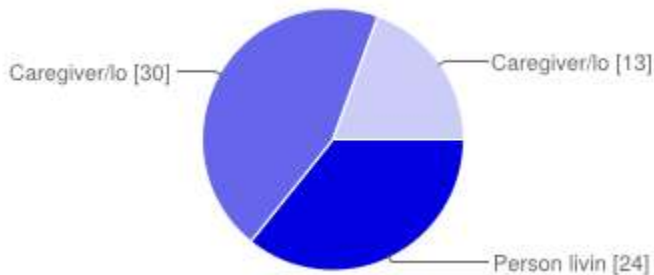




data*MSA Survey for Multiple System Atrophy

Summary of Survey Results:
03/01/14 – 04/04/14

Who is completing this survey?



Person living with MSA	24	36%
Caregiver/loved one of an individual currently living with MSA	30	45%
Caregiver/loved one of an individual lost to MSA	13	19%

In which country/region does/did the individual reside?

Region I: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

Region II: New Jersey, New York, Puerto Rico, Virgin Islands

Region III: Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia

Region IV: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee

Region V: Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin

Region VI: Arkansas, Louisiana, New Mexico, Oklahoma, Texas

Region VII: Iowa, Kansas, Missouri, Nebraska

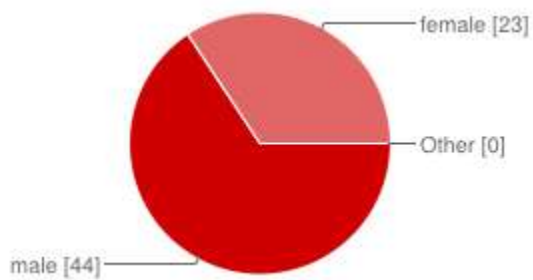
Region VIII: Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming

Region IX: Arizona, California, Hawaii, Nevada (American Samoa, Guam, Northern Mariana Islands, Trust Territory of the Pacific Islands)

Region X: Alaska, Idaho, Oregon, Washington

- Region XI: Canada
- Region XII: Central America
- Region XIII: Asia
- Region XIV: Africa
- Region XV: South America
- Region XVI: Antarctica
- Region XVII: Europe
- Region XVIII: Australia (continent)

What is/was the individual's gender?



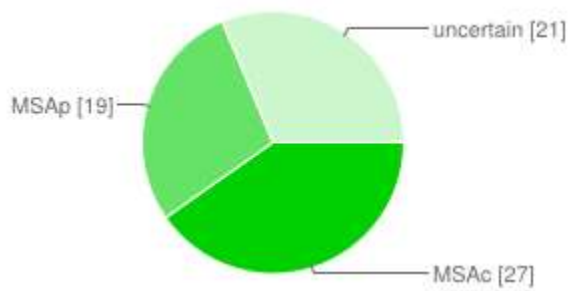
male	44	66%
female	23	34%
Other	0	0%

At what age was the individual diagnosed with MSA?

20-25	0	0%
26-30	0	0%
31-35	2	3%
36-40	0	0%
41-45	2	3%
46-50	12	18%
51-55	12	18%
56-60	11	16%
61-65	21	31%
66-70	4	6%

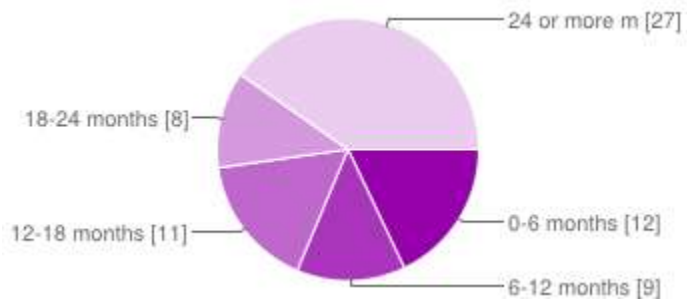
71-75	2	3%
76-80	0	0%
80 or older	1	1%

With which type of MSA was the individual diagnosed?



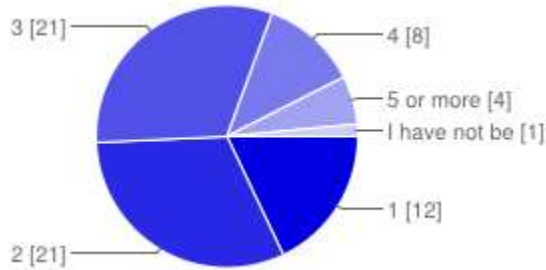
MSAc	27	40%
MSAp	19	28%
uncertain	21	31%

How long did it take for the individual to secure a formal diagnosis of MSA?



0-6 months	12	18%
6-12 months	9	13%
12-18 months	11	16%
18-24 months	8	12%
24 or more months	27	40%

How many neurologists did the individual consult during the diagnosis process?



1	12	18%
2	21	31%
3	21	31%
4	8	12%
5 or more	4	6%
I have not been seen by a neurologist	1	1%

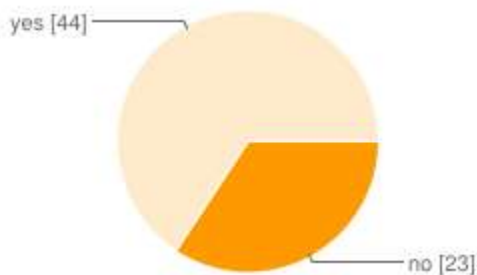
If the individual's diagnosis of MSA was not administered by a neurologist, please state

how the diagnosis was formed:

My general doctor said "this May be MSA" I'm currently waiting to see a neurologist with MSA experience. He was yet to be confirmed MSA-P patient, autonomic test left undone, before he died. Electro physiologist GP, MD, OD Will be going to Vanderbilt for confirmation Nov 2014 REBECCA'S TRIAL SURVEY ONLY. DELETE I also have had Epilepsy since age of 5. was first diafnosed by a doctor I seen at a MS clinic. Been seeing Neurologists all my life. A Physician

Was the individual diagnosed with any condition(s)/illness(es) prior to receiving a

diagnosis of MSA?



no	23	34%
yes	44	66%

If the individual was diagnosed with conditions/illnesses prior to receiving a diagnosis of

MSA please state the condition(s)/illness(es):

