



Current Healthcare Trends for Dystonia

Care4Dystonia, Inc.

The following survey was intended to help us at Care4Dystonia (C4D) to identify current trends in the health care; whether it be office visits, quality of care etc. being provided to you, as a patient with dystonia today. We obtained 298 responses to this non-scientific based survey. It provides some great information and clues to the present day management of dystonia, including needs and desires of those with dystonia. If you would like to utilize any of the information in a patient-newsletter or magazine, please do contact us first. Feel free to pass the C4D Dystonia Healthcare Trend Survey Results to friends, colleagues and medical professionals. We have placed the results for informational purposes only in hopes of generating a dialogue and interest in the need for multidisciplinary dystonia care.

1. What type of dystonia do you have?

Response	Percent	Response Total
▶ Blepharospasm	0.8%	2
▶ Oromandibular	1.2%	3
▶ Meige's	1.6%	4
▶ Focal Dystonia (ie. writer's cramp)	4.5%	11
▶ Cervical _ torticollis	48%	118
▶ Spasmodic dysphonia	6.9%	17
▶ Embouchure's dystonia	0%	0
▶ Hemidystonia	2%	5
▶ DYT1 generalized dystonia	3.7%	9
▶ Dopamine_responsive dystonia	1.6%	4
▶ Idiopathic generalized dystonia	8.9%	22
▶ Drug_induced dystonia	4.1%	10
▶ Tardive dyskinesia	0.8%	2
▶ Other (please specify)	15.9%	39

Total Respondents 246
(skipped this question) 0

2. What is your gender?

Response	Percent	Response Total
▶ Female	73.1%	179
▶ Male	26.9%	66

Total Respondents 245
(skipped this question) 1

3. What is your Race?

Response	Percent	Response Total
▶ White_Caucasian	94.7%	232
▶ African_American	0.8%	2
▶ Asian_Pacific	0.8%	2
▶ Hispanic	0.8%	2
▶ American Indian	0.8%	2
▶ Other (please specify)	2%	5

Total Respondents 245
(skipped this question) 1

4. What is your current marital status?

Response	Percent	Response Total
▶ Single	18.8%	46
▶ Married	63.7%	156
▶ Divorced	9.8%	24
▶ Separated	2.4%	6
▶ Widowed	3.7%	9
▶ Other (please specify)	1.6%	4
▶ Total Respondents		245

(skipped this question) 1

5. What is your age?

Response	Percent	Response Total
▶ Under 18	2.4%	6
▶ 18_24	2%	5
▶ 25_34	11.4%	28
▶ 35_44	20.8%	51
▶ 45_54	41.2%	101
▶ 55_64	15.5%	38
▶ 65+	6.5%	16

Total Respondents 245
(skipped this question) 1

6. What is your current employment status?

Response	Percent	Response Total
▶ Disabled	31.3%	76
▶ Employed full_time	23%	56
▶ Self_employed	6.6%	16
▶ Homemaker	7.8%	19
▶ Employed part_time	7%	17
▶ Not employed	6.6%	16
▶ Retired	9.1%	22
▶ Student	2.5%	6
▶ Other (please specify)	6.2%	15

Total Respondents 243
(skipped this question) 3

7. What is your household annual income before taxes?

Response	Percent	Response Total
▶ Less than \$ 15,000	12%	25
▶ \$ 15,000 _ 24,999	14.8%	31
▶ \$ 25,000 _ 34,999	12.4%	26
▶ \$ 35,000 _ 50,000	23%	48
▶ \$ 50,000 _ 74,999	18.7%	39
▶ \$ 75,000 _ 99,999	6.7%	14
▶ \$ 100,000 +	12.4%	26
▶ Total Respondents		209

(skipped this question) 37

8. Do you have a family history of a movement disorder?

Response	Percent	Response Total
▶ Essential Tremor	23.1%	31
▶ Myoclonus	0.7%	1
▶ Cervical Dystonia	9%	12
▶ Dysphonia	3.7%	5
▶ Blepharospasm	5.2%	7
▶ Restless Leg Syndrome	11.2%	15
▶ Generalized Dystonia	3.7%	5
▶ Parkinson's disease	16.4%	22
▶ Other neurological disease	11.9%	16
▶ Other (please specify)	44%	59

