at treating Cervical Dystonia.
  11. I will conduct an interview with two people who have a lot of experience in this condition, and I will share their knowledge with the group. My objective is to interview:
    - Gabrielle Hupfeld; Physical Therapist at L. Cross Institute,
    - Abigail Brown; Director of the Recovery Clinic for spasmodic torticollis.

## **1**

### **RESEARCH**

### **FINDINGS**

The results of the investigation evaluate these unique sources for alternative treatments to treat Cervical Dystonia effectively:

#### **1 a) Dr. FARIAS, NEUROPLASTICITY TRAINING**

Dr. Farias, who obtained a PhD in medicine and sciences applied to sport and exercise, has applied these self-taught practices to develop an economical and drug-free method to rehabilitate others with the condition. His technique relies on neuroplasticity, the brain's ability to rewire itself. Teaching clients to move again, he says, helps their brains learn to process motor and sensory signals normally again (Leung, 2015).

303 His effort has been influenced by his own experience. As a 21-year-old studying to become a professional  
304 musician in Spain, he was diagnosed with dystonia in his right hand. His fingers would involuntarily curl into a  
305 fist. Progressively, it became very difficult to play the piano (Leung, 2015).

306

307 The innovation of the phenomenon of neuroplasticity is also significant for healing of all kinds of brains  
308 diseases and brain damage. Norman Doidge's book *The Brain's Way of Healing* is devoted to this topic. He  
309 defines three concepts which considers enable neuroplastic healing and five phases which are often  
310 happening in neuroplastic healing Dr. Farias, Neuroplasticity Training applied these therapies: (Visser, 2015)

- 311 • Neuroestimulation
- 312 • Neuromodulation
- 313 • Neurorelaxation
- 314 • Neurodiferenciación

315

316 **Neuroestimulation:** Is a therapy that stimulates brain cells by light, sound, electricity, vibration, movement,  
317 or thought so that the making of new connections is stimulated.

318 Besides this therapy help manages chronic pain and improves the quality of life. Benefits may include:

319 A decrease in pain 50% or higher

320 Increases activity levels

321 It is a therapy that is designed to mask pain by blocking pain signals before they reach the brain (Visser, 2015).

322 **Neuromodulation:** It is a treatment that regulates nervous activities by mode of controlling the physiological  
323 levels of different types of neurotransmitters; this treatment involves stimulus to the body's nervous system  
324 for healing purposes. This assistance to modulate a state of target cells as an approach to pain activity and  
325 neurological dysfunction by treating movement disorders and spasticity. The overall level of arousal of the  
326 brain is reorganize which re-establishes the balance between excitation and inhibition (Visser, 2015).

327 **Neurorelaxation:** This therapy can assist by relaxing the nervous system the person unwinds and catches up  
328 on lost sleep. Therefore, the brain gathers new energy required for additional recovery

329 **Neurodiferenciación and learning:** New capacities are learned (or old skills are relearned) through a method  
330 of training of gradually refined discrepancies in movements, sounds, images, or whatever is relevant for the  
331 affected function.

332 Dr. Farias, assist you with some tips to increase your dopamine levels in your brain (Visser, 2015).

333 Low dopamine levels on the brain activates nerve damaging, inflammation in the brain, leading to difficulties  
334 with learning, memory, decision maker and motor coordination. Neurotransmitters have a particular function  
335 in the brain when they work properly (Boeree, 2009).

336

337 **Noradrenaline:** This neuromodulator dramatic plays a critical function in inflecting plasticity learning and  
338 memory via de hippocampus within the brain (Boeree, 2009).

339 **Dopamine:** This neurotransmitter is centrally active in reinforcement approaching behaviour, exploration and  
340 several aspects of cognition. Change in this neuromodulator function appear to be connected with differences  
341 in personality. This dysfunction outcome in changes in relatively steady patterns of behaviour, motivation,  
342 emotion and cognition

343 **Serotonin:** It plays an important part in mood, anxiety and happiness (Boeree, 2009).

344 **Acetylcholine:** has a function in the control of autonomic functions, but is probable that it also modulate  
345 adaptive responses to environmental and metabolic state. The hypothalamus is vital in homeostatic. It is likely  
346 to be essential in adjustment to peripheral autonomic signals to the brain, in some brain areas might also be  
347 crucial for stress responses (Boeree, 2009).

348

349 Dr. Farias, learned that damage to the cerebellum and the frontal part of the brain could be some of the  
350 causes of developing the condition.

351

352 **The cerebellum** (“little brain”) is a structure that is located at the back of the brain, underlying the occipital  
353 and temporal lobes of the cerebral cortex. Although the cerebellum accounts for approximately 10% of the  
354 brain’s volume, it contains over 50% of the entire number of neurons in the brain. The cerebellum has been  
355 considered a motor structure, because injury in the cerebellum leads to deficiencies in motor control and  
356 posture and because the majority of the cerebellum’s outputs are parts of the motor system. Motor  
357 instructions are not started in the cerebellum; rather, the cerebellum alters the motor controls of the  
358 descending pathways to make movements more adaptive and precise (Knierim, 2016).

359 The cerebellum is responsible for the following functions:

360 **Conservation of balance and posture.** The cerebellum is vital for making postural alterations in order to keep  
361 balance. Through its input from vestibular receptors and proprioceptors, it modulates instructions to motor  
362 neurons to compensate for changes in body position or variations in load upon muscles. Patients with  
363 cerebellar injury suffer from balance disorders, and they often develop stereotyped postural tactics to  
364 compensate for this issue (e.g., a wide-based stance) damage to Cerebellum Produces Movement Disorders  
365 (Knierim, 2016).