Dysautonomia, Syncope, Pre-Syncope. Also probably unrelated. PTSD, Dissociative Identity Disorder, Hashimoto's, Pernicious Anemia, Asthma, SVT, iron deficiency anemia, TMJ possible stroke Enlarged prostate Irritable bowel Urinary retention Urinary incontinence REM Sleep Disturbance, Gait Disturbance dysuria Cerebellar degeneration dizziness, lightheadedness. falling down. bladder control, staggered walking Parkinson Ageing Parkinsons Low heart beat - pacemaker Low blood pressure, dropping when standing Balance & walking issues Hand shaking Postural hypotension Mental illness Neuropathy Headaches Dry eye Memory issues Bladder issues Depression Irritable bowel syndrome Inner ear balance issue and was told it would go away. High Blood Pressure A nerve inflammation, then parkinson. Prostate cancer. Parkinsons Disease in 2007, MSA in 2011 Dysautonomia, POTS, IST 2003 via tilt table test and holter monitors Fibromyalgia 1989 PTSD 1998 Pernicious anemia 2006 Iron deficiency anemia treated by IV iron infusions 2008 Diabetic for 12 years, but he maintained pretty well almost all the years. Parkinsons Pacemaker, seizure (uncontrollable), psychological problems Everything I always was told it was either a symptom of having seizures or a side effect of a medication I was taking. Prostate Cancer Postural Hypertension Irritable Bowel Syndrome Charcot-Marie-Tooth disease Possible mini-strokes, memory loss, orthostatic hypotension, general anxiety disorder, depression, panic attacks, dizziness, lightheadedness, benign paroxysmal positional vertigo, arthritis, kidney stone, ruptured disk with nerve involvement, enlarged prostate, overactive bladder, chronic anemia, obstructive sleep apnea, REM sleep disorder. Heart disease Spinal Stenosis Complex regional pain syndrome type 1 Parkinsons and Parkinsons Plus Yes, he was diagnosed with Parkinson's first. He did very well park. Meds. Only later to go a different path and had another MRI to find the MSA present. His Dr. Was Dr. Stewart Factor of Emory in Atlanta. He is the head of neurological, movement disorders. My husband had symptoms on both sides of Parkinson's. Parkinsonism secondary to cardiovascular disease of the heart and brain and another Parkinsonism plus Blood pressure problems Gastrointestinal problems Gait changes parkinsons Syncope, falls. Orthostatic Hypotension High Blood Pressure ED. They told her it was frozen shoulders and bladder prolapse which she had surgery for where they performed a hysterectomy which didn't help we her family knew there was something more serious going on and insisted her doctor refer her to hospital. seizure, essential tremor, cervical dystonia plus had Freidricks Ataxia test Balance & Gait issues Vision issues Tremors hypothyroidism urinary urgency/ frequency and then retention orthostatic hypotension overactive bladder bladder retention issues possible ibs (due to constipation) Ataxia, pre Parkinson's syndrome, slurred speech, vasovagal response, bowel and bladder dysfunction, rem behavioral disorder, dysphagia, tremors, anxiety,

hemochromatosis, hypertension, hypotension, low testosterone, falling, impaired motor skills, dystonia, Nesdioblstosis COPD, Emphysema, CAD, S/P MI, CABG, cardiomyopathy, respiratory insufficiency, CHF, Ca of Prostate In remission, recurrent rectal bleeding, post radiation colitis , Obstructive Sleep Apnea, cardiac arrhythmias, permanent pacemaker and defibrillator Balance, breathing, swallowing problems 1. "You have either lupus or MS, and we should know once you check 'one more box' that will land you in one or the other." 2. "Parkinsonism" Complex regional pain syndrome type 1 Hard to say since he sought help from three neurologists for the tremor in extremities. Parkinson's tremors started at age 46. Within the second year, the low blood pressure and urology problems and difficulty speaking began.

At what age did the individual first notice symptoms, later attributed to MSA?

20-25	0	0%
26-30	1	2%
31-35	1	2%
36-40	2	3%
41-45	14	21%
46-50	10	15%
51-55	8	12%
56-60	20	30%
61-65	7	11%
66-70	3	5%
71-75	0	0%
76-80	0	0%
80 or older	0	0%

Please indicate the first/earliest symptom(s), which caused the individual to seek

diagnosis:

Neuropathy (numbness, tingling in extremities)	13	3%
Excessive Neuro-Response (jumpy reflexes)	4	1%
Difficulty Walking	28	7%
Impaired Balance	38	9%
Fainting	18	4%
Falling	25	6%

Unstable Blood Pressure	19	5%
Dystonia (muscle spasms/ rigidity)	11	3%
Neuro-Motor Freeze (temporarily unable to move at all)	3	1%
Myalgia (muscle pain)	9	2%
Tremors in Extremities	13	3%
Impaired Fine Motor Skills	12	3%
Head Droops Down or To One Side	3	1%
Dry Eyes	4	1%
Teary Eyes	2	0%
Impaired Vision	6	1%
Eye Fatigue	2	0%
Optic Nerve Damage	1	0%
Difficulty Swallowing/Choking	5	1%
Excessive Coughing	1	0%
Dry Mouth	4	1%
Overly Moist Mouth	1	0%
Difficulty Breathing	4	1%
Impaired Speech	9	2%
Digestive Disorder (diarrhea, constipation)	10	2%
Excessive Gas/Bloating	5	1%
Irregularity	7	2%
Impaired Bowel Control	6	1%
Impaired Bladder Control	24	6%
Impotence	25	6%
Chronic Fatigue	12	3%
Insomnia	8	2%
Impaired REM Sleep Cycle	14	3%
Confused Thought/Cognition	7	2%
Impaired Memory - Short, Intermediate, Long Term	4	1%
Inappropriate Emotions (crying, anger, etc)	6	1%
Excessive Reaction to Minor Stressors	3	1%

Chronic Headaches	3	1%
Depression	9	2%
Anxiety	8	2%
Suicidal Ideation/Thoughts	2	0%
Attempt(s) at Suicide	0	0%
Chills/Sweating/Overheating	8	2%
Rashes, Dry Skin, Itchiness	2	0%
Puffiness Under the Skin	2	0%
Other	9	2%

Please indicate all symptom(s) which the individual experiences/experienced since

receiving a diagnosis of MSA:

Neuropathy (numbness, tingling in extremities)	27	2%
Excessive Neuro-Response (jumpy reflexes)	25	2%
Difficulty Walking	56	5%
Impaired Balance	60	5%
Fainting	26	2%
Falling	48	4%
Unstable Blood Pressure	46	4%
Dystonia (muscle spasms/ rigidity)	37	3%
Neuro-Motor Freeze (temporarily unable move at all)	25	2%
Myalgia (muscle pain)	26	2%
Tremors in Extremities	31	3%
Impaired Fine Motor Skills	47	4%
Head Droops Down or To One Side	29	2%
Dry Eyes	17	1%
Teary Eyes	21	2%
Impaired Vision	33	3%
Eye Fatigue	21	2%
Optic Nerve Damage	8	1%

Difficulty Swallowing/Choking	46	4%
Excessive Coughing	17	1%
Dry Mouth	21	2%
Overly Moist Mouth	18	1%
Difficulty Breathing	28	2%
Impaired Speech	45	4%
Digestive Disorder (diarrhea, constipation)	45	4%
Excessive Gas/Bloating	11	1%
Irregularity	18	1%
Impaired Bowel Control	25	2%
Impaired Bladder Control	45	4%
Impotence	33	3%
Chronic Fatigue	30	2%
Insomnia	18	1%
Impaired REM Sleep Cycle	27	2%
Confused Thought/Cognition	26	2%
Impaired Memory - Short, Intermediate, Long Term	27	2%
Inappropriate Emotions (crying, anger, etc)	27	2%
Excessive Reaction to Minor Stressors	21	2%
Chronic Headaches	8	1%
Depression	29	2%
Anxiety	22	2%
Suicidal Ideation/Thoughts	4	0%
Attempt(s) at Suicide	1	0%
Chills/Sweating/Overheating	30	2%
Rashes, Dry Skin, Itchiness	21	2%
Puffiness Under the Skin	6	0%
Other	8	1%