Total Respondents 134
(skipped this question) 112

9. Prior to your diagnosis were you ever exposed to any of the following medications groups?

Response	Percent	Response Total
▶ Anti_nausea (ie. reglan, compazine)	28.3%	30
▶ Neuroleptics (ie. haldol, thorazine)	19.8%	21
▶ Antidepressants (ie. prozac, zoloft)	56.6%	60
▶ Anti_cholinergics (ie. benadryl, artane)	41.5%	44

Total Respondents 106
(skipped this question) 140

10. Which is your dominant writing hand?

Response	Percent	Response Total
▶ Right	88.2%	217
▶ Left	11.8%	29

Total Respondents 246
(skipped this question) 0

11. How long did it take for you to obtain a correct diagnosis of dystonia?

Response	Percent	Response Total
▶ Less than 3 months	19.6%	48
▶ 4 to 6 months	11.8%	29
▶ 6 months to 1 year	13.5%	33
▶ 1 to 2 years	13.5%	33
▶ 3 to 5 years	12.2%	30
▶ 5 +	18%	44
▶ Other (please specify)	11.4%	28

Total Respondents 245
(skipped this question) 1

12. Who was the individual who made the correct diagnosis?

Response	Percent	Response Total
▶ Primary care physician (general internist)	4.7%	11
▶ General neurologist	49.8%	117
▶ Movement disorder specialist	28.5%	67
▶ Physical Therapist	2.6%	6
▶ Psychiatrist	0.4%	1
▶ Nurse	0.4%	1
▶ Self	13.6%	32

Total Respondents 235
(skipped this question) 11

13. During the diagnosis phase did you have any of the following screening tests?

Response	Percent	Response Total
▶ Bone Skull and Neck Xrays	33.2%	67
▶ CT scan	47%	95
▶ MRI	73.8%	149
▶ PET Scan	4.5%	9
▶ FDOPA	0.5%	1
▶ Video monitoring	16.8%	34
▶ Copper, eye lamp slit exam	10.9%	22
▶ DYT1 gene testing	10.4%	21
▶ Nerve conduction tests	26.7%	54
▶ Muscle Biopsy	4%	8
▶ Lumbar puncture (spinal tap)	13.4%	27
▶ EEG	29.7%	60
▶ EMG	29.2%	59
▶ VEP	1.5%	3
▶ Other (please specify)	17.3%	35

Total Respondents 202
(skipped this question) 44

14. Does your past medical history include:

Response	Percent	Response Total
▶ Thyroid disease	10.3%	18
▶ Arthritis	25.7%	45
▶ Frequent viral infections	13.1%	23
▶ Scoliosis	15.4%	27
▶ Drug and/or alcohol abuse	11.4%	20
▶ Mental illness (ie. depression, schizophrenia)	17.7%	31
▶ Tobacco abuse	32.6%	57
▶ Insomnia	15.4%	27
▶ Anxiety disorder	29.1%	51
▶ Autoimmune disease such as multiple sclerosis, SLE	3.4%	6
▶ High blood pressure	23.4%	41
▶ Heart disease	5.1%	9
▶ Diabetes	2.9%	5
▶ Other (please specify)	30.3%	53

Total Respondents 175
(skipped this question) 71

15. With your dystonia, do you have any of the following co-symptoms?

Response	Percent	Response Total
▶ Pain	81.3%	191
▶ Tremor	61.3%	144
▶ Sensory trick	38.3%	90
▶ Swallowing difficulties	36.6%	86
▶ Abnormal gait	37.9%	89
▶ Posturing	54%	127
▶ Numbness in affected limb	29.4%	69
▶ Other (please specify)	22.6%	53

Total Respondents 235
(skipped this question) 11

16. Does your current dystonia management plan include any of the following modalities?

Response	Percent	Response Total
▶ Oral medication	71.2%	163
▶ Botulinum toxin injections	55%	126
▶ Phenol	0.4%	1
▶ Intrathecal Baclofen	3.5%	8
▶ Physical therapy	19.7%	45
▶ Water therapy	7%	16
▶ Massage therapy	17%	39
▶ Tai Chi	2.2%	5
▶ Acupuncture	7%	16
▶ Herbal medicine	5.2%	12
▶ Biofeedback	1.7%	4
▶ Chiropractic care	10%	23
▶ Other (please specify)	23.1%	53

Total Respondents 229
(skipped this question) 17

17. Currently are you taking any of the following medications for your dystonia?

Response	Percent	Response Total
▶ Artane	12.5%	23
▶ Baclofen	19%	35
▶ Valium	16.3%	30
▶ Ativan	7.6%	14
▶ Klonopin	39.1%	72
▶ Sinemet	8.7%	16
▶ Zanaflex	9.8%	18
▶ Neurontin	12%	22
▶ Mexilitine	1.1%	2
▶ Other (please specify)	41.3%	76