366 Patients who have cerebellar damage display clumsy voluntary movements and problems sustaining balance  
367 and posture. The following are some symptoms of cerebellar damage:

368 **Decomposition of movement:** The majority of our movements involve the synchronised activity of numerous  
369 muscle groups and different joints to produce a smooth route of the body part through space. Patients with  
370 cerebellar dysfunction are incapable to produce these coordinated, fluid movements. Instead, they often  
371 interrupt the movements down into their parts to perform the preferred path (Knierim, 2016).

372 **Intention tremor:** When making a movement to a target, cerebellar patients frequently produce an  
373 uncontrolled tremor that grows as they approach closer to the target

374 (Knierim, 2016).

375

376 **Frontal lobe:** It contains most of the dopamine -sensitive neurons in the cerebral cortex. The dopamine  
377 system links with recompense attention, short-term memory task, planning, and motivation.

378 It is an integral connexion between a person's personality and the functions of the prefrontal cortex. This brain  
379 region involves planning of complex cognitive behaviour. This vital activity of this brain region is considered to  
380 be the organisation of thoughts and actions with inner goals (The Frontal Lobe, 2015).

381 The frontal lobe is the part of the brain that manage main cognitive skills in humans, such as emotional  
382 expression, problem solving, memory, language, judgment, and sexual behavior. It is the hard drive of our  
383 personality and our capability to connect.

384 It is also responsible for primary motor function, or our ability to consciously move our muscles, and  
385 connection to speech (The Frontal Lobe, 2015).

386 Dr. Farias also theorises that individuals with hyper-plastic brains – those who are remarkably fast learners –  
387 may be more vulnerable to the disorder.

388 Solving repressed motions can't be done through talk therapy, but through movement, he believes, since  
389 dystonia involves parts of the brain involved in motor function, rather than language (Leung, 2015).

390 The first stage is to define, and make clients conscious of the motions they have suppressed. Then, he trains  
391 them to recuperate those lost movements, and the patient has to repeat them until the movements feel  
392 natural, controlling any related sensations of pain or distress (Leung, 2015).

393 He does this by getting his clients to copy his own movement, to practise in front of a mirror, and to move in  
394 different settings. For example, if clients show no signs of dystonia when dancing, Dr. Farias trains them to  
395 relocate those movements to walking or standing.

396 After four following days (at a cost of \$1,600 for six hours of sessions), most of his/her clients are able to  
397 recover some lost movements after a few months of training,

398 He declares. The course of getting them to “feel right” while doing those motions, however, may take a long  
399 period of time. Even though he started off working with musicians with focal dystonia, he has found his  
400 approach has worked on clients with various forms, including general dystonia related to Parkinson’s disease.  
401 But he recognizes he is still refining his techniques and has developed only an alternative to traditional  
402 therapy, not a cure (Leung, 2015).

403

#### 404 **1b) S.T.R. RECOVERY CLINIC: ABIGAIL BROWN, DIRECTOR**

405 S.T.R.C, Inc. is a non-profit organization founded in 1986 by Abigail Brown after she developed this program in  
406 a desperate attempt to recover from her battle with Spasmodic Torticollis another name for Cervical Dystonia  
407 This program is a natural approach, healthy and risk-free if it is done as prescribed.

408 This program can be accessed directly or as a long distance program. The clinic provides a manual and a DVD  
409 with all the exercises which will help the patients to achieve and ongoing recovery from the symptoms of  
410 Cervical Dystonia.

411 A non-aerobic exercise program specifically geared to address the problems shared by those with S.T., they  
412 should adapt the exercise program to their ability and pace, overdoing it or using too much weight will hinder  
413 their progress. The program has some suggestions for a balanced nutritional diet to hasten and maintain  
414 recovery, as well some tools to cope with some pain that can be experimented during the beginning of the  
415 routine, until the body gets adjusted to it.

416 Most of the exercises requires the chin to be tucked, the continual practice of the "Military Brace" position  
417 which realigns the head and neck over the spine. The daily exercise routine is as follows:

- 418 • The patient has to stretch both sides of neck
- 419 • Elongate shortened side (to which the head turn)
- 420 • Increase flexibility
- 421 • Target trigger points to defuse spasms

422 The results are strengthening of the muscles and restoration of voluntary control.

423 By correct daily habit patterning: how we sit, sleep, work at the computer, etc. the patient will experience  
424 good spasms and bad spasms. Bad spasms occur with wrong habits patterns, like sleeping on a contour pillow.  
425 Good spasms occur when the patient is following the recovery via the program, and the body is reacting to the  
426 realignment process the "good spasms" will eventually disappear as the patient comes into recovery.

427 The long distance program provides:

- 428 ▪ A printed manual with all the information and help for the process of recovering



- 429       ▪ A DVD with all the rehabilitation exercises including daily stretching, gym strengthen exercises and pool
- 430       exercises
- 431       ▪ A DVD with specific Massage for CD
- 432       ▪ A manual with daily patterns or habits
- 433       ▪ Stress management suggestions
- 434       ▪ Faith and good attitude encouragement
- 435       ▪ Nutrition, and medications to avoid
- 436       ▪ Adaptive equipment
- 437       ▪ Crisis management

438

439 **1c) PHYSICAL TREATMENT AND TRAINING L.CROSS INSTITUTE**

440 L. Cross Institute has treated over 35 years mainly musculoskeletal disorders, such a knee and hip joint  
441 disease, disc herniation, thoracic, cervical spine and TMJ disorders, and Cervical Dystonia for over twenty  
442 years with great success. Cervical Dystonia patients are treated by their physiotherapist and massage  
443 therapist daily. This institute is the only one in Germany that deals with this condition, therefore, patients  
444 come from all over Germany and abroad to be treated.