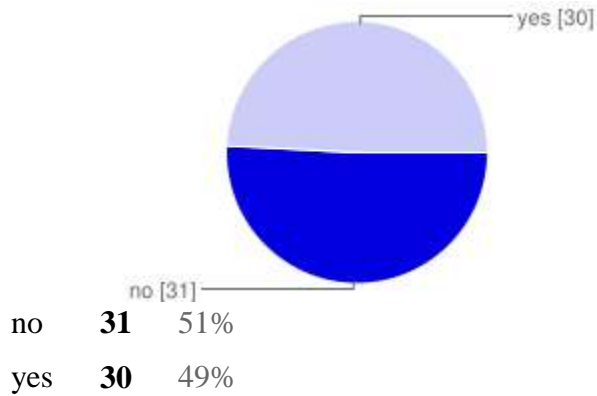
Please indicate events which cause/caused the individual's MSA symptoms to worsen?

None	8	4%
Exposure to heat	26	13%
Stress	36	17%
Fatigue/exertion	38	18%
Lack of sleep	26	13%
Diet	9	4%
Medication	9	4%
Loud noise	11	5%
Bright or pulsing/flashing light	12	6%
Confusion	10	5%
Depression	13	6%
Other	9	4%

Please list other events which cause/caused the individual's symptoms to worsen:

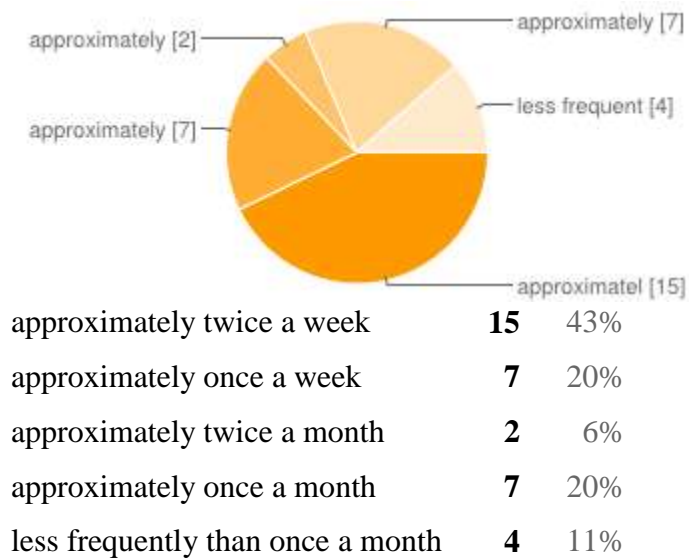
Seems that when the diet is high in carbs etc tends to do worse. Sitting for excessive time alcohol It seems strange but every time I've been on holiday I've gotten worse and ended up in hospital Infections Warm or chilly temperatures Had a appointment with Neurologist, Dr. Novak of Worcester. He put me on Levidopa and Carbidopa. I had no improvement and stopped taking it, not knowing that I wasn't supposed to stop taking it abruptly. Because of this, I fell, and was hospitalized and was found to have a UTI infection and severely dehydrated. I feel that because of this, I had to rely more on the walker, unable to walk on my own. I also feel that these two drugs had a profound affect on me and caused me to progress in my disease. he has worsen since his diagnosed 4years ago Meds needed to be regulated all the time., diet depends on his bowel movements. Heat, seemed to make him weak. Depression, and fatigue because he could not do the things he use to do and his mind said he could but his body would not respond. She found swallowing very hard but she had a very strong appetite and was hungry all the time even after eating which wasn't normal for her Progression of MSA Anticipation of any event outside normal routine, such as doctor's appointment, visit from relatives, trip to the store, etc. Before the event he is weak, his blood pressure is low and he can't think. While attending such events may be stimulating at the time, he tends to exhibit extreme fatigue afterwards. medicarion seems to be managing very well symptoms and minimizing some daily issues Extreme warm temperatures I would say any shift in temp, routine, sleep, travel, crowds, that will set me back, to Bed and testing only for several days to a week. medications taken for seizures, seizures menstration time of month

Are/Were any cycles observed with regard to periods of worsening of the individual's symptoms?



If cycles are/were observed with regard to worsening of the individual's symptoms, on

average, what was the frequency of the cycles?



If cycles are/were observed with regard to worsening of the individual's symptoms, what

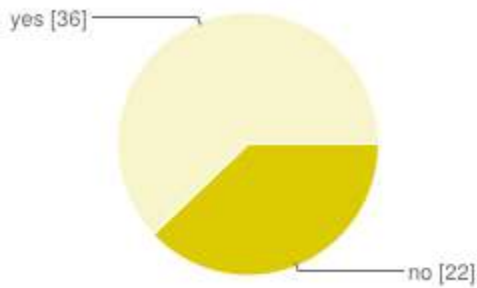
was the duration on the cycle?

less than 6 hours	4	13%
6-12 hours	6	19%

13-18 hours	1	3%
19-24 hours	2	6%
one to two days	11	34%
more than two full days	8	25%

Are/Were there any strategies/interventions that help(ed) reduce the individual's

symptoms?



no	22	38%
yes	36	62%

If yes, what are/were the strategies/interventions that help(ed) reduce the individual's

symptoms?

Diet	13	14%
Exercise/Physical Activity	21	23%
Physical Therapy/ Movement Therapy	20	22%
Accupuncture	4	4%
Light Therapy	0	0%
Speech Therapy	10	11%
Supplements (please describe below)	6	7%
Socialization	10	11%
Games, Puzzles, etc.	6	7%

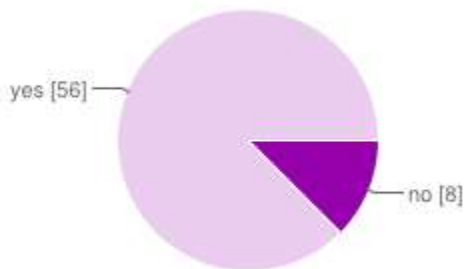
Please list other strategies/interventions that may help/have helped reduce the

individual's symptoms:

