

# **SPASMODIC DYSPHONIA**

**What's wrong with your voice?**

**(the Story of Spasmodic Dysphonia in Australia)**

**Don Edgar**

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## **Acknowledgements**

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This study would not have been possible without the hard work and enthusiasm of Cynthia Turner, President of the Spasmodic Dysphonia Support Group (Australia) Inc. Cynthia has worked indefatigably to establish Support Groups across Australia and coordinate their efforts so the condition known as Spasmodic Dysphonia becomes better known among medical practitioners and the wider public. Her regular newsletter 'News From Home and Abroad' keeps Spasmodic Dysphonia sufferers up to date on the latest advances in research and treatment, and on events in which they can participate. It was also Cynthia who successfully obtained a grant from Lend Lease Foundation that helped pay for some of the data analysis. Hers was a major contribution to the Survey reported on here and the grant from Lend Lease was much appreciated.

Nor would the study have been possible without the contribution of my wife, Dr. Patricia Edgar, who was the first Australian identified as having Spasmodic Dysphonia (in 1978). In particular, we want to express our gratitude to Dr. Michael d'Asaro of Los Angeles, and Dr. von Leden, early pioneers in the search for solutions to the voice problem now known as Spasmodic Dysphonia. It was my wife's idea to conduct this study as a way of bringing to public attention (particularly to doctors, speech therapists and those who make decisions about workers' disabilities) just how devastating is this comparatively unrecognised neural disorder. Both she and Cynthia Turner suggested a range of hypotheses to be tested in the study, and designed questions to elicit an accurate description of the effect SD has on people's lives.

As well, Grace Soriano of the Australian Institute of Family Studies did the data coding and analysis for us, at minimal cost and with great patience.

We are also grateful for the State SD Support Group leaders who agreed to publicise the Survey and allowed us in some instances to talk with their members about it. We are very grateful to the Support Group leaders for assisting in this way. (See complete list of contacts at end of report).

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## **Foreword**

We all think we know how bad it would be to be blind, or deaf, or crippled.  
But try to imagine what it would be like to lose your voice.

Not just a temporary cold, or laryngitis, but a loss of control over your vocal cords such that no-one – your family, friends, work mates – can understand what you are trying to get out. You croak, you rasp, you choke on words, the sounds don't flow smoothly, you are breathy and panic-stricken because no-one can understand you and everyone looks at you as though you are upset and emotional.

Imagine what that is like on the telephone, or when you are teaching a class, running a business meeting, giving a talk to a group, even ordering a sandwich for lunch at the corner Milk Bar. You can't even say the words, "It's OK, I'm not about to cry, it's just that I've got Spasmodic Dysphonia."

What? Sounds spastic anyhow, sounds like a mental problem, sounds as if you are out of control. And since I can't understand what is coming out of your mouth, it's embarrassing, and I'd rather not have to try and work it out. Social isolation results. Even the deaf and blind can communicate with words, a physically disabled person can explain what happened, an accident, or an operation, or being born that way. But how do you explain a condition that even most doctors have never heard of, can't diagnose, and certainly cannot treat?

Welcome to the world of a recently-discovered medical condition – Spasmodic Dysphonia – a form of the wider group of dystonias, or muscle disorders affected by the central nervous system. You've heard of writer's cramp, leg twitching, uncontrollable eye-blinking, neck and shoulder muscle spasms and facial ticks. Now medical science has added two forms of vocal spasms to the list of dystonias:

- Adductor Type Spasmodic Dysphonia, or Laryngeal Dystonia, where the vocal cords spasm together, causing tight, squeezed, strangled sound, speech that sounds like a real effort to get out; and
- Abductor Type Spasmodic Dysphonia, where the vocal cords spasm apart, causing breathiness, sound separation, the voice dropping out in the middle of words and sentences.