445 The therapists have found that the following treatments are particularly useful:

446 1- Three Underwater massage for week

447 2-Physiotherapy based on neurophysiological CNS

448 3-Electrical stimulation treatment

449 The Training rehabilitation program is done every day for one hour and a half (five days per week).

450 Relatively new compared to conventional methods of treatment is the use of a meter Acromiopelvimeter for  
451 the differentiation of anatomical and functional leg length differences, as well as for constant review of statics  
452 and pelvis alignment.

453 In the general spine treatments the patient needs about 14 days to learn the exercises, so he/she will be able  
454 to perform them at home daily. It is crucial to be consistent with the program to see positive results.

455 Cervical Dystonia rehabilitation program takes two or 3 visits to the Institute; the first treatment last three  
456 weeks and then they will treat the patient twice a year for about a week for further assessments.

457 The total number of therapies on each patient changes depending on the severity of the condition and the  
458 improvement the patient have achieved.

459 Previously they have only treated patients who had no carried out botulinum toxin, these patients were  
460 sufficiently restored mainly after two years that could not be spoken of this condition from a medical  
461 perspective.

462

463 Since 1993, they have only treated patients who use Botox injections as the first treatment. Unfortunately,  
464 these patients take longer to recover.

465 The Statement of a German University "the intramuscular injection of botulinum toxin A", leads to an  
466 irreversible blockage of cholinergic nerve endings in the treated muscle by sprouting of new nerve endings  
467 within 3 to 4 months the muscle regains his strength. After the prolonged use of Botox injections, the muscles  
468 are significantly impaired. According to their knowledge, these patients recovery time will take between 3 to 4  
469 years.

470 Several patients who follow the program have been incorporated after years of illness and partial retirement  
471 are now back to work.

472 Their therapy is a holistic treatment; they have an interdisciplinary work that is complemented with doctors  
473 that prescribe and guide the treatment, dentist, that treat temporomandibular joint static, Ophthalmologist,  
474 and opticians, because the condition in some cases affects the eye alignment and an orthopedic technician  
475 who control the feet static.

476 Their objective and approach of the therapy is that patients can recognize and eliminate their static disorders  
477 independently and work consistently in the reconstruction of correct movement patterns.

478 The cost of each treatment is around 70 EUR and the cost of a Therapeutic accommodation is between 135  
479 EUR for a room and 185-230 EUR for an apartment per week.

480 L. Cross Institute wishes that the therapy will find more recognition of the insurance companies, and hopefully  
481 physiotherapist and some health practitioners develop a greater interest and carry out this interdisciplinary  
482 treatment.

483

484 **2**

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486

487 ***Efficacy of evaluation.***

488 ***Survey Data Analysis:***

489 After determining the analysis of the survey data from 24 participants ( the results have been tabulated in  
490 Appendix A) the purpose of the survey was to acknowledge if the people on the online support group were

491 aware of the alternative treatments for Cervical Dystonia and how they have been coping whit the condition  
492 to manage the symptoms.

493 The questionnaire revealed the following:

494 After analyzing the summary of responses, I learned that 60% of the people that answer the survey were  
495 women and 40 % were men.

496 50% of the people are between the edges of 46-55 years old

497 20% 56-65 years

498 20 % 36-45

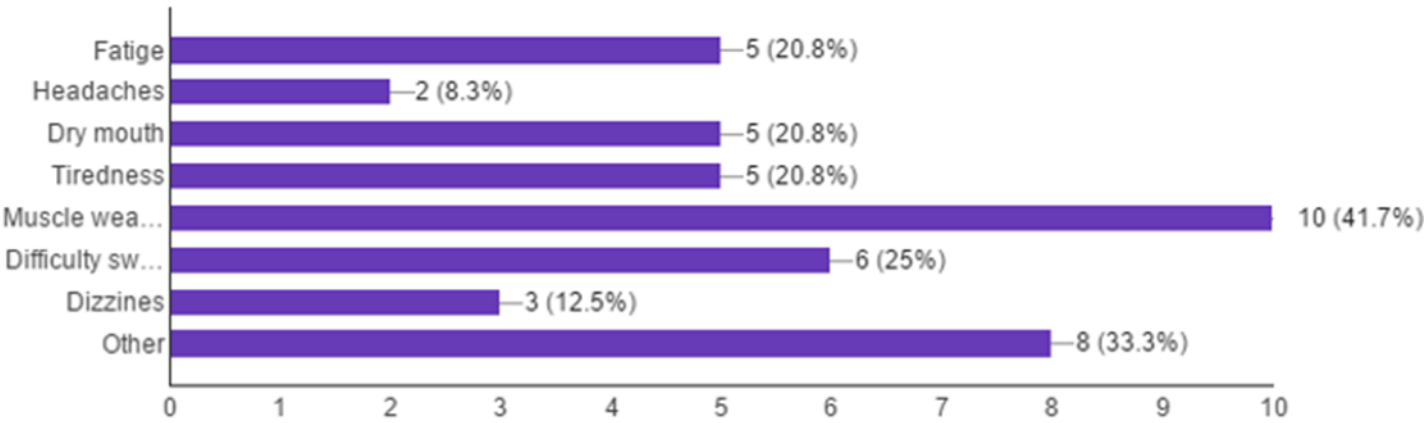
499 10% 46-55 years old.