Resting medication/walking COQ10 - Levodopa Pool exerisessi 1. LSVT "Big" (for movement and LSVT "Loud" (for speech a AND swallowing) 2. Yoga, and in particular, yoga-styled breathing in all I do. 3. I think my daily core strength exercises have been invaluable...noticing now as movement in decline but my core strength helps me do lots on my own still. 4. Things I do which I "think" help but hard to know for certain since I do so many different things: A. Gluten-free diet (following Dr. Perlmutter's "Grain Brain" book's guidance) B. Hyperbaric oxygen therapy (HBOT).....every six months, I do two weeks of 2X daily HBOT. C. Glutathione IV injection, and a B-12 shot...twice per week. Bedrestsleep and the symptoms really worsen after a 2 day dart tournament due to pain and fatigue Reduce family drama..... Removal of causes of stress Speech therapy Exercise therapy Socialization Rest tried to keep watch on b/p control seizures with changing dosages of meds to changing meds totally,watched if there was any type of paiern to symptoms Sleep Water therapy in pool. Symptoms were reduced to a degree, but short term help. Liquid vitamins,bee pollen,green's,protein powder,chlorophly.Maintaining normalcy. There is usually a lot of laughter in this household, lots of family jokes and "messaging" with each other. We joke about his symptoms and make him laugh. For instance when his walk is slow and unsteady my daughter calls him Speedy. Biotronik Evia Pacemaker resolved syncope, IV fluids resolve per syncope and dysautonomia for a few days Keeping active, e.g. getting out of the house, interacting with outside world and interacting with other people. Laughing and being 'silly' Deep Brain Stimulation (DBS) has made a big difference with his movement. when we turn it off occasionally to 'reboot' his movement is far more limited. Warm therapy. Blankets and warm electric blankets. Sleeping a lot. I am utilizing various integrative therapies. Biophoton therapy, QiGong, prayer, supplements, nutrition.Try to exercise as I can. Sleep helps if I am overtired. Also workign with LDN(low dose naltrexone) Earlier, he was helped by Lee Silverman speech therapy and always by OT and PT. Avoid hot weather or cold weather. Reiki messages helped Massage sodium bicarbonate tablets stretching My father had a procedure where they drained fluid from his spinal cord which made his balance slightly better, for a while Planning! Travel time, meals on time, meds on time, increased fluids, taking lots time to get ready for any event. No movies theaters. For a while fish oil helped ease the neuropathic pain in the soles of my feet. Since my last decline it does not. Compression stockings for pooling in feet and legs Compression belt for pooling in abdomen Cannabis stopped the tremors

Has/Had the individual regularly taken any prescription medication prior to or after

diagnosis of MSA?



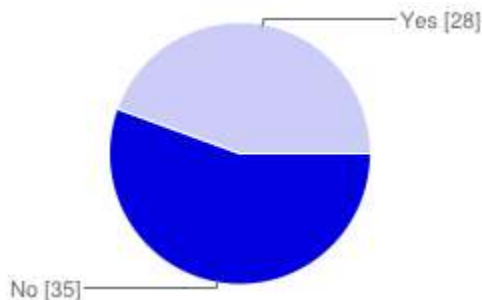
no	8	13%
yes	56	88%

If yes, please list the prescription medication(s) taken regularly by the individual:

felbatol-600mg tid lamotrigine100mg bid clonazepam0.5mg ai bedtime Various medications for high blood pressure since the mid eighties and medication for depression at different times. Various medication for high blood pressure since aprox mid-20's, various bouts with depression also various meds taken from 2001-2007..Medications after diagnosis of MSA include: midodrine,captopril, Atacand Somac Cipramil Baclofen Madopar Clonazepam Motilium Ditropan Dulcolax drops Movicol Coloxyl Oroxine Vitamin DCarbidopa/Levodopa Seniment Sinemet, midodrene, fludrocortisone Lovastatin not here.. Personal request will send script info citalopram fludrocortisone acetate, 1mg., nortriptyline hcl 10mgs.,mestinon timespan 180 mgs. Levodopa Metoprolol Fludro cortisone AlfuzosinHCC ER Sinemet Trazadone Imdur, minnax, somac, sinemet, Lipitor, Frisid, panadol osteo, sifrol, spriva, poly tears, nasonex, asasantin, endone., mirtazapine, baclofin, lyrica, Florinef, ventolin, fentanyl patches Topzole for gastric refluxBaclofen, cymbalta, neurontin, klonapin, namenda, trazadone Artane Cymbalta Valium Carbadopa/Levodopa, cymbalta,,blood pressure meds.,a sleeping pill that worked for sleep and restless leg.,forgot,the names of the last two.,they worked very well.,I,would have to,look them up., Madapor Domperidome Clonazepam All the Parkinson's meds and thyroid medication synthroid for graves disease synthroid lipitor (now stopped) nexium Alfuzosin (Uroxatral) 10. Mg qd Azilect .5 Mg qd Clonazepam (Klonopin) .25 Mg qd Clopidogrel (Plavix) Finasteride (Proscar) Fludrocortisone (Florinef) Levothyroxine (Synthroid) Namenda Myrbetriq Paxil Pyridostigmine (Mestinon) Sertraline (Zoloft) Sinemet Veneflaxion Omperozole Neupro patch Clonozapam Simvistatin clonazepam, baclofen, omeprazole, diclofenac, Spiriva, symbacort, ventolin, Tylenol 3 morphine sulfate; lyrica; levothyroxine; zolpidem; amitriptyline; Flomax; carbidopa/levodopa; hrt patches, movicol, macrodantin syndopa 125, urimax d, gemer ds 2, zevert md 24mg, rozaval 5, nuala e, delok 30, zinetac 150 Fludrocortisone Betmiga syntroid Carbodopa -levodopa Clonazepam .5 mg Florinef Quetiapine 25 mg Senna-plus tablet Digoxin Albuterol Pulmicort Prednisone Singular Tenormin Imodium Lomotil Guafenasine Zomax Lipitor Blood pressure meds Cholesterol meds Sinemet for Parkinson's, meds for bladder. Stalevo Sinemet Florinef Thyroxine Effexor Prolopa, Cialis, Nexam, Diclofenac, antidepression Keppra - for seizures The only med I was on was sinemet. I am slowly going off that and trying LDN. There has been alot of success with this reducing Parkinson symptoms. Something to look into... Dexilant for GERD Ambien for REM sleep disorder Clonazepam for startle response , RBD sleep disorder Gabapentin for neuropathy Vyvanse to increase blood pressure lunesta 3mg po od Sinemet, amantadine, nexium, clonazepam, midodrine, baclofen, zoloft, B-12 injections Fludrocortisones Phamipexole Sertraline Diazepam Amitripyline Fiorinal florineff midodrine Sinemet,mirapex, proamatine 2.5 mg midodrine 4 times daily Mestinion Lyrica Requip Pinpoint Vicodan Zoloft Pristine Trazodone Flexeril Midodrine Lorazepam Fludrocortisone toviaz Exforge, clonapin, wellbutrin, seroquil Coreg, Lasix, plavix, anti-depressents, cholesterol med, levothyroxin, estrogen, Digoxin, albuterol, Pulmicort, tenormin, Prednisone,Lopresor, , Imodium, Flomax , Singulair Effexor Sinemet (started taking 2/21/14) Have tried many different meds Lexapro, levothyroid, B12 injections, IV Iron Fereheme, IV Fluids, klonopin, trazodone, skelaxin, max all, xoponex

Has/Had the individual regularly taken any over-the-counter medication(s) prior to or

after diagnosis of MSA?