Actually, the story is more complicated than that, because Spasmodic Dysphonia (SD) has been an identified medical condition for over 20 years, and is increasingly being researched. Doctors are now more likely to refer patients on to a throat specialist, who in turn is more likely nowadays to be alert to the condition. Though voice therapists have worked intensively with SD patients, the only consistent, known 'cure' for SD is an injection into the vocal cords of a diluted mix of the world's most deadly poison – Botulinum Toxin. The impact on voice quality is dramatic, but it does not last and patients have to have repeated injections if they are to maintain good voice quality.

The Human Genome Project has identified some 12 genes apparently related to dystonias and one (called the DYT1 gene) is linked to the voice-related Dysphonias. DYT1 dystonia is caused by a mutation in the gene which codes for a protein named TorsinA. This mutation is a three base-pair deletion in the gene. According to the website of the Medical Research Foundation, "Dystonia is a neurological movement disorder characterised by involuntary muscle contractions, which force certain parts of

the body into abnormal, sometimes painful, movements or postures. Dystonia can affect any part of the body, including the arms, legs, trunk, neck, eyelids, face, or vocal cords.” The Human Genome Project (though much hyped recently for ‘completion’ of gene-mapping) has not yet mapped all the regulatory sequences, introns, and complex interactions that may explain diseases or mutations in normal functions. It is unlikely that scientists will simply identify a gene for dystonia, let alone one for Spasmodic Dysphonia. We need to know what factors cause a mutation in persons who carry the ‘disease’ gene(s). These may be other genes or environmental ‘insults’ that are possibly avoidable.

Moreover, genetic causation is hard to prove, especially when one member of a family can develop the disability while other family members (who share the same genetic makeup) do not. Some physical traumas (such as a head injury or throat damage) can bring on Spasmodic Dysphonia, but the research is in its infancy and few clear patterns of causation have emerged. Most victims don’t even know they have SD, they just struggle on with a disabled voice and try to explain it away – “I’ve got a bit of a cold. Can’t talk.”

This report draws on the findings of the first comprehensive Australian study of a sample of Spasmodic Dysphonia patients, and a comparison group of people of similar age, gender and socio-economic status. It was conducted by the author, much assisted by his wife Dr. Patricia Edgar and the President of the Spasmodic Dysphonia Support Group (Australia) Inc., Cynthia Turner, with a much appreciated grant from the Lend Lease Foundation to pay Grace Soriano (of the Australian Institute of Family Studies) for data analysis work.

The SD sample was drawn by contacting members of the SD Support Groups in each Australian State and in New Zealand. All those SD patients who agreed to fill in the Questionnaire were asked to pass on a copy of the General Health Survey Questionnaire to an acquaintance of similar age and education, and of the same sex. Other family members were not accepted, since we wanted a comparison group with no likely genetic similarity. Confidentiality was guaranteed, but SD people were able to give their names and addresses for further research purposes if they so desired.

A total of 133 made up the ‘Experimental Group’ and 103 non-SD people made up the ‘Comparison Group’. All respondents filled in what we called a ‘General Health Survey’ Questionnaire, and the SD patients were given an extra section on their ‘Current Dysphonia Condition’. As a result, we are able to compare the results and try to detect any significant differences between the two groups, plus we are able to give a detailed description of the experiences of Spasmodic Dysphonia patients from its onset, through diagnosis, to treatment and the overall impact this troubling voice condition has had on their lives.

The report involves two main foci – one dealing with comparisons between the SD and the non-SD groups, looking for possible explanations; the second dealing with the experience of SD patients and its impact on their lives.

We want, in particular, to thank all those who participated in the study. SD is a condition that causes self-doubt and often quite serious social dysfunction and depression. It is a brave thing to expose yourself to detailed questioning about how you reacted to and now deal with SD and we admire their openness and clear desire to assist with research that might both clarify the causes of SD and publicise it so that others who cannot speak but

who have been told to ‘have a Bex and a good lie down’ will understand that SD is a real, physiologically-based medical condition, not a psychologically-caused ‘weakness’, and that it can be treated successfully in many cases.