Total Respondents 184
(skipped this question) 62

18. If you are currently receiving botulinum toxin therapy, which 'strain' are you receiving?

Response	Percent	Response Total
▶ Botulinum toxin type A (Botox)	82.9%	102
▶ Botulinum toxin type B (MyoBloc)	17.1%	21

Total Respondents 123
(skipped this question) 119

19. What is the name of your movement disorder or neurology group, that is, the place you go to for your dystonia care? Please include the location (ie. state,city)

Total Respondents 216
(skipped this question) 30

20. During the past YEAR, how many times did you see your healthcare provider at the above center?

Response	Percent	Response Total
▶ None	10%	23
▶ 1 time	10.5%	24
▶ 2 times	13.5%	31
▶ 3 to 5 times	45%	103
▶ 6 or more times	11.4%	26
▶ Other (please specify)	9.6%	22

Total Respondents 229
(skipped this question) 17

21. How long has it been since you last visited your provider for dystonia care?

Response	Percent	Response Total
▶ Less than 1 month	27.5%	66
▶ 1 to 3 months	40.8%	98
▶ 4 to 6 months	12.1%	29
▶ 7 to 12 months	5.4%	13
▶ More than 12 months	8.3%	20
▶ Other (please specify)	5.8%	14

Total Respondents 240
(skipped this question) 6

22. Once you arrive for a scheduled appointment with your provider, how long do you USUALLY wait including the reception and exam room to see her or him?

Response	Percent	Response Total
▶ Less than 10 minutes	19%	44
▶ 10 to 15 min	32.8%	76
▶ 16 to 30 min	26.7%	62
▶ 31 to 45 min	11.2%	26
▶ More than 1 hour, but less than 2 hours	6.5%	15
▶ Don't know	3.9%	9

Total Respondents 232
(skipped this question) 14

23. When you go for scheduled dystonia care, how often do you see the SAME doctor?

Response	Percent	Response Total
▶ Always	84.4%	190
▶ Most of the time	8.9%	20
▶ About half the time	2.2%	5
▶ Sometimes	0.9%	2
▶ Rarely or never	3.6%	8

Total Respondents 225
(skipped this question) 19

24. How would you rate:

Excellent	Good	Fair	Very poor	Poor	Response Total
▶ Convenience of the location where you get dystonia care					
27% (61)	33% (74)	26% (58)	9% (20)	6% (14)	226
▶ Quality of care					
45% (101)	35% (79)	13% (29)	4% (10)	3% (7)	226
▶ Medical staff listening to what you say					
47% (106)	32% (73)	12% (27)	4% (10)	4% (9)	225
▶ Arrangements for parking					
34% (75)	34% (75)	20% (43)	6% (14)	5% (11)	218
▶ Office staffs' efforts to make your visit comfortable					
38% (84)	41% (91)	15% (33)	5% (11)	2% (5)	224
▶ Hours that the place you get dystonia care is open					
36% (79)	43% (96)	15% (33)	3% (6)	3% (7)	221
▶ Ease of getting prescriptions filled, toxin availability etc.					
46% (97)	37% (77)	11% (24)	3% (6)	4% (8)	210
▶ Quality of actual exams_procedures by physician					
45% (100)	36% (81)	13% (28)	2% (5)	4% (9)	223
▶ Thoroughness and accuracy of treatments					
39% (84)	34% (74)	19% (40)	5% (10)	4% (9)	216

▶ Attention given to you						
48% (109)	32% (73)	12% (26)	4% (8)	4% (10)		225
▶ Explanations of tests, procedures given to you						
44% (95)	36% (79)	14% (31)	2% (5)	4% (8)		218
▶ Personal interest in dystonia						
53% (118)	27% (60)	14% (31)	3% (6)	4% (9)		223
▶ Explanations about prescribed medications						
35% (72)	39% (82)	19% (39)	4% (9)	3% (7)		208
▶ Reassurance and support provided						
34% (74)	31% (69)	21% (47)	7% (16)	6% (14)		220
▶ Amount of time given to you during visit						
41% (90)	37% (81)	15% (34)	3% (7)	4% (9)		221
▶ Training, skill, experience of physician						
56% (126)	28% (62)	12% (28)	2% (5)	2% (4)		224
▶ Training, skill, experience of NURSING staff						
35% (71)	40% (80)	15% (31)	6% (12)	4% (8)		202
▶ Availability of printed educational material about dystonia						
18% (39)	25% (53)	25% (54)	19% (40)	14% (30)		216
▶ Office environment						
34% (73)	43% (94)	18% (39)	5% (10)	0% (1)		217
▶ How well your dystonia care meets your needs						
24% (52)	35% (76)	28% (61)	7% (16)	8% (17)		220