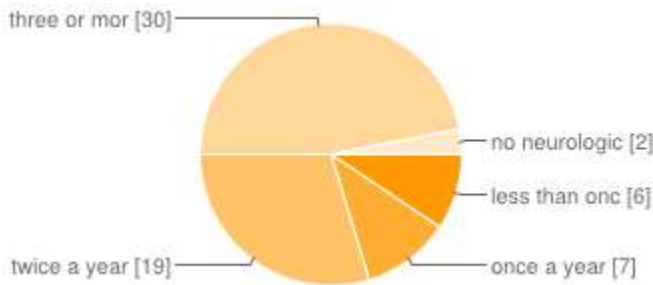


No 35 56%
 Yes 28 44%

If yes, please list the over-the-counter medication(s) taken regularly by the individual:

Advil Aspirin Anti diarrhea med Pain reliever Pain patch Multi vit Eye drops aspirin,ibuprofen I'm sure there others I just cant think of them presently.. Stool softeners Psycillium Husk Fiber Men's multiple-vitamin Vitiman D3 1000 IU Aspirin 325mg Melatonin 5mg Multi-vitamin fish oil benedryle sudafed Rifampicin,ragaziline,citaliprambayer cildren aspirin , stool softeners , different laxatives, eye drops, nasal sprays different pain meds Aspirin 81 mg aspirin daily; COQ10 Prilosec multi vitamin She suffered bad hay fever and sinus problems all her life and was always buying nasal inhalers like sudofed to try and breath better syndopa 125, urimax d, gerner ds 2, zevent md 24mg, rozaval 5, nuala e, delok 30, zinetac 150 Guafenesin Sudafed Aleve Mirolax Echinacea, excedrin, vitamins, stool softener miralax Advil, aleve, tums, pepto, excedrine Aleve Motrin Aspirin COQ10 B12 and B6; D3; vitamin C; zinc; multi-vitamin; magnesium complex Niacinamide; acetyl carnitine; probiotic vitamins coconut oil vitamin d/ca++ Guafenesin, Sudafed, Aleve (Naproxen) Ferrous sulfate (Iron) Immodium Florastore Multivitamine w/o Vitamins A&E Phazyme Vitamine B-12 Oral Vitamin D-3Vitamin C Vitamin D Ibuprofen q Q10 Aspirin Senna Papaya enzyme tablets

On average, what is/was the frequency of the individual's neurological care?



less than once a year	6	9%
once a year	7	11%
twice a year	19	30%
three or more times a year	30	47%
no neurological care since diagnosis	2	3%

What is/was the nature of the neurological care the individual receives/received during

these visits?

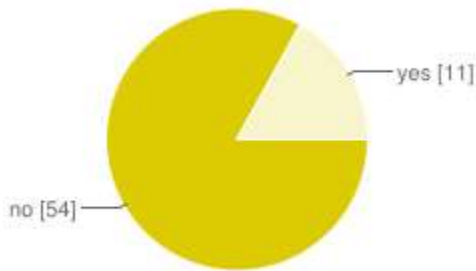
neurological consultation	44	34%
neurological assessment	47	36%
MRI	21	16%

CAT scan	12	9%
Other	7	5%

If 'Other" - please describe:

He had deep brain stimulation (DBS) in 2010 when about 3 years after he was diagnosed with Parkinsons Disease. We see a psychiatrist together 1-2 a year to talk through issues. this was particularly useful when he was able to discuss that he had hypersexuality issues and was finding that he had been attracted to men. This had been quite distressing and combined with impulse control issues caused by both disease and medication meant that he had acted on this impulses. This was resolved when the medications where lowered but caused much distress to the family. He has botox quarterly to keep his eyes open Nerve conductivity test, spinal tap, 8 MRI, EEG, EMG NCS test for testing numbness of hand and foot nerves 2-hour psycho-neuro exam, nerve conduction study Neurologist always makes sure spouse sees her compassion and care - and gives hugs and comfort prior to leaving. had uncontrolled seizures since age of 5. cannot find any causes.found out that epilepsy runs on fathers side of family. seizures were always worsened just before and during mensrtuation

Has/Had the individual participated in clinical research regarding MSA?



no	54	83%
yes	11	17%

If the individual participated in clinical research, which agency/group oversaw the study?

University of Michigan No Beth Israel Deaconess Hospital Hershey Medical Beth Israel of Boston Mayo Clinic Jacksonville Emory university of medicine.Atlanta, gaMichael got part in a few trials at the Royal Hospital Belfast with Dr Gibson unfortunately Dr Gibson passed away during trials mayo Clinic trial of Rifampicin No neurologist, respiratory professor, virtually all scans tests and examinations covered over the last twelve months Mayo Clinic

If the individual participated in clinical research, what was the purpose of the study?

It was for Parkinson's. Symptoms, everyday , gave blood also. None Efficacy of Rifampicin, results negative,study stopped,still taking because of no ill effects. no changes. also taking ragaziline and citlipram. No n/a Epilepsy earlier detection of MSA compare to Parkinsons The affects of rifampin an How if at all what effect Rifampicin has on MSA... They stopped the trial early due to actually make some patients worse.I was on a placebo. Rifampicin Trial Rifampin Dr. Gilman was researching for MSA, my husband donated his brain upon death

If the individual participated in clinical research, what were the outcomes of the study?

They had to stop the study None Didn't help unknown n/a Above Not sure! No study see previous answer ongoing Noneffective

If the individual participated in clinical research, please describe the individual's

satisfaction with the study experience:

very good experience, researchers were amazing people I knew i was on placebo so i was glad trial ended early. satisfied with competency None Wished it had helped I didn't want to,participate because I knew I had the placibo Overall lacked feedback. excellent None good Not.

With regard to possible MSA-contributing factors, which of the following did the

individual experience prior to receiving a diagnosis of MSA?

Prior single traumatic brain injury	3	2%
Prior multiple traumatic brain injuries	1	1%
Prior single head trauma resulting in concussion	5	4%
Prior multiple head traumas resulting in concussion	11	9%
Prior history of chronic headaches	11	9%
Prior neck injury	8	6%
Prior multiple neck injuries	5	4%
Prior exposure to chemicals/toxins	16	12%
Prior exposure to high levels of stress	23	18%
Prior diagnosis of Post Traumatic Stress Disorder	5	4%
Prior diagnosis of Seizure Disorder	3	2%
Family history of Alzheimer's Disease	4	3%
Family history of Parkinson's Disease	8	6%
Family history of Multiple Sclerosis	1	1%
None of the above	18	14%
Other	7	5%

Please tell more about the contributing factors stated above:

He was a aircraft mechanic, worked around a lot of fumes.,also , when a small boy his mother and him was found unconscious and brought back. He owned a porcelain fixture sanitation business in the