500 40% of the people got diagnosed after a period of 6 month, 20% in a year and the rest of more than one year.

501 I learned that: 70% of the people acquired the condition after a whiplash and head injury, 10% family history  
502 and the other 10% unknown causes.

503

504 Figure 1 Shows the percentage of the different side effects that individuals who use Botox injections  
505 experienced.



506

507

508 After analyzing this chart which was obtained from google forms after the 24 responses were received from  
509 the Cervical Dystonia online Group survey, we can conclude that the whole group experienced one or more of  
510 the side effects listed.

511 66.7% of people experienced muscles weaknesses and difficulty swallowing for the first weeks following  
512 injection; and the rest have other side effects like fatigue, dry mouth, dizziness plus 33.3% experienced others  
513 side effects besides the expected one.

514 Most of the people experienced a combination of side effects with oral medications such as the following:

515 6 Dry mouth, nausea, dizziness, cognitive cognition, weight gain and others side effects.

516 The group have tried different alternative therapies such as follows:

517 100% of the people have tried chiropractor adjustment, but just 4 of the people was satisfied with this  
518 approach.

519 30% of individuals tried acupuncture and were somewhat satisfied with the treatment.

520 50% of the individuals have tried physiotherapy and are somewhat satisfied, and the other 50% have not tried  
521 or are somewhat dissatisfied with it.

522 30% have tried psychotherapy and are somewhat satisfied

523 70% have never tried

524 90% have tried massage therapy and are satisfied and somewhat satisfied with this treatment the rest are  
525 neutral.

526 98% of people are somewhat satisfied and very satisfied with stretching exercises just 2% are somewhat  
527 satisfied

528 50% have never tried Mindfulness meditation

529 40% have tried meditation, and they are satisfied.

530 10% are neutral or dissatisfied with it.

531

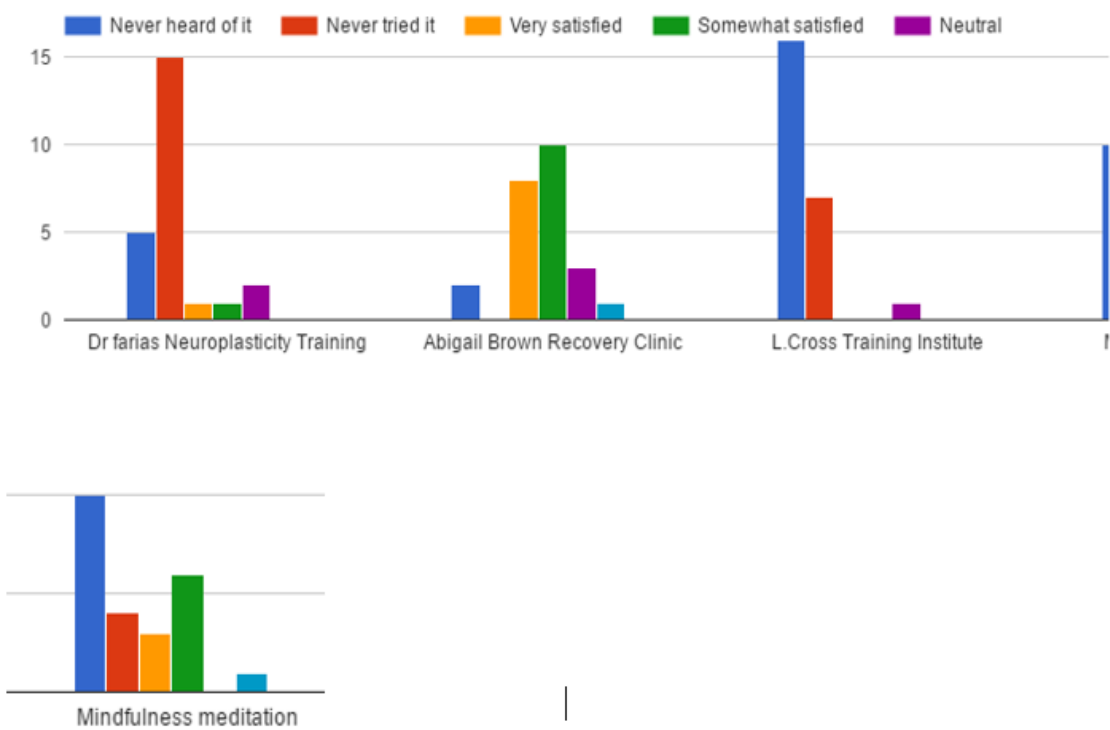
532 Figure 2.Shows the number of the individuals who have tried or heard of these treatments.

533 ☐ Dr. Farias, Neuroplasticity Training

534 ☐ S.T.R. Recovery Clinic

535 ☐ L. Cross Institute

536



538 After analyzing this chart which was obtained from google forms after the 24 responses were received from  
539 the Cervical Dystonia online Group .survey, we can conclude:

540 Eighteen people knew about Abigail Brown; Recovery Clinic and are very satisfied or somewhat satisfied with  
541 the program. The rest are Neutral.

542 Fifteen people have known of Dr. Farias Neuroplasticity training, but just 3 people had tried it and are  
543 somewhat satisfied with the training.

