



DEMYSTIFYING

DYSTONIA....

A
Guide
For
Managing
Your
Dystonia

Setting the PACE www.care4dystonia.org Care until a Cure

About Care4Dystonia, Inc. (C4D)

Care4Dystonia, Inc. is a nationwide community- based voluntary health organization dedicated to Setting the P.A.C.E -

- ◆ Patient care,
- ◆ Awareness,
- ◆ Collaboration and
- ◆ Education in the movement disorder community.

You may make copies of this guide and freely distribute it to others suffering with dystonia, their families, friends and others as desired.

About the Author of DeMystifying Dystonia :

Beka Serdans, R.N. is the Founder of C4D; author of several published brochures and other educational material for patients. She continues to work as an ICU nurse in the Cardiac-thoracic Unit at New York-Presbyterian Hospital in NYC despite having dystonia herself. She remains active in the media venue generating public awareness for dystonia. She has been instrumental in producing stories with Dateline NBC, CNN, ABC, New Age Magazine and other in-print media forums. She also serves as a public speaker.

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DEMYSTIFYING DYSTONIA revised by
Beka Serdans, RN., BSN., CDE.
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Movement Disorders Program and the
Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.
at the Mt.Sinai Medical Center in New York City, U.S.A.

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We hope you find this guide useful !
Please send us your comments and suggestions for
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About DeMystifying Dystonia :

Care4Dystonia is providing you with this basic informational guide about Dystonia so that you can learn more about this rare neurological disorder. Great new strides have been made in the diagnosis and management of dystonia recently. Today, people with dystonia can lead normal and productive lives.

There are several sections to this guide. Each section covers a subject that is important to managing your dystonia. We have tried to address the most important issues pertaining to Dystonia. Your Movement Disorder Team is ready to help guide you through the various treatments plans for dystonia. Your team is committed to providing you with up-to-date, efficient and high quality care. It is their goal to provide individualized care to You. Our job at Care4Dystonia is to help educate you about your dystonia. We welcome your comments, questions and suggestions. Together with you and your family, we and your Movement Disorder Team dedicate our efforts to your well-being.

My Movement Disorder Team :

Neurologist : _____ Phone : _____

Social Worker : _____ Phone : _____

Nurse : _____ Phone : _____

Neurosurgeon : _____ Phone : _____

Local Pharmacist : _____ Phone : _____

This guide belongs to : _____ (name)

GENERAL INFORMATION ABOUT DYSTONIA

DYSTONIA is a neurological disorder characterized by overactivity of a specific muscle and/or group of muscles. It is the over-activity of these specific muscles that causes :

- involuntary movements and tremors
- sustained muscle contractions, and
- abnormal postures.

DYSTONIA is a movement disorder that is often misdiagnosed. It is not unusual for a person to be correctly diagnosed with dystonia after exhibiting symptoms for several days, weeks or even years. Dystonia can be correctly diagnosed by a neurologist who has specialized training in the diagnosis and treatment of MOVEMENT DISORDERS. For most people,

DYSTONIA is not

- 1) a PSYCHIATRIC disease
- 2) a disease caused by STRESS
- 3) a "simple" MUSCLE disease.
- 4) a FATAL disease
- 5) a SEIZURE disorder.

A key factor that differentiates dystonia from other movement disorders is that there are sustained abnormal postures that occur at some time during the movement. The involuntary movements and spasms caused by dystonia sometimes are blamed on stress, stiff neck, dry eyes, tics, or psychogenic disorders. A significant clue to dystonia lies in the fact that dystonia often worsens during activity, stress and anxiety; but diminishes during relaxation and sleep. Therefore, it is important to seek care from a neurologist who has specific training in the field of MOVEMENT DISORDERS.

Visit online <http://www.movementdisorders.org> to learn more.

It is estimated that over 350,000 people have some form of dystonia in NA alone. However, this value does not take into account that dystonia can coincide with other medical conditions such as Parkinson's disease, Multiple Sclerosis, Cerebral Palsy, Wilson's disease etc.