90's. Had MVA April 2012. By the end of May 2012 full blown picture developed. Had a head trauma with a sub arachnoid hemorrhage self es absorbed developed. Fell off a school roof at the age of 11 and hit his head , chipping his teeth and had a concussion.the stress level was from the work he did . My neck has always been a problem for me and I remember when I was young jumping out of a tree and hurting my neck but I recoverd ok without medical attention. I have spasms off and on and tightness quite a bit. I am a type A personality and have lived with stress most of my adult life. I have often thoguht that the neck and stress might be contributing factors. Some major stressful events happened about 10-15 yrs. prior to diagnosis.No family history of anything neurological. Eldest sister did have shaky hands and a twitch in her mouth later on in life. Several falls causing concussions (from horse, gymnastics), rear end car accidents, neck injury with horses, Multiple injuries in car crash, 20 surgeries, both orthopaedic and related to intestinal injury in the crash. Head injury, ptsd, headaches, all from crash. I worked in a building that was not properly ventilated during renovation on other floors. Strong toxins where used to clean marble walls (old government building, lots of marble) Exposure to pesticides like Agent Orange in Viet Nam. hi level leadership accounting role. I was in 2 car accidents that resulted in whiplash and had a few falls earlier in life that resulted in concussions. My father and his father have/had Alzheimers. Maternal grandmother had tardives dyskinesia. Was also in a motorcycle accident 2 months after dx Worked for fire department for 13 years. That accounts for high levels of stress and exposure to toxins, mainly smoke. aunt with parkinsons She lived in Belfast Northern Ireland during The "Troubles" and experienced a lot of stress years ago and she was always stressed out about everything her husband died of Motor Neurone Disease at aged 45 when they met they worked in a toy factory together, there were solvents used there it was early 1960's always wondered if there could have been something they were both exposed too. For 4 yrs he had to do an hour-long flight commute weekly, to work. Early rising, late night return home and extremely stressful job. All this coincided with our daughters' wedding, which added to the stress. n/a He is a business owner and whenever a stressful situation with partnership etc occurred , symptoms increased. paternal grandfather with alzheimers at 60-70 years of age 6 concussions from age 15 to 32 As a high school multi-sport athlete, and a scholarship collegiate basketball player, I broke my nose twice; and separately had my front teeth knocked out. I also suffered 2-3 neck injuries that were in the late '70's-early 80's called "whiplash" but led to 4 herniated cervical disks. I also have two herniated disks in lower lumbar. Ironically, since being diagnosed with MSA nearly 6 years ago, and quickly embracing yoga and a focus on proper posture, I have had a much improved experience with neck/lumbar spine-related pain and stiffness.....the best stretch since my early 20's. My Dad was diagnosed with Parkinson's Disease at age 70 and died at age 82 of PD complications. No immunizations as a child, had mumps, german measles, scarlet fever, almost constant strep. Victim of childhood neglect until I left home at 16 Married 11 years to an alcoholic, drug addicted bipolar abusive teacher. Had three kids by age 23 Battered womens shelter with kids, stalked and threatened for years after leaving. One child mentally ill, bipolar and schizophrenic, had to homeschool This child moved in with me pregnant and abused me mentally and physically the year MSA symptoms stared. After raising three girls as a single mom with no support, I am now raising my granddaughter as a single mom with no support, very limited resources and no physical help. She us three and has never had a sitter because I cannot afford one. wonder about COQ10. Over the years I had blows to the head. I did not seek medical attention, so I don't know if I had a concussion or not. He had been depressed thrice majorly in lifetime, his father had similar symptoms died at the age of 65. The neck injury was whiplash motor vehicle accident Chemical exposure was in my job used l the cleaning of machinery for food production Regular exposure to aviation fuels during a 30 year flying career Worked for 20 years in air conditioning repair using chemicals such as freon, etc Father and grandfather had Parkinson's. Primarily an electrician but involved in all phases of construction and remodeling, including gluing, painting. Worked at the railroad on diesel engines. High stress job as manager of all construction shops at Federal government agency. His father had some form of dementia. Stuttering from childhood to present (except when angry or singing), and dyslexic, i.e., seeing the letters in a word from right to left. My husband fell 10ft onto concrete, hitting his head, resulting in a serious concussion, this happened at ah What i was having the symptoms for MSA was told by some doctors and family members that they were all symptoms of epilepsy or having for so long that this is what it had done to my body. also would say something to someone and they would say it was a sign of aging Made me think it was all in my head and the only one that could make alot of the symptoms go away was me.have been a very nervous person all my life.by the time MSA was even spoke,had never yet heard of the disease. Pt swam in a chlorinated pool 2 hours a day, 7 days a week for 20+ years ! Pt had and still has a child who is highly socially dis functional (questionable bi-polar) who created and still does

complete havoc 24/7! She is currently 24 years old ! Exposed to mercury in early teens. Exposed to DDT, Deildren, Sheep and Cattle dip and other toxic chemicals in childhood. Never officially diagnosed with a concussion, I never went to hospital the several times i had blows to my head The condition presented in full after MVA with head trauma wi secondary small hemorrhagic subarachnoid hemorrhage in April. By May full blown picture.

In the past/last year, how would you describe the rate of progression of the individual's

MSA illness?



(1) very few signs of any progression in the past/last year	1	2%
(2) some subtle signs of progression in the past/last year	6	10%
(3) definite signs of progression in the past/last year	33	52%
(4) rapid progression in the past/last year	23	37%

Please add any comments related the individual's rate of progression in the past/last

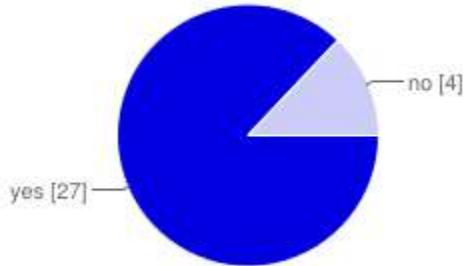
year:

After an extremely stressful eight weeks, I woke up with new symptoms of choking, slurring, hoarseness and shuffling gait and respiratory insufficiency. This happened overnight. My older symptoms were much worse. None of the signs found before 3-4 years(except shouting while asleep), fit enough to walk daily 4-5kms and cycling, everything started happening rapidly, increase in fall, faint(after 2-3 years diagnosed postural hypotension), urinary bladder disorder, bowel disorders, slurry voice etc, rigidity, lost the strength to get up without using hands if set below knee level, HE HAD IMPROVED IN LAST TWO MONTHS - constipation (ayurvedic medicines helped) , urinary incontinence(urimax d helped), electric/tingling pain in legs(delok 30 helped), slurry speech (with the help of physical therepy also had moderate to severe cervical disease too), He died within 3 years, though yet to get confirmed MSA_P ,autonomic test left undone, he had fever and cough in his last 2 days. While he has been having increasing difficulty in the last couple of years now he cannot walk or talk. In the last few months he has lost control of his bowels, his hands have become very rigid and he cannot raise his arm to indicate yes. He has trouble swallowing and occasionally breathing. is full care. unable to walk, speech difficult to understand and has problems sometimes choosing the appropriate word, supra pubic tube inserted 8 months ago, chronic issues with bowels, very slow, struggling a little with swallowing, tremors, Speach went, couldn't walk or stand, swallowing got worse, nil by mouth, on oxygen to help him breath Hard to walk Hard to get out of a chair Hard to get in and out of bed Swallowing sometimes a problem Very tiny writing Voice comes and goes Falling in the past 2 years went from a minor ear infection and being called drunk as a joke by neighbors to seeing more drs. and types of drs. than i have seen my whole life and having MSA which I had never heard of. Drs.should know that there is such a disease even if they havent got cure yet. they havent got