With this study (and we shall describe people’s reactions to the condition in more detail) we asked them, as the final questionnaire item, to “Please comment on the impact Spasmodic Dysphonia has had on your life overall.”

Their comments were coded into categories which indicate the severe damage such a disabling communication/voice condition can have. (See also Chapter 8 for detailed examples of their responses to this item.)

Personality change	29.8%
Loss of ability to communicate with others	29.8%
Depression	7.6%
Ruined or hurt my career	22.9%
Ruined my family life	31.8%
You learn to live with it	18.8%

This non-technical report is addressed also to members of the medical profession, because it shows how damaging is a dismissive response along the lines that ‘it’s just nerves’, or ‘too much stress, calm down and it will go away’, or ‘it’s just old age, everyone’s voice gets a bit frail’. Spasmodic Dysphonia can affect children as well as adults, can be either sudden or gradual in its onset, is not curable simply by ‘trying harder’, and needs to be handled by voice specialists who are fully aware of the research and current treatment regimes.

## **Chapter 1: What made my voice go funny?**

As mentioned already, the voice difficulty now called Spasmodic Dysphonia was not recognised until quite recent times, so research into its causes or antecedents is very new and basic. In fact, all the forms of dystonia were associated with muscle spasms and “fell in the cracks” between neurology and psychiatry. (de Long, 1999) Either it was put down to a weakness in the muscles (of the neck, leg, eye or hand, etc.) and thus likely to be remedied by exercise, or it was put down to a mental or psychiatric disorder, and thus subject to treatment by psychotherapy, counselling or perhaps psychogenic drugs. Research has now established that all the dystonias derive from an underlying movement disorder and are problems arising in the central nervous system, in the basal ganglia which send messages to the muscles affected.

Because of the long tradition of treating voice disorders like stuttering as being caused either by poor speech habits learned as a child, or by ‘nerviness’ or anxiety in social situations, the natural reaction of medicos to a loss of voice itself (breathiness or raspiness) was to send people either to a speech therapist or to a psychologist/psychiatrist. The former should be able, by devising the correct breathing and speech exercises, to teach SD people how to pronounce words properly again and get some fluency back into their speech patterns. Since no-one knew why, however, the loss of voice often occurs later in life, or why with some people it was a gradual process, with others almost an overnight phenomenon, the odds seemed to lie in psychological distress, depression, ‘nerves’, the sort of anxiety that characterises agoraphobia. And because women were, as usual, more likely to go to a doctor and ask for an explanation and solution than men (who could get away with shouting, or being silent and uncommunicative as normal) many doctors thought of it as a women’s problem, part of the expected hysteria and over-dramatic health problems of the female sex.

### **First Signs of Voice Difficulties**

It may be of interest to note some of their descriptions of how the voice problem later diagnosed as Spasmodic Dysphonia came to be noticed. For some it was a gradual loss of functional speech, for others a sudden and dramatic loss of voice control. Quite a few people noticed difficulties following an operation, cold or flu, or some other trauma in their lives.

The first set of responses below to the question ‘What were the first signs of the problem that you noticed?’ come from the **Adductor** group (i.e. where the vocal cords spasm together rather than apart, causing tight, squeezed, strangled sound, and speech that is very effortful).

#### 1. Sudden onset:

*It came on very quickly – no first signs, it was just there and hasn’t changed. (F, 29)*

*Breaks on vowel ‘i’ and ‘n-i-ne’ when refereeing a squash match. Tightness of throat. (F, 41)*

*My voice just wouldn't come out. (M, 42)*

*My best friend and I sang on a tape recorder and the fluency was not good. It was the first time I was embarrassed by it. (F, 51)*

*I was in hospital with pulmonary embolism due to hormone replacement therapy being given to me post-op. I was in shock with overload of hormones and fear of dying. My voice just cut out. (F, 56)*

*A rather tight, strained voice which appeared to be from a cold. I thought it was an allergy maybe. (F, 54)*