The symptoms of dystonia vary and may include discomfort, pain, disability, and lack of muscle control. The symptoms of dystonia are thought to be due to the abnormal functioning of the BASAL GANGLIA, an area deep within your brain, that helps to coordinate the movement of muscles.

What causes Dystonia ?

Dystonia can exist in multiple forms. Each form may be unique, and the same form of dystonia may not affect all persons in the same manner. The precise causes of dystonia are not well understood, scientists have focused much of their attention on:

1) HEREDITY

Genetics play an important role in dystonia, especially in early onset dystonia that develops during child-hood. Recently research has identified several genes that are linked to several forms of dystonia. A person with a family history of a movement disorder (tremor, Parkinson's disease, etc.) may be more likely to develop a form of dystonia than someone who has no family history of it at all. Keep in mind that many things may modify a gene's function. Also not all people who inherit a gene for dystonia develop dystonia.

2) ETHNIC ORIGIN

Some forms of dystonia are more prevalent in families in particular ethnic backgrounds.

3) NEUROTRANSMITTER "DEFECTS"

Your body produces chemicals called neurotransmitters that help your nerve cells, called neurons, to communicate vital information with one another. A defect or "error" in the body's ability to make these necessary chemicals (e.g. dopamine, serotonin, acetylcholine and others) may contribute to the development of dystonia.

4) MEDICATIONS

We know that certain medications used to treat other ailments may unmask and/or aggravate dystonia. Please inform your health-care provider if you have ever taken any of the drugs listed later on in this guide.

IT IS IMPORTANT TO LEARN THE SIDE-EFFECTS OF ALL PRESCRIBED MEDICATIONS.

5) BASAL GANGLIA ABNORMALITIES

Many scientists are directing their attention to this area of the brain. Your brain controls all your body activities by sending electrical signals throughout your body. Scientists believe that when these electrical signals begin to misfire, voluntary muscle movements are altered, leading to symptoms of dystonia. There is intense research regarding the role of the Torsion A protein and the onset of neurological disease.

Online Websites!

About Genes and Dystonia :

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

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

About Dopamine-Responsive Dystonia :

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

About the Torsion A protein :

<http://www.dystonia-foundation.org>

Forms of dystonia are classified according to


- age of onset
- involved body part(s)
- clinical symptoms
- cause (etiology)

Based on your medical history, description of symptoms, physical and neurological exams, your neurologist can best determine your type of dystonia. For most patients, there is no clear-cut test for dystonia at the present time.

You may have a type of dystonia that is best described by several of the following terms :

TYPE of DYSTONIA	DESCRIPTION
<i>EARLY-ONSET</i>	<i>Dystonia symptoms that begin before the age of 26 that can progress to other body areas.</i>
<i>LATE-ONSET</i>	<i>Dystonia diagnosed after the age of 28 Typically remains limited to one body area</i>
<i>PRIMARY (Idiopathic)</i>	<i>Dystonia occurs as a single neurological illness, often of unknown cause, or genetic cause</i>
<i>SECONDARY</i>	<i>Dystonia develops due to another illness or neurologic entity Can result in "fixed" or "stiff" postures</i>
<i>GENERALIZED</i>	<i>Dystonia that affects the entire body Usually develops during childhood (ie: early onset)- it is often idiopathic (unknown or genetic cause)</i>
<i>SEGMENTAL</i>	<i>Dystonia that affects 2 or more adjacent body parts, such as an arm and leg or neck and vocal cords</i>
<i>FOCAL</i>	<i>Dystonia affecting a single part of the body such as the neck(torticollis) Onset usually occurs between the ages of 35-65 (ie:late onset) Tends to occur insidiously May progress slowly over time Spontaneous remissions may occur Can progress to generalized forms but this is rare Most common type of dystonia</i>

Classifying your type of dystonia allows your movement disorder specialist to develop an optimal DYSTONIA MANAGEMENT PLAN for you!