the cure for cancer yet they know they have cancer. Not knowing is harder on me than knowing what is wrong. Plus you can deal with having MSA. People know what Cancer means. When people say MSA all you hear is "what's that"? Weaker, using walker and scooter completely, loss of bladder control, eyes dry/tear, breathing difficulties, a meow sound upon exhale. Forgetfulness, emotional, tired easily. Balance off. I walk like I am drunk and have tremors when I am doing something, not so much when I am still. Required insertion of supra pubic catheter Chronic constipation and loss of muscle tone affecting defecation Muscle wastage despite physio routine Worsening parkinsons symptoms with debilitating fatigue Require two wheel frame with sliders in home and wheelchair for outings due to parkinsons symptoms and balance impairment as well as BP fluctuations..postural drop, bradycardia.. Autonomic dysfunction Swallowing problems..tolerating small amounts of moist minced diet. Cranial nerve dysfunction Gastroparesis, oesophageal spasm, nausea and vomiting Cognitive dysfunction, confusion and memory impairment Require assistance with personal care and home help, cooking Balance issues have worsened Speech is worse Over production of saliva has worsened He recently suffered a serious gastrointestinal issue that hospitalized him for a 10 days. While there he contracted a UTI. The medications, especially Flagyl, made him out of his mind among other things. He did not fully come back from that event, and is now required to be on Flagyl again. The medicine is working but the side effects are devastating. He can barely stand let alone walk, and last night he was hallucinating. If he can come back this time I know it will be weeks, and he doesn't have that many weeks to spare. His mobility is much more compromised, hence he has become far more dependent on my help. He can no longer do all the myriad chores he used to do to help me around the house. Cannot lift his grandchildren or play with them anymore. As making himself understood is difficult, he doesn't like to talk on the telephone anymore, and he participates far less in general conversation. Hospitalization seemed to increase symptoms Too rapid I had a fall in June 2013 that led to a "mild" concussion but it worsened all my symptoms. Then in late November 2013 I was hit with back-to-back incidents of Shingles. This produced new symptoms (Raynaud's, and serious neuropathy in arms, hands and feet), as well as worsening existing symptoms. I am using a walking stick for the first time since diagnosis, to help with balance especially out in public, and/or when fatigued. She only lived for about a year after diagnosis Actually , it was his last two month he progressed very fast. Went to his dr. At the end of Aug.,and he passed Sept. 17th , 2013. His meds just did not work, he could not eat, swallow, could not use walker and could not even strong enough to stand with help. His breathing was shallow, on oxygen. Since seeing the doctor in August. He went less than a month and he was gone.,he went into,a coma last 24 hours. He was on morphine the last 4 days., all meds were pulled when the doctor said they were not working anymore. It was a slow progression of symptoms until this last year. Diagnosed with MSA informally in february and told in August. Since then the decline appears to be steady. More frequent episodes More frequent spells of my neurological manifestation. At least twice a week minimum. I saw Dr.Novak in Worcester, Ma april/2013 At that time he put me on carbidopa& levodopa for which it didnt help so i stopped taking and didnt know i was supposed to ween off the drugs. I fell while getting out of shower,couldnt get up and ended up in the hospital for a few days.. since the fall in a weakened state, I've never got back to cond prior to going on those drugs & getting sick,, From being diagnosed last year in Jan 2013, she was walking by herself and talking. She now can't talk and goes everywhere in the wheelchair and has huge difficulty trying to get out of her chair. Stridor breathing, many falls and more of the progression in the symptoms they already had. I was only diagnosed 13 months ago with Parkinsons /mild case. Symptoms did not improve with sinet and went for 2nd opinion. Received second diagnosis in Nov/2013 of MSA. In this past year there has been a definite change in my balance and walking. /Before slightly off balance....now need to hold on to someone, use a cane.I do better now with the bladder, insomnia. Received diagnosis in 3/13 and since then has lost more mobility, worsening swallowing and speech problems, incidence of infections increased, incontinence worsened, body's ability to regulate temperature has also worsened, head tilt and Pisa syndrome have become more pronounced Rapid since October 2013..... Especially cognitively More difficulty with walking and balance. I wear a brace on right leg and use walking sticks. Now use a scooter if I am shopping. More falls. More cognitive changes, trouble focusing one more than one thing, forgetful and some confusion. Biggest change is greater fatigue, spend most of the hours of the day laying in bed. Motor skill drop too much, can't walk any more. He was hospitalized for serious bronchitis, pneumonia and possible flu during which time he was very close to dying. He recovered remarkably well but not to the pre-pneumonia state. No walking, we need to rectally remove her bowel, unstable emotionally extreme fatigue etc! Stopped driving. There was 2 yrs between the sleep disturbances and

gait disturbance, with eye, Speech, fine motor skills and bladder problems following quickly New symptoms keep appearing.

Does/Did the individual receive adequate support to live comfortably?



yes	27	87%
no	4	13%

If the individual does/did not receive adequate support to live comfortably, please

indicate what is/was lacking:

individual has/had no caregiver	4	27%
caregiver is/was unable to meet the individual's needs	0	0%
individual lacks/lacked financial resources needed for adequate care	2	13%
individual lacks/lacked health insurance to pay for service(s)	0	0%
individual lacks/lacked access to knowledgeable medical care providers	4	27%
individual lives/lived at a great distance from medical care/support	1	7%
individual refuses/refused assistance	0	0%
Other	4	27%

If the individual was lost to MSA, please indicate the cause of death:

Respiratory failure (stopped breathing)	5	42%
Respiratory infection (e.g.: pneumonia)	2	17%
Respiratory blockage (choking, obstruction)	0	0%
Heart attack	1	8%
Stroke	0	0%

Other complications from blood clot(s)	1	8%
Digestive system failure (unable to digest food)	0	0%
Digestive system blockage	0	0%
Head injury due to fall	0	0%
Other injury due to fall	0	0%
Other	3	25%

If the individual was lost to MSA, how long after MSA diagnosis did he/she live?

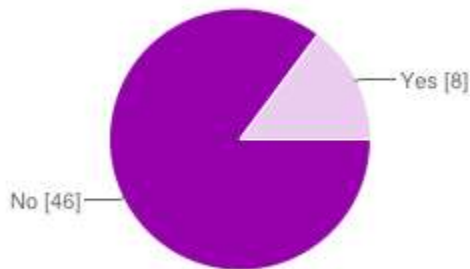
one year	1	8%
two years	1	8%
three years	1	8%
four years	3	23%
five years	2	15%
six years	2	15%
seven years	0	0%
eight years	0	0%
nine years	0	0%
ten years	1	8%
Other	2	15%

If the individual was lost to MSA, what was his/her age at the time of death?