544 None of the people in the group knew about L. Cross Training Institute in Germany.

545

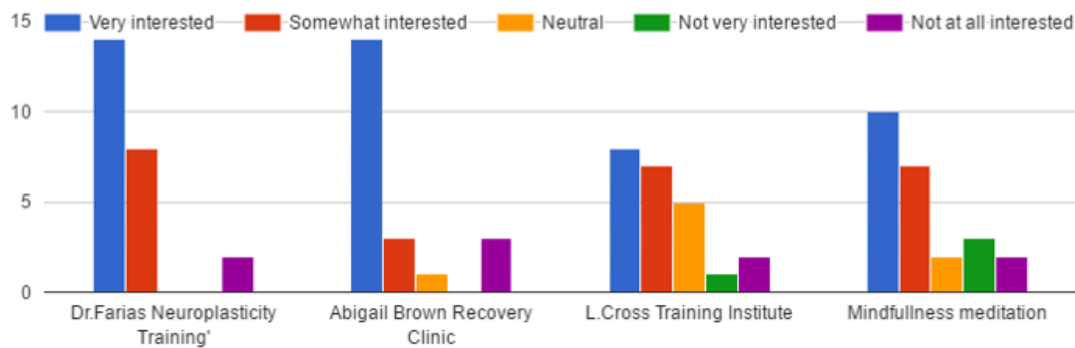
546 Figure 3. Shows how interested are these individuals in these treatments.

547 ☐ Dr. Farias, Neuroplasticity Training

548 ☐ S.T.R. Recovery Clinic

549 ☐ L. Cross Institute

550



551

552 After analyzing this chart which was obtained from google forms after the 24 responses were received from  
 553 the CD Online Group survey, we can conclude:

554 Twenty two of the people in the group are somewhat and very interested in trying Dr. Farias  
 555 Neuroplasticity Training t, the rest are not at all interested

556 Eighteen of the individuals are very and somewhat interested in Abigail Brown Recovery Clinic, just a few are  
 557 not at all interested.

558 Fifteen of the people in the group are somewhat and very interested in L .cross Training Institute and the rest  
 559 are not interested or neutral.

560 Eighteen of the people in the group are interested in trying meditation and the rest are neutral or not very  
 561 interested.

562

563 **3**

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565

566

## 567 **INTERVIEW SUMMARY**

568 S.T.R Recovery Clinic; Abigail brown, Director.

569 L. Cross Institute: Gabrielle Hupfeld, Physical therapist.

570 The unique attributes of the S.T. R recovery clinic are that people can do it directly at the Institute of as a long  
 571 distance program it includes a manual with all the exercises printed and DVD including an explanation of how  
 572 they should be performed. A DVD with a massage therapy and recommendations for daily habit patterns.

573 L .Cross Institute has a unique device call Acromiopelvimeter to control pelvic alignment. As well an intensive  
574 routine of training exercises with the purpose of self-correction and functional movements, without muscles  
575 power to center the head.

576 The Recovery Clinic states that the program can be successful and easier to follow with the help of Botox  
577 injections. On the other hand, L. Cross Institute learned that it took longer for patients to recover with the use  
578 Botox injection during the program. Patients can benefit more from the rehabilitation program if they get  
579 some other issues addressed such as TMJ alignment, an eye therapy or feet orthotics to level the pelvis and  
580 relaxation techniques (Meditation and Tai-chi).

581 Recovery Clinic states that for patients to see positive results all depend on many factors: patient attitude  
582 towards the program, awareness of habits patterns, nutrition, and stress management techniques. For those  
583 patients that follow the program with consistency there is 100% success rate.

584 L. Cross Institute noticed that the percentage of patients who have recovered after following the program had  
585 changed through the years. Ten years ago, the percentage of patients who were free of symptoms was 70%,  
586 and has since gone down to 40%.One of the reasons for this is that some people who had come from abroad  
587 are not able take the time to come to the Institute for two weeks and learn the exercises, and come back for  
588 reassessments. On top of that some insurance companies do not pay for it, or patients do no commit to the  
589 program.

590 This rehabilitation program takes a long time for patients to see the results, and unfortunately, some patients  
591 quit before they get into a recovery state.

592 L. Cross Institute and S.T.R. Recovery Clinic agree that this holistic approach is a good choice when Botox  
593 stops working or as a combination treatment. Botox injections are very expensive, and some people  
594 experience side effects from it, but patients can achieve faster recovery without the botulinum toxin  
595 treatment. Unfortunately when the dystonia is severe, patients need the botulinum toxin treatment to be able  
596 to do the exercises.

597

598

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600

## 601 **CONCLUSIONS**

602 Based on the information provided from these professionals in treating cervical dystonia with alternative  
603 treatments the conclusions are as follow:

- 604 1. These holistic- natural approaches are free of side effects and the goal is to help people with the  
605 condition to manage the symptoms of cervical dystonia and obtain and maintain a high quality of life,  
606 with Botox as a complementary treatment or without it.