<i>FOCAL FACTS AND FIGURES</i>	
Blepharospasm	<ul style="list-style-type: none"> • Involuntary eye closure • Uncontrollable blinking Visit http:// www.blepharospasm.org online
Oromandibular Dystonia	<ul style="list-style-type: none"> • Muscles of jaw or tongue affected • Speech/swallowing difficulties
Spasmodic Dysphonia	<ul style="list-style-type: none"> • Vocal cords are involved • Hoarseness, voice strain, breathy speech Visit http:// www.dysphonia.org online
Meige's Syndrome	<ul style="list-style-type: none"> • Combination of blepharospasm and oromandibular dystonia Visit http://www.blepharospasm.org online
Writer's Cramp 	<ul style="list-style-type: none"> • Contraction of hand/arm muscles • May occur following other repetitive tasks
Cervical Dystonia	<ul style="list-style-type: none"> • Pulling and twisting of head/neck to one side or direction or a combination of directions Visit http:// www.torticollis.org AND www.spasmodictorticollis.org online

ORAL MEDICATIONS

A number of oral medications (pills) have been used to treat and manage dystonia. Your health-care provider at your Movement Disorder Clinic will most likely initiate your DYSTONIA MANAGEMENT PLAN with one of these medications. Sometimes it takes a combination of several drugs to obtain a beneficial effect. These drugs do not work overnight! It often takes a little bit of medication "juggling" to obtain an optimal benefit. Do not get discouraged! The following rules should make things easier for YOU when it comes to taking an oral medication.

KEY DYSTONIA MEDICATION RULES:

- ❖ Follow the directions for using the medicine prescribed by your health-care provider.
- ❖ If you miss a dose of the medicine, take it as soon as possible.
- ❖ If it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule.
- ❖ Do not take 2 doses at once unless instructed to do so.
- ❖ Do NOT suddenly stop taking any of these medications without checking with your doctor FIRST.
- ❖ Changing dosages on your own can be detrimental to your well-being.
- ❖ Never take anyone else's medication.
- ❖ The dosages of these medications varies from person to person. Not everyone responds to the same drug and dose in the same way.
- ❖ Many of these medications cause fatigue, drowsiness, altered abilities to 'think' at high doses. Plan your activities wisely.
- ❖ Some of the drugs used to treat dystonia will add to the effects of alcohol and other depressants. Your local pharmacist can help answer your questions.
- ❖ Read up and learn about all of your medications. The use of oral medications is based on trial-and-error. Currently the available oral medications benefit only a minority of patients, and the benefit is usually not complete.

Key Point : With all oral medication trials, the rules of thumb are to (1) start at the lowest possible dose and increase the dose slowly, and (2) use the lowest effective dose for maintenance therapy.

COMMON ORAL MEDICATIONS USED TO TREAT DYSTONIA (GENERIC ,trade name):

BENZODIAZEPINES

CLONAZEPAM (Klonopin)
DIAZEPAM (Valium)
LORAZEPAM (Ativan)

- ### SKELETAL MUSCLE RELAXANTS

LIORESAL (Baclofen)
CYCLOBENZAPRINE (Flexaril)
CARISOPRODOL (Soma)

ANTICHOLINERGICS

TRIHENIPHENIDYL (Artane)
BENZTROPINE (Cogentin)
ETHOPROPAZINE (Parsidol)

DOPAMINE STIMULATION

LEVODOPA/CARDIDOPA (Sinemet)
BROMOCRIPTINE (Parlodel)
PERGOLIDE (Permax)
PRAMIPEXOLE (Mirapex)
REQUIP (Ropinerol)

DOPAMINE DEPLETION

TETRABENAZINE (Nitoman)
RESERPINE (Serapes)

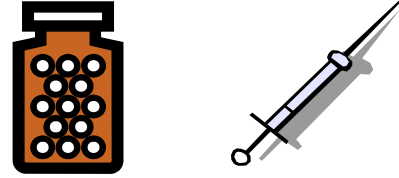
Additional drugs that have been utilized in the treatment of dystonia include ZANAFLEX, BENADRYL, MEXILITINE, TOPAMAX, DILANTIN, TEGRETOL, NEURONTIN and AMITRIPTYLINE (trade names).