20-25	0	0%
26-30	0	0%
31-35	0	0%
36-40	0	0%
41-45	0	0%
46-50	0	0%
51-55	2	15%
56-60	1	8%
61-65	8	62%

66-70	2	15%
71-75	0	0%
76-80	0	0%
81-85	0	0%
86-90	0	0%
90 or older	0	0%

Has/Had the individual made arrangements to donate his/her brain to an agency for research?

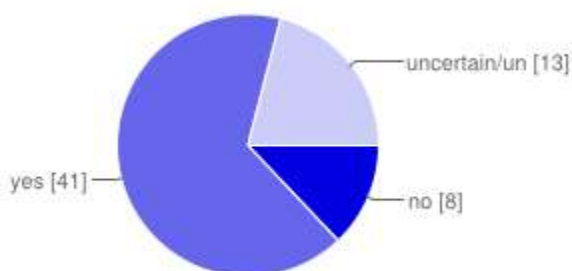


No	46	85%
Yes	8	15%

If the individual has/had made arrangements to donate his/her brain for research, please identify the agency to which the donation was made:

On my todo list. national My dad wishes was to leave his brain to msa but unfortunately he's was left out longer then 4 hour, so we where told they could take his brain which really upset us all as that was my dad wishes BMI Drivers License Indiana cannot find a place in Canada for brain donation University of Michigan Planning to make arrangements to donate brain to Mayo Clinic Jacksonville , FL We were supposed to see the dr about donating brain but he died about 15 hrs before his appointment!! BMI through drivers Licensebut I intend to, and must do the paperwork ASAP!! I want to donate my brain for study but I don't know who,to contact. We are in the process of arranging donation Mayo Clinic not sure yet

Does/Did the individual with MSA support a "patient's right to die?"



no	8	13%
yes	41	66%
uncertain/undecided	13	21%

Please feel free to add comments, observations and experiences which you feel may be

helpful to others who research, educate and raise awareness of MSA:

The beginning started with an infection, at which time the bladder issues started. At the same time, he became hyperthyroid (like hasimotos) and then hypothyroid. i would describe flare ups almost like an autoimmune disorder. My husband appears to be calm, but it is almost with the stress of situations, I can tell the symptoms are increased (bladder issues and stability). I do feel like when his diet is high in carbs (even natural carbs) he tends to become more symptomatic. I'm struck by the differences in presentation and outcome of people with MSA-P vs. people with MSA-C. I think this makes it confusing for doctors, and patients. As a MSA-P guy who has clearly been so far dealing primarily autonomic related issues (as opposed to movement), I hope the autonomic disorder folks are sharing information across disease silos. I notice on Michael J Fox recently a focus on "the other issues caused by PD, and they list out all my MSA-P autonomic issues...so again, the confusion and the need for cross-silo collaboration. My father had fever and cough in his last 2 days, he was getting better before that for the past two months. Patient was misdiagnosed with Parkinson's in 2006. Was diagnosed with MSA in 2010. Passed away in 2013 due to inability to either swallow or eat. Did not want feeding tube. Also had chronic bladder infections the last four months. there is a lot of focus on the physical issues of MSA but i believe that there are cognitive issues that need to be addressed. I believe that there are issues with impulse control, executive planning etc that patents and carers would benefit form information and support. Improved education of GPs in MSA required His first diagnosis of cerebellar atrophy was in 2000. A fall resulting in a fractured hip put him in a wheelchair in 2008. He has a very strong will to live and continues to enjoy life despite being in the late stages of the disease. More research needs to be done and brain donation is very important. Also to donate my brain in Canada where I received my dx, it would cost my daughter money. If we are willing to donate our brain, there should be no cost. Awareness of this disease is very important! A good support system is important. Doctors should tell people more about the disease when dx'd. I was told the day I was diagnosed that I had MSA. I would end up in a nursing home and go home and look it up on the computer. Written materials need to be available through your neurologist. I found this a very stressful way of learning about MSA. I have also offered myself up as a teaching patient for the medical studies of neurlogists at my hometown university Disease has so many negative features it's difficult to explain all that happens. Every symptom gets worse over time and for the patient and caregiver this is the biggest challenge. There is a lot of confusion regarding symptomology of MSA. More education amongst medical professionals is needed. Cognitive dysfunction and memory impairment makes it difficult to be able to express yourself and be specific about symptoms etc. need to have someone with you at medical appointments. How does a person prepare for what is to come next with such a disease? We all know that sometime we are going to die. Not knowing you have symptoms to finding someone dead with a rare

disease is a lot for anyone to handle! Even a well person. In our country (South Africa) there doesn't seem to be any follow-up post diagnosis. My husband was finally diagnosed after 18mths of tests, scans, MRI's and second opinions, and then basically sent home and told nothing more could be done. We (family members) did our own research online, joined an MSA support group on Facebook, thereby getting in touch with other MSA patients in our country. Our support group is made up of friends & family who come on a rotational basis to do speech or exercise therapy with him, or just to chat about work, his previous sport (squash) or news events. His symptoms began 15 years ago when he was 75. For him 75 is not old. Paxil and Florinef kept him stable and active for 10 years. At age 85 I noticed that his considerable muscle mass disappeared seemingly overnight but probably within 2 months. He began to have strange sensations in his legs. His determination to find out what it was took him on a 3 year journey of discovery through a dozen doctors, and straight into MSA-C. He's 90 now and just last month he was helping my daughter lay sod. His longevity tells us not everyone dies within 4 - 6 years. Doctors don't seem to know much about this disease More info needs to be available My mother lived in Belfast N. Ireland We feel no one knew much about this Disease only one consultant even the middle aged family doctor had never heard of it, it was very frustrating knowing there was something wrong but no one knew what or what to expect next we her family got most of our information on line, my mother couldn't except this illness her whole personality changed she was very depressed and we felt we got no support from anyone because it was so rare they couldn't tell us what to expect next, the worst part for her was the bladder and bowels problems and for us it was knowing how much thickener to put in her food we were scared of her choking all the time, she died in her sleep she was snoring loudly then it just stopped and she was gone. Because this illness is rare and presents differently with each person, neurologist in particular seem to have no knowledge of it and are unable to make a diagnosis. I am experimenting with a variety of integrative therapies in a controlled manner. Understanding possible causes helps to direct the pathway one chooses. I do not know that answer but possible considerations are pleomorphic organisms, previous injuries, exposures to toxic , etc. When the symptoms started I had Lymes disease. I also had neck problems as previously stated and I also worked with some chemicals in earlier years. In addition I have had a hair analysis done and it came up with some heavy metals . I believe there is something to detoxing the system that I will be doing. A friend of mine who has MSA once told me the only time she felt disease free was when she had a colonoscopy. Something to think about!

end