- 607 2. Dr. Farias, learned that damage to the cerebellum and frontal lobe were some of the causes of  
608 developing the condition. He uses Neuroplasticity to heal these areas of the brain by applying these  
609 therapies: Neurostimulation, Neuromodulation, Neuro- relaxation and Neurodifferentiation.
- 610 3. Dr. Farias believes that through movement by creating a unique rehabilitation program with specific  
611 exercises patients, the brain can relearn the regular movements that they have lost, and the individuals  
612 can recover the function of these two critical brain areas.
- 613
- 614 4. S.T.R Recovery Clinic: Abigail Brown director states:
- 615 5. Patients can take this course directly in the clinic or as a long distance program.
- 616 6. The Director provides a manual which contains all the training exercises printed and a DVD to guide the  
617 patient to perform the exercises correctly.
- 618 7. She offers a DVD that shows specific Cervical Dystonia massage for patients, water, and gym activities.
- 619 8. The manual contains the recommendations and support to go through the program successfully and  
620 achieve recovery.
- 621
- 622 9. L. Cross therapy uses a unique device call Acromipelvimeter for constant review of statics and pelvis  
623 alignment. The patient has to perform the exercises in front of a mirror so he/she can be aware and  
624 maintain proper alignment of the head and neck.
- 625 10. Patients interested in this rehabilitation program need two weeks to learn the intensive rehabilitation  
626 exercise.
- 627 11. It takes 2 or 3 visits to the Institute for two years to further reassess the patient dystonic movements  
628 and correction of exercises if it is needed.
- 629 12. L. Cross Institute have an interdisciplinary work which they complemented with other physicians to  
630 treat other parts of the body related or affected by the condition which are the jaw, eyes, teeth and  
631 feet to realign the whole body and reach a complete recovery of the symptoms.
- 632

633 Based on literature found on the Internet and periodical databases the conclusions are as follow:

634 (Stated as see Appendix B)

- 635 1. Botulin toxin is the primary treatment for cervical dystonia but when Botox injections stop working  
636 patients can benefit from alternative therapies to manage the symptoms of cervical dystonia and be  
637 able to function and perform basic tasks.



- 638 2. People who have Cervical Dystonia do not have as much connectivity in specific parts of the prefrontal  
639 cortex, premotor cortex and superior parietal lobule affecting the sensorimotor and the executive  
640 control network and primary visual system. This abnormality is the cause of defective or lack of motor  
641 planning and disturbed spatial cognition.
- 642 3. Physical therapy will improve motor control in combination whit botulinum toxin or oral medications  
643 or by itself when Patients became resistant to Botox injections.
- 644 4. The goal of physical therapy is to increase and preserve range of motion, strengthen weakened  
645 muscles and stretching exercises to elongate them.
- 646 5. Some patients have found other alternative approaches to complement with physical therapy, some of  
647 these therapies such as the following:
- 648 ☐ Acupuncture
  - 649 ☐ Electrotherapy
  - 650 ☐ Biofeedback training
  - 651 ☐ Massage therapy
  - 652 ☐ Orthodontic work for jaw alignment
  - 653 ☐ Also, brain-based physical rehabilitation and auditory stimulation to influence both of the brain  
654 hemispheres and growth neurological command over dystonic muscles.
- 655

## 656 **RECOMMENDATIONS**

- 657 Based on the information obtained from the institutes that treat cervical dystonia and from the  
658 experiences of patients that have successfully managed the symptoms from Cervical Dystonia we can  
659 recommend the following:
- 660 1. People who suffer from the condition should look for support for himself/herself and family members  
661 to understand and learn more about the condition.
  - 662 2. The rehabilitation training can be a treatment combined with botulinum toxin or without it,  
663 understanding that people who do not use Botox injections in most of the cases can achieve recovery  
664 faster because the muscle does not get impaired.
  - 665 3. To be successful in recovering from the symptoms of cervical dystonia patients have to stick to the  
666 rehabilitation plan and adopt a significant commitment towards the training exercises and be aware of  
667 postural habits patterns.

- 668 4. To get into a state of recovery, patients have to understand that it is a long process and a lifetime  
669 commitment to manage the symptoms and achieve a productive and better quality of life.
- 670 5. The patient should keep a positive attitude to be able to continue the program.
- 671 6. It is vital for the patient to address any personality issues, behaviors, thoughts, emotions, anxiety,  
672 depression and stress levels to have good mental health, so the body and mind will work in harmony.
- 673 7. It is beneficial and healthy to find an activity which can bring happiness and purpose to their lives as  
674 well to find a support group to relate to when going through hard times and be socially active in the  
675 group by learning new therapies and sharing them.

676 Some of these therapies have been found helpful besides The Rehabilitation exercises:

677 (Stated as see appendix B)

- 678 • Cognitive behavioral therapy
- 679 • Pain management program
- 680 • Different types of meditation, especially ones that can balance mind and body connection.
- 681 • Stress management
- 682 • Biofeedback

#### 683 **Daily activities to enhance body movements and energy:**

684 Lower stress exercises: such as water exercises, swimming, walking, some yoga postures, low impact  
685 aerobics, stationary bike riding, dance classes, and some coordination exercises.

686 Recommended Books to Read: ***Diagnosis Dystonia – Navigating the Journey*** by Tom Seaman. This book  
687 takes you on a personal and educational journey full of valuable information for those newly diagnosed as  
688 well as those who have been living with dystonia for years. Tom's perspective as a long time dystonia  
689 patient is invaluable, offering coping skills, healthy living strategies and treatments options. Tom now uses  
690 his experience and education as a certified professional life coach to help with dystonia and other life  
691 changes. Patients can get the book at [www.disgnosisdystonia.com](http://www.disgnosisdystonia.com) and other information at  
692 [www.balanceyourlifecoaching.com](http://www.balanceyourlifecoaching.com)

693 Dr. Joaquin Farias will present his next book ***Limitless how your movements can change your brain*** In in  
694 Toronto. October 30, 2016. 1pm to 3pm.