Managing dystonia can be complex and challenging whether it involves oral medications, botulinum toxin injections, surgical interventions, physical therapy and/or complimentary modalities. But with the advent of new treatments developed over the last fifteen years, it has improved dramatically. Dystonia cannot be treated overnight. Treatment may involve one or more multiple options and may affect you differently over a period of time.

BOTULINUM TOXIN

Botulinum toxin is a toxin produced by a bacteria called Clostridium botulinum. It causes *temporary* muscle weakness when injected into muscles affected by dystonia. Botulinum toxin quiets muscle activity.

But how does Botulinum toxin work?



- ◆ Botulinum toxin is a nerve impulse “BLOCKER”. There are 7 serotypes of the toxin— A, B, C, D, E, F and G. Toxin types A and B are approved for use by the FDA.
- ◆ It binds to nerve endings found in your muscles preventing the release of chemical transmitters that cause muscle contraction.
- ◆ The transmitters are the chemicals in your body that carry messages from your brain to your muscles which cause muscle contraction. Botulinum toxin blocks these messages at the muscular level, so the muscle does not contract.
Hence dystonia relief!!!
- ◆ Eventually new nerve endings develop connections to new muscle sites which causes the wearing off of the toxin effects. Dystonic spasms may change after treatment and over time. Thus, your doctor may need to modify your treatments to search and treat other muscles as time passes.
- ◆ The correct selection and “targeting” of the dystonic muscles is crucial. Your health-care provider at your Movement Disorder Clinic may use electromyography (EMG) to help identify the involved muscles during your Botulinum toxin treatment. The EMG utilizes an needle electrode that records muscle activity. You may hear “sizzling” ,“cooking popcorn”, and “**static-like**” noises coming from the EMG speaker. The louder the noise, the more activity in that area. You should expect Botulinum toxin to be injected in those areas. Not all movement disorder specialists use EMG during the injection process. EMG use may not be necessary in ALL cases. You should clarify this with your specialist.
- ◆ Keep in mind that the degree of your clinical improvement is related to the extent of the local Botulinum toxin blockade—which is affected by the number, size, and location of involved muscles as well as the dose of Botulinum toxin. **BE PATIENT !!!**

Botulinum toxin is a temporary treatment. You should expect these injections every 3 to 4 months. More frequent injections with higher doses can result in the formation of toxin antibodies. When antibodies develop, the effectiveness of the toxin is reduced significantly, or stops altogether. Therefore your physician will recommend a conservative dosing program, hopefully to prolong the usefulness of the toxin.

Botulinum Toxin Information - Resources and Assistance

Allergan, Inc. - Botox® Advantage Program
2525 Dupont Drive
Irvine, California 92623
Telephone Hotline 1- 800-530-6680
Website : <http://www.botox.com>



Click to the Consumer Connection section to learn more.

NORD—Medical Assistance Programs
National Organization of Rare Diseases
55 Kenosia Avenue
PO Box 1968
Danbury, CT 06813-1968
Phone Number: (203) 744-0100
Tollfree: (800) 999-6673 (voicemail only)
Website : <http://www.rarediseases.org>
Email : orphan@rarediseases.org

MyoBloc ® (Botulinum toxin type B)
Website : <http://www.myobloc.com>

This website has product information primarily for healthcare professionals.

NOTES :

SURGICAL OPTIONS....

At the present time there are several Dystonia management surgical procedures available. These procedures have helped some people but not all.