*Had a bad cold and was left with a hoarse, strangulated voice. (F, 69)*

*14 years ago, when attempting to sing a nursery rhyme to my grandson, and I couldn't. (F, 84)*

*Sudden voice failure, speaking at a religious gathering. (F, 84)*

*Voice almost completely gone after flu in 1996. Voice had to be forced out. (F, 73)*

*I had a very bad flu, then laryngitis, and my voice never came back. (F, 76)*

*A type of mild laryngitis after a number of virus infections. (F, 73)*

## **2. Gradual onset:**

*Breathiness, inability to complete sentences without taking a breath, certain words catching in my throat (usually starting with a vowel) (F, 34)*

*Couldn't get words out properly. People telling me to speak properly. (F, 49)*

*Sore throat, difficulty swallowing, hoarse voice. (F, 49)*

*Raspy voice – 'croaky', deep. (F, 49)*

*Reluctance to speak, feeling it was an effort. (M, 46)*

*Shaky voice – people thought I was very 'nervous'. (F, 60)*

*Was working with children and the elderly and in both situations found it harder and harder to project my voice. (F, 53)*

*Lack of volume. (M, 46)*

*Gradual hoarseness, weight loss. (F, 58)*

*The first year I think I could feel the tightness and hear a different quality. I doubt if others noticed anything and probably thought I was a hypochondriac saying I was concerned. Later, others noticed, but the effort is more troublesome than the sound. (F, 55)*

*A slight 'missing' in my voice. (M, 57)*

*Some clipping of words and difficult to start from time to time. (M, 67)*

*A feeling in my lower throat that I felt and had to clear by coughing or throat clearing. (M, 59)*

*At age 17 I noticed a slight hesitancy in my speech. (M, 67)*

*Voice breaking up. (F, 55)*

*Nerve problem to right ear. Tremor from neck to head. Then voice problems. (F, 66)*

*Slight difficulty in swallowing, making 'mmm' sounds. Started May '92 and progressively worse until November '92 when it was diagnosed. (M, 57)*

*Voice became shaky. (F, 65)*

*After I had a cyst removed from my throat which had caused speech problems. For a while my voice was normal, perhaps 1-3 years. Then it started again, but different. (F, 70)*

*Small twitch in upper lip, spreading to whole face, over about 5 or 6 years. I then contracted a virus in the larynx, two small ulcers which lasted 4 months. By then the larynx was in spasm, voice breathy but still normal. My breathing was affected so a tracheotomy was performed. (F, 76)*

*Probably realising that people weren't understanding me. Then became more and more exhausting and was trying to force it. (F, 76)*

*Unable to get words out properly. (M, 74)*

*Paralysis of a cord was diagnosed 6 years before onset of SD. Had problems with hoarseness, difficulty in speaking several years prior to diagnosis. Voice became progressively worse after a bad cold about 6 months before diagnosis of SD. (F, 72)*

*Whispering voice. Very sore after speaking for some time. (F, 71)*

The next set of responses comes from those who were diagnosed as having the **Abductor** type of SD (i.e. where the vocal cords sag or spasm apart, causing a separation of sounds, the voice drops out and intermittent breathiness occurs.) There seems to be less evidence of a sudden drop-off, and fewer mentions of the flu as a starting point.

*A shaky, restricted voice, not always, but when it did shake it sounded like I was nervous and upset. (F, 45)*

*Difficulty speaking, not being able to get the words out, exhausted from speech. (F, 34)*

*Interruption in vocalising some words – breathiness. More effort required in speaking. (F, 33)*

*Breathiness. (F, 50)*

*Voice fading out, was clearing my throat a lot. (F57)*

*Loss of holding a note in choir practice. Dryness in throat, difficulty in swallowing, loud noises out of the blue, speech sudden cut off. (F, 60)*

*Husky laugh. I'd had chronic fatigue syndrome after a heavy bout of laryngitis, thought loss of voice was another symptom of that. (F, 55)*