695 Thanks to the Dystonia Medical Research Foundation Canada.

699 The event will be held at Metro Hall in downtown Toronto from 1:00 pm to 3:00 p.m. on October 30th.

700 Dr. Farias is a leading specialist treating dystonia with movement therapy. He has a doctorate in biomechanics, as well  
701 as master's degrees in neuropsychological rehabilitation and psych sociology

702 Since 1996 Dr. Farias has helped more than 500 people to have their lives and livelihoods back after being affected  
703 by different movement disorders characterized by dystonia, tremors and other problems with coordination. He is the

704 director of the Neuroplasticity Training Institute Toronto and adjunct professor at the University of Toronto at the Music  
705 and Health Research collaborative. Register for the event by emailing: [info@dystoniacanada.org](mailto:info@dystoniacanada.org)

719 APPENDIX A

## 721 cervical dystonia survey online support group

722 to research alternative treatments to treat cervical dystonia .

723 Please complete this survey before march 19 2016 .to be able to collect data and analyzed , By answering these  
724 questions , you are providing us with information which can be used to better understand the disease processes and/or  
725 possible future treatments for cervical dystonia. Thank you for your participation !

726 1. **Name** \* not required

727 2. **Email address** \* not required

728 3. **Gender**

729 60% Female

730 40% male

731 4. **Age**

732 1) 50% of the people are between the edges of 46-55 years old

733 2) 20% 56-65 years

734 3) 20 % 36-45

735 4) 10% 46-55 years old.

736

737 **5. How long did it take to get accurate diagnoses of Cervical Dystonia?**

738 1) 40% 2-6 months

739 2) 20% 7-12 months

740 3) 15% 13-18 months

741 4) 10% more than 1 year

742 5) 15% other

743

744 **6. History Prior to diagnosis?**

745 2 people more than one whiplash

746 4 people family member with Cervical Dystonia

747 5 people whiplash

748 7 people head injure

749 6 other

750

751 **7. Please indicate if there were any of these side effects with Botulinum Toxin Injections? (Check all that**  
752 **apply)**

753 5 fatigue

754 2 headaches

755 5 dry mouth

756 5 tiredness

757 10 muscles weakness

758 6 difficulty swallowing

759 3 dizziness

760 8 other

761

762 **8. Please indicate if there were any side effects with this treatment? Oral medications (check all that apply)**

763 6 dry mouth

764 4 Nausea

765 1 Insomnia

766 2 Low libido

767 2 weight gain

768 5 dizziness

769 4 cognitive

770 1 headaches

771 14 other

772

773 9. **Which treatments have you tried to deal with the symptoms?**

774 **Chiropractor**

775 4 somewhat satisfied

776 9 somewhat dissatisfied

777 7 very dissatisfied

778

779 **Acupuncture**

780 5 somewhat satisfied

781 3 very satisfied

782 2 somewhat dissatisfied

783 5 very dissatisfied

784 6 never try

785

786 **Physiotherapy**

787 7 somewhat satisfied

788 3 very satisfied

789 3 somewhat dissatisfied

790 2 very dissatisfied

791 5 never try

792

793 **Psychotherapy**

794 15 never tried

795 5 somewhat satisfied

796 2 very satisfied

797 1 neutral

798

799 **Massage therapy**

800 4 never tried

801 12 somewhat satisfied

802 4 very satisfied

803 2 somewhat dissatisfied

804

805 **Stretching**

806 13 somewhat satisfied

807 7 very satisfied

808 2 somewhat dissatisfied

809 2 neutral

810

811 **Mindfulness meditation**

812 12 never tried

813 4 somewhat satisfied

814 4 very satisfied

815 2 very dissatisfied

816 2 neutral

817

818 **11. For how long have you tried these treatments?**

819 **Chiropractor**

820 3-not applicable

821 12- 0-3 months

822 4- 4-6 months

823 3- 13-18 months

824 2-more than 18 months

825

826 **Acupuncture**

827 8-not applicable

828 5- 0- 3 Months

829 5- 4-6 months

830 2- 7 -12 months

831 2- 13-18

832

833 **Physiotherapy**

834 10-not applicable

835 7- 0 -3 months

836 5 -7 – 12 m months

837 2-more than 18 months

838

839 **Psychotherapy**

840 15-not applicable

841 3- 0- 3 months

842 2- 4 – 6 months

843 2 -7-1 2moths

844 2- 13-18 months

845

846 **Stretching**

847 1-not applicable

848 1- 0-3months

849 1- 4-6 months

850 3- 7-12 months

851 7- 13-18 months

852 11-more than 18 months

853

854 **Massage therapy**

855 7-not applicable

856 3- 0 – 3months

857 3 -7- 12 months

858 2- 13-18 months

859 9-more than 18 months

860

861 **Mindfulness**

862 13-not applicable

863 4- 0 -3 months

864 3- 4-6 months

865 4- 7-12 months

866

867 **12. Have you tried or heard of these treatments? (Check all that apply)**

868 **Dr. Farias Neuroplasticity training**

869 5 never heard of it

870 15 never tried it

871 1 very satisfied

872 1 somewhat satisfied

873 2 neutral

874

875 **Abigail Brown Recovery clinic**

876 3 never heard of it

877 7 very satisfied

878 11 somewhat satisfied

879 3 neutral

880

881 **L. Cross training Institute**

882 17 never heard of it



883 6 never tried it

884 1 neutral.