A referral to a neurosurgeon who has experience with these procedures is absolutely necessary. Generally speaking surgical interventions are considered when medical treatments have failed. If you have any questions regarding these treatment options PLEASE ask your Team at your Movement Disorder Clinic or Center.

SELECTIVE PERIPHERAL DENERVATION:

This procedure was first developed in the early 1980's. Since its introduction varying success rates have been reported. It is primarily used in the management of cervical dystonia (torticollis). Denervation involves cutting the nerves that supply the specific group of muscles that play a role in your dystonia. Once the nerves have been cut the muscle or group of muscles atrophy (weakens) permanently. Denervation cannot be reversed. Therefore, it is extremely important to correctly identify which muscles are contributing to your symptoms. This information can be obtained from a detailed electromyography (EMG) exam.

You can be a candidate for this procedure if:

- *Your symptoms have not improved with oral medications or botulinum toxin injections.
- * Your symptoms are limited to one direction and/or muscle group.
- * You have no other major medical problems that may interfere with the procedure.

The four to six hour procedure is performed on an in-patient basis under general anesthesia with a three to five day hospital stay.

You may experience some of the following symptoms after surgery:

Pain	Mild neck swelling
Mild numbness	Hoarseness
Lack of balance	Neck stiffness/weakness
Difficulty swallowing/chewing	
Unsteadiness when walking	

INTRATHECAL BACLOFEN

Over the past decade, new therapies for the treatment of dystonia have been explored. One of these therapies being Intrathecal Baclofen or ITB.

ITB has been proven to be effective in patients with spasticity and is approved for use in the treatment of spasticity by the U.S Food and Drug Administration (FDA).

SURGICAL OPTIONS cont'd.

Several medical centers including the (name of facility– center) in New York City have studied the effects of ITB in several dystonia patients. Oral baclofen is one of the common oral medications used to treat dystonia. However, some patients develop a number of side-effects including drowsiness, dizziness, weakness, and nausea. Some simply do not acquire adequate control of their dystonia symptoms with the oral form of baclofen. ITB is the liquid form of baclofen and can be given through a 'pump-like' device to the area surrounding the spinal cord (intrathecal space).

It is best to thoroughly discuss this treatment option with your physician. Prior to implantation of the pump (similar to the size of a pacemaker), you must undergo 1 or 2 test doses of ITB in the hospital to test for effectiveness of this form of baclofen on your dystonia. This is done through a lumbar puncture or spinal tap procedure. The pump is then implanted underneath the skin with a long thin catheter that extends to the intrathecal space. The pump is filled and programmed to deliver a set amount of liquid baclofen on a hourly basis continuously. The pump is refilled every few months in your physician's office with the help of computer that helps to adjust your dose. ITB is not FDA-approved for dystonia. Cost of ITB is not always covered by medical insurance. Thus, it is important that you research and learn as much as possible about ITB first. ITB has primarily been successful in the treatment of spasticity associated with cerebral palsy.

DEEP BRAIN STIMULATION

In deep brain stimulation (DBS), an electrode is implanted in the area of abnormal electrical activity and a test stimulation test is done. If there is a beneficial response the electrode is secured to the skull with an " extension wire" that is attached to the electrode which is then tunneled underneath the skin towards the collar bone area to be attached to a pacemaker.

DBS minimizes involuntary movements by delivering mild electrical stimulation to block brain misfiring signals that cause the abnormal movements. The pacemaker is used as a programmer to deliver counter-acting impulses. One of the main advantages of DBS is that the effects of DBS are reversible barring any complications.

The risk for any of the above procedures include death, bleeding in the brain, stroke, seizures, infections and device malfunctions.

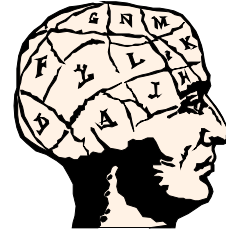
For more info you can visit the website run by Dr. Mike Kaplitt, MD from NY-Cornell-Presbyterian for answers to FAQs.