Total Respondents 229
(skipped this question) 17

25. Would you recommend your current dystonia care provider to family or friends?

Response	Percent	Response Total
▶ Definitely not	7.2%	16
▶ Probably not	9.5%	21
▶ Probably yes	29.9%	66
▶ Definitely yes	53.4%	118

Total Respondents 221
(skipped this question) 24

26. The following questions pertain to your current Health Plan. How do you rate...

Excellent	Good	Fair	Poor	Very Poor	Response Total
▶ The range of different services your plan covers?					
23% (47)	44% (92)	23% (47)	3% (7)	7% (14)	207
▶ How well your plan informs you about the costs of dystonia care?					
17% (32)	27% (51)	23% (44)	18% (33)	15% (28)	188
▶ Coverage for dystonia treatments (botulinum toxin, EMG etc.)					
32% (62)	31% (60)	17% (32)	9% (18)	11% (21)	193
▶ The TOTAL COST to you for the dystonia care you receive?					
34% (67)	31% (60)	18% (35)	9% (17)	9% (17)	195
▶ Extent to which treatments, office visits are covered?					
37% (73)	31% (61)	18% (35)	9% (18)	6% (12)	199
▶ Coverage for supplementary services (ie. chiropractic, physical therapy etc.)?					
19% (36)	25% (49)	25% (48)	13% (25)	19% (37)	194
▶ Coverage for mental health services?					
20% (33)	26% (43)	25% (42)	16% (26)	13% (21)	165

▶ Coverage for botulinum toxin therapy?	36% (64)	29% (51)	14% (25)	9% (16)	12% (21)	177
▶ Coverage for prescription drugs used for dystonia?	35% (66)	28% (54)	15% (28)	9% (17)	14% (26)	191
▶ The process of obtaining out_of_area dystonia care?	20% (32)	26% (41)	23% (37)	14% (22)	18% (28)	159
▶ Coverage of X_ray services (ie. CT Scans, MRIs)?	32% (60)	37% (68)	20% (38)	4% (8)	6% (12)	186
▶ Overall quality of service provided by your health plan for dystonia care?	25% (50)	32% (64)	27% (53)	6% (12)	10% (20)	198
Total Respondents	209	(skipped this question) 37				

27. Have you had a problem with...

	Yes, a BIG problem	Yes, a SMALL problem	No, not a problem	Don't know	Response Total
▶ Confusion about what services are covered by your plan?	22% (46)	26% (53)	44% (90)	8% (17)	206
▶ Treatment or services recommended for dystonia are not approved by your health plan?	25% (51)	18% (36)	44% (89)	13% (26)	202
▶ Having to pay for services not covered?	28% (55)	21% (42)	44% (87)	8% (16)	200
▶ Having to pay for botulinum toxin therapy?	13% (24)	11% (21)	57% (108)	19% (36)	189
▶ Having to pay for surgical intervention (denervation, DBS, ITB)	12% (20)	5% (9)	35% (60)	48% (82)	171
Total Respondents	210				
	(skipped this question) 36				

28. Have you ever received financial assistance from Allergan's Botulinum Toxin Reimbursement Program? ANSWER if you are receiving Botox.

Response	Percent	Response Total
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▶ Yes	3.7%	7
▶ No	96.3%	181

Total Respondents 188
(skipped this question) 57

29. What kind of health insurance do you have?

Response	Percent	Response Total
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▶ Medicare	17.9%	42
▶ PPO, IPA or other prepaid plan	26.9%	63
▶ HMO	21.8%	51
▶ Medicaid	6.4%	15
▶ Private, fee_for_service insurance	5.6%	13
▶ Don't know	1.7%	4
▶ None	6.8%	16
▶ Other (please specify)	32.5%	76

Total Respondents 234
(skipped this question) 12

30. Where do you get the most information about dystonia?

Response	Percent	Response Total
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▶ The World_Wide Web	94.5%	222
▶ Printed brochures	15.3%	36
▶ Published Books	5.1%	12
▶ My Movement Disorder Specialist	18.3%	43

Total Respondents 235
(skipped this question) 11