885

886 **Mindfulness Meditation**

887 10 never heard of it

888 4 never tried it

889 3 very satisfied

890 7 somewhat satisfied

891

892 **13. How interested are you in these treatments? (Check all that apply)**

893 **Dr. Farias neuroplasticity training**

894 15 very interested

895 7 Somewhat interested

896 2 not at all interested

897

898 **Abigail Brown Recovery Clinic**

899 15 very interested

900 3 somewhat interested

901 4 not at all interested

902 2 Neutral

903

904 **L Cross Training Institute**

905 8 very interested

906 6 somewhat interested

907 5 Neutral

908 2 not very interested

909 3 not at all interested

910

911 **Mindfulness meditation**

912 10 very interested

913 7 somewhat interested

914 2 Neutral

915 3 not very interested

916 2 not at all interested

917

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921 6

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925

926 APPENDIX B

927

928

929 INTERNET RESEARCH

930

931 **Physical Therapy may be an important component of treating dystonia for many people.**

932 Under the assistance of a physical therapist an individual can learn the right postures and learn the activities  
933 that aggravate symptoms.

934 Physical therapy will improve motor control, in combination with oral medications /or botulinum injections.

935 Physical therapy is a long-term commitment by performing the exercises consistently the individual will see  
936 positive results, he/she will benefit by managing symptoms and control body movements (Albany & Gordon,  
937 n.d.).

938 The goal of physical therapy is:

939 Increase and preserve range of motion and mobility required for performance.

940 Strengthen weakened muscles that may be inactive in the presence of dystonia movements.

941 Encourage awareness of posture and preservation of the individual optimal body alignment.

942 Frequent check of the dystonia and re-assessments of the personal necessities of the affected individual are  
943 necessary to optimize benefits from the physical therapy program (Albany & Gordon, n.d.).

944 Daily Activity and Exercise:

945 Lower stress exercises such as water exercise. Walking, yoga, ballet, low-impact aerobics or stationary bike  
946 riding

947 Stress Management:

948 A stress management program may be combined into a physical therapy program, and relaxation exercises  
949 may be personalized to address specific motor problems (Albany & Gordon, n.d.).

950

951 **Dystonia in MSA: Non Pharmacological Treatments options:**

952 A physical therapist can aid in the management of cervical dystonia symptoms mobilizing joints to preserve  
953 range of motion and stretching muscles to achieve stable muscles function. Physical Therapy for Cervical  
954 Dystonia consist of a method of motor retraining. The individual performs repetitive movements with the neck  
955 and head and some stretching exercises to elongate the muscles (The multiple system Atrophy Coalition,  
956 2014).

957 In some cases Electrical stimulation can help to activate the non-dystonic muscles, the results are decreasing  
958 the hyperactivity of the dystonic muscles. This therapy in combination with Botulinum Injections reduced pain  
959 levels. The patient benefits from this treatment by achieving good mental health, an increase in energy and  
960 positive attitude for active social life. It can take up to 2 years for the individual to recover posture and muscle  
961 function, decrease pain and lower the doses of Botox injections (The multiple system Atrophy Coalition, 2014).

962

963 **Dystonia Gaining Control through Movement:**

964 This is a holistic approach that combines relaxation practices, mild physical motion, body-mind connections  
965 and posture such as yoga, Tai-chi and Pilates. Breathing exercises deliver more oxygen to the muscles  
966 decreasing spasms. Stretching and strengthening exercise relieves stiffness and pain, it prevents dystonic  
967 muscles from shortening. Some of these exercises can be perform by lying down, standing or seated. Other  
968 physical therapy is moderate aerobics and balance exercises. In addition brain-based physical rehabilitation  
969 and auditory stimulation to influence both of the brain hemispheres and growth neurological command over  
970 dystonic muscles.

971 Through handling the brain's natural plasticity trough exercise, movement rectification can be made. Brain-  
972 based physical rehabilitation looks to repair the connections that improve motion (Dystonia getting control  
973 trough movement, 2011).

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**PERIODICAL DATABASES RESEARCH**

**1- Task-free functional MRI in Cervical Dystonia Reveals Multi Network Changes That Partially Normalize with Botulinum Toxin:**

This article explains that people who have Cervical Dystonia do not have as much connectivity in specific parts of the prefrontal cortex, premotor cortex and superior parietal lobule affecting the sensorimotor and the executive control network. It concludes that treatments with Botulinum Toxin result in a partial restoration of connectivity abnormalities in the sensorimotor and primary visual system. This abnormality is the cause of defective or lack of motor planning and disturbed spatial cognition.

I find this information fascinating because it is related to Dr. Farias’s findings in the cause of developing the condition; he learned that there is a malfunction of the prefrontal cortex and alterations in the cerebellum. The objective of his rehabilitation is to balance the two brain hemispheres right and left to improve connectivity and connect the multiple neural networks involve in cervical dystonia (Delnooz, Pasman, Beckman &Warrenburg, 2013).

**2-Effectivenes of acupuncture in Cervical Dystonia:**

This article describes the benefits of treating Cervical Dystonia using acupuncture versus Botox injections. In this case a patient shows positive results. The acupuncture reduced the pain, and the muscles spasms decreased, she continues with this treatment every 8 to 10 weeks, and she has reduced the regular treatments with Botox injections which are usually every three months.

I find this article relevant to my topic, because, from the survey that I conducted, I learned that some people have found acupuncture somewhat helpful in treating some symptoms (Deepak, Mathew & Koshy, 2010).

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