<http://www.beatparkinsons.net>

Surgical Options cont'd.

Complications include:

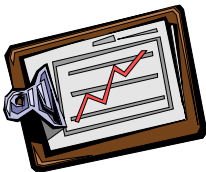
- Stroke
- Speech and swallowing difficulties
- Visual changes
- Memory problems
- Headaches
- Confusion, sleepiness
- Abnormal movements
- Infection
- Bleeding in the brain



All of these procedures are time-consuming, intense and require a collaborative team effort, patience, stamina and family and friend support. Review these procedures with your physician first before embarking on them.

Visit **MEDTRONIC** online for additional information about stimulators, deep brain stimulation and medical centers offering this procedure in your area

Medtronic Online : <http://www.medtronic.com>



You can find more information and links on our website @ www.care4dystonia.org

Write any Questions here :

LIVING WITH DYSTONIA . . .

Living with a illness such as dystonia can heighten feelings of stress and depression in **some** people. There will be days when you feel angry about having dystonia and the limitations (physical) it can cause in your life. You may dislike taking medications on a daily basis. You may dislike the uncertainty and unpredictability of dystonia. You may feel guilty about having dystonia. You may worry about dystonia and the "genetic factor". You may fear needles and electromyographic machines. You may feel rejected by "being different". There will be days when you feel "lost", "lonely", and "sad".

Should this be the case, try to remember that just about everyone with any illness (eg: asthma, diabetes, heart disease) might at times have similar feelings. But you , as an individual, can choose the way you handle DYSTONIA on a daily basis. A "Take Charge!" attitude is a major step in dealing effectively with dystonia.

Review the following signs of stress and depression. If you're feeling any of these symptoms on a CONTINUOUS BASIS, please inform any member of your Movement Disorder Team. It is important to recognize that the following signs may also be a direct result of your dystonia(example:headaches can occur with cervical dystonia) or the medication used to treat dystonia.

COMMON SIGNS OF STRESS/ DEPRESSION

- Feelings of helplessness/hopelessness
- Difficulty sleeping or sleeping too much
- Trouble falling or staying asleep
- Nervousness, crying, feelings of self-blame
- Irritability, restlessness
- Difficulty concentrating, fatigue
- Change in appetite and/or weight
- Alcohol or drug abuse
- Lack of social interests

What to do when signs of stress and/or depression intensify:

1. Ask for help.
2. Inform your Team and review your treatment strategy.
3. Talk about your feelings (spouse, family member, friend, etc.).
4. Don't avoid your feelings.
5. Seek individual or group support.
6. Get involved in social activities.
7. Get plenty of rest.
8. Maintain good nutritional habits.
9. Learn about Dystonia.

KEEPING TRACK OF ORAL DYSTONIA MEDICATIONS

	NAME OF DRUG:	START DATE	STOP DATE	START DOSE:	MAXIMUM DOSE REACHED:	SIDE-EFFECTS FELT DURING DRUG USE:	WHY STOPPED?
1)							
2)							
3)							
4)							
5)							
6)							
7)							
8)							

AVAILABLE RESOURCES. . . . Write, call or surf the Web

Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.

One Gustave L. Levy Place, Box 1490
New York, NY 10029 USA
TEL: (212) 241-5614
FAX: (212) 987-0662
E-mail: Bachmann.Strauss@mssm.edu
Web Site: <http://www.dystonia-parkinsons.org>

Benign Essential Blepharospasm Research Foundation, Inc.

PO Box 12468
Beaumont, Texas 77726-2468 USA
TEL: (409) 832-0788
FAX: (409) 832-0890
E-mail: bebrf@sbcglobal.net
Web Site: <http://www.blepharospasm.org/>

Care4Dystonia, Inc.

440 East 78 th Street
New York, NY 10021 USA
E-mail: infoc4d@aol.com
Web Site: <http://www.care4dystonia.org>

Dystonia Medical Research Foundation

One East Wacker Drive, Suite 2430
Chicago, IL 60601-1905 USA
TEL: (312) 755-0198 in Canada (800) 361-8061
FAX: (312) 803-0138
E-mail: dystonia@dystonia-foundation.org
Web Site: <http://www.dystonia-foundation.org>

Online Newsletter !

National Spasmodic Dysphonia Association

Contact: Dysphonia Association
One E. Wacker Drive, Suite 2430
Chicago, IL 60601-1905 USA
E-mail: NSDA@dysphonia.org
Web Site: <http://www.dysphonia.org>

National Spasmodic Torticollis Association

9920 Talbert Avenue #233
Fountain Valley, CA 92708 USA
TEL: (800) HURTFUL
E-mail: nstamail@aol.com
Web Site: <http://www.torticollis.org>

Spasmodic Torticollis/Dystonia, Inc.

Contact: Howard Thiel

P.O. Box 28

Mukwonago, WI 53149 USA

TEL: (888) 445-4598

E-mail: info@spasmodictorticollis.org

Web Site: <http://www.spasmodictorticollis.org> Newsmagazine available !

European Dystonia Federation

Contact: Secretariat

69 East King Street

Helensburgh G84 7RE UK

TEL: 44 (0) 1436 678799

FAX: 44 (0) 1436 678799

E-mail: alistair@newton1.co.uk

Web Site: <http://www.dystonia-europe.org>

WE MOVE

204 West 84th Street

New York, NY 10024

Tel: 800-437-MOV2

Fax: 212-875-8389

E-mail: wemove@wemove.org

Website : <http://www.wemove.org> Online Newsletter available !

Medtronic, Inc.

710 Medtronic Parkway

Minneapolis, MN 55432-5604

Phone: (+1-763) 514-4000 or 574-4000

Website : <http://www.medtronic.com>

<http://www.newhopefordystonia.com>

Finding others with dystonia can be an important component to 'living well with dystonia', minimizing the development of depression, anxiety and reducing potential complications that can develop as a result of lack of proper diagnosis and care. We encourage you to contact the above groups. Please note that some of the Bulletin Boards are 'moderated' while others are not.

- ◆ [Http:// www.drdcentral.com](http://www.drdcentral.com)
- ◆ [Http:// www. Dystonia-support.org](http://www.Dystonia-support.org)
- ◆ [Http://www. Dystonia-bb.org](http://www. Dystonia-bb.org)
- ◆ [Http://www.friendswithdystonia.com](http://www.friendswithdystonia.com)
- ◆ [Http://www.stsupport.com](http://www.stsupport.com)
- ◆ [Http://www.dystonia-support4u.co.uk](http://www.dystonia-support4u.co.uk)

MEDICATIONS that CAN Cause and/or Worsen Dystonia

Signs of dystonia may appear 24-48 hours after drug exposure but appear to be related to individual sensitivity and drug dosage. Symptoms may disappear once the drug is discontinued or if the dose is reduced. In some people symptoms may appear days or months after exposure to these medications. The exact mechanism of drug-induced dystonias are not well known. The mechanisms are probably complex. Currently this is an area of intense investigation by researchers.

DRUGS TO AVOID if possible:

Generic(Trade Names)

Acetophenazine(Tindal)	Amoxapine(Asendin)
Chlorpromazine(Thorazine)	Fluphenazine(Permitil, Prolixin)
Haloperidol(Haldol)	Loxapine(Loxitane, Daxolin)
Mesoridazine(Serentil)	Metaclopramide(Reglan)
Molindone(Lindone, Moban)	Perphenazine(Trilafon or Triavil)
Piperacetazine(Quide)	Prochlorperazine(Compazine, Combid)
Promazine(Sparine)	Promethazine(Phenergan)
Thiethylperazine(Torecan)	Thioridazine(Mellaril)
Thiothixene(Navane)	Trifluoperazine(Stelazine)
Triflupromazine(Vesprin)	Trimeprazine(Temaryl)

If you are unsure about the side-effects of any medication TALK to your local pharmacist as well as your doctor.

Your Movement Disorders Clinic-Center will be happy to talk with you about any new research developments regarding this subject.

Many major movement disorder centers collect information from many people who have dystonia. Researchers use this information to develop insights into the causes and treatment of dystonia. From time to time staff may ask you to participate in a research study. Participation is always voluntary.

You can learn more about clinical trials @ <http://www.clinicaltrials.gov>.

Published Works...

The following books have been published by a number of people living with various forms of dystonia today. Many describe experiences with various forms of dystonia. All of the books can be obtained online or can be ordered at your local bookstore (listed in no specific order) :

- ◆ Surviving Dystonia by Carmine Petrangelo
- ◆ Learning, Coping, Living: A Woman Who Describes Her Life Living Successfully with Dystonia, a Neurological Disorder by Bette Levine
- ◆ The Official Patient's Sourcebook on Dystonia Disorders: A Revised and Updated Directory for the Internet Age by Icon Health Publications
- ◆ Dystonia: The Disease That Distorts by Eugene Smith
- ◆ Holding the Hope: A Parent's Guide to Living with Dystonia by Karen K. Ross, PhD
- ◆ The Victim Is Always the Same by Irving Spencer, Cooper, M.D.
- ◆ The God Squad by Paddy Doyle
- ◆ The Voice Gallery: Travels with a Glass Throat by Keath Fraser
- ◆ The Thunder Within by John J. Heney
- ◆ Speechless : Living with Spasmodic Dysphonia by Dot Sowerby
- ◆ Voices of a Soft-bellied Warrior : A Memoir by Mary Saracino
- ◆ I'm Moving Two by Beka Serdans, RN
- ◆ I'm Moving On...Are U ? By Beka Serdans, RN
- ◆ Dystonia is...by Beka Serdans, RN

American Academy of Neurology
1080 Montreal Avenue
Saint Paul, MN 55116
Tel: (800) 879-1960 or (651) 695-2717
Website : <http://www.aan.com>

Locating a Movement

Disorder Specialist

Care4Dystonia, Inc
Website : <http://www.care4dystonia.org>

The Dystonia Medical Research Foundation
Website : <http://www.dystonia-foundation.org/health>

Movement Disorder Society
611 East Wells Street
Milwaukee, WI 53202, USA
TEL: +1 414-276-2145
Website : <http://www.movementdisorders.org>
E-mail: info@movementdisorders.org

DEMYSTIFYING DYSTONIA QUIZ !

Try to answer some of the following questions about dystonia. The correct answers can be found after reading the DEMYSTIFYING DYSTONIA guide!
Circle T if the statement is TRUE, or F if it is NOT TRUE (false).

- ◆ Dystonia is a neurological disorder. T or F
- ◆ Dystonia is NOT a fatal disease. T or F
- ◆ Overactivity of a certain muscle or group of muscles is a key feature of dystonia. T or F
- ◆ Dystonia only develops in people over the age of 65. T or F
- ◆ No diagnostic test is available for dystonia. T or F
- ◆ Heredity is an important factor in the development of dystonia. T or F
- ◆ Different forms of dystonia exist. Classification is important for proper treatment. T or F
- ◆ Dystonia is rarely treated successfully. T or F
- ◆ The most common side-effects of many oral (dystonia) medications is DROWSINESS. T or F
- ◆ None of the oral medications used to treat dystonia are HABIT-FORMING. T or F
- ◆ Botulinum toxin is effective in treating focal dystonias. T or F
- ◆ Botulinum toxin acts as a temporary nerve impulse blocker. T or F
- ◆ There are no post-botulinum toxin injection side-effects. T or F
- ◆ All movement disorder specialists are neurologists. (But, are all neurologists movement disorder specialists ???) T or F