*At 14 years of age I was asked to read to two classes at school. I was very nervous and then shocked with the way my voice could not produce itself. Breathiness and trembling lasted for a term and then seemed OK. After, just on and off problems. (F, 62)*

*Hoarse voice. Having to clear my throat like when you have a cold. People on the telephone asking if I had a cold. (M, 55)*

*Unable to talk freely, especially in meetings. Strong feelings of anxiety. It was a busy time at work. (M, 52)*

*I contracted what seemed to be a normal bout of flu. When the flu went, so did the voice. The vocal cords spasmed. (M, 57)*

*At age 69-73 (I was) going through a stressful time with my husband as his illness became worse. Embarrassed speaking on the phone. (F, 75)*

*Husky voice, but understandable, got worse over a period of months. Marriage breakup and death of a young son-in-law didn't help. (F, 71)*

*Friends had to listen to me and concentrate on what I was saying; some talking back to me slowly. I'd had laryngitis, but it was different. (F, 71)*

*In 1957 I noticed in preaching a click came to my voice and noises in the ears. Didn't trouble me till 1986 when my voice failed almost completely. (M, 80)*

*Came on gradually, no apparent cause, volume disappearing. (M, 75)*

*Then we have some people who claim to have/or have been diagnosed officially as having both the Adductor Type and the Abductor Type of Spasmodic Dysphonia.*

*Now and then my voice would cut out when talking to my parents. Our relationship was bad at the time. My health was fine, but I was stressed about not being able to get a job. This thing happened over about one month. (F, 27)*

*It was a very stressful time, fighting for the rights of my husband (killed) and daughter (seriously injured) after a car crash. I got a cold and lost my voice, then it came back stuttering, very nervous type of speech.(F, 43)*

*Occasional strain on my voice every now and then, for no apparent reason. Then I experienced repeat bouts of tonsillitis and throat infections, with laryngitis as well. It emerged gradually over a period of weeks. (F, 30)*

*Recurrent soreness around throat – muscular due to straining my voice. Use of the telephone became difficult. My speech became forced up to 10 years ago, and everything was happy then. But my husband lost his job later and felt useless, we had financial worries, and my throat problems made me very stressed looking for an answer (doctors basically said ‘It’s all in the mind.’) But it started long before that. (F, 49)*

*Over several months, I got a shaky voice, not able to start words, or finish sentences. Whispered sound only. Not able to pronounce ‘h’ sounds, losing parts of words, running out of breath, rasping sounds. Dreadful! (F, 58)*

*I started to find it difficult to talk and project my voice. Lost vocals completely, no sound whatsoever coming out regardless of effort. (F, 55)*

*Voice quavered, then I lost my voice completely over a week. As a child I had a tremor in my hands and my handwriting was very irregular. I believe stress triggered a latent condition. (F, 61)*

*Difficulty in making myself understood when shopping and on public transport, gradually became more extreme. Took some years, more difficult to continue with committee work, public speaking and generally leading a normal life. I do at times have a voice tremor as well. (F, 80)*

*Very gradual, took several years, more noticeable when stressed. (M, 72)*

## **Initial diagnosis**

The initial diagnosis given by the first medico consulted was as follows –

The problem is imagined	3%
It’s physical	10.5%
It’s caused by stress (real)	3.8%
Misuse/overuse of vocal cords	5.3%
Nerves	8.3%
Did not know what was wrong	6%
Correct SD diagnosis	10.5%
No response at all	48.9%

## **Pathways to correct diagnosis**

But the pathway to correct diagnosis was long and frustrating. People desperate for an explanation of why their voice had failed them went from specialist to specialist. Virtually everyone had started with their own GP, but only 3 per cent of GPs recognised it as a real vocal cord condition needing referral on to a specialist. 44 per cent had seen an otolaryngologist (of whom 64% correctly diagnosed SD); 78.9 per cent had seen a neurologist (of whom 72% diagnosed SD); 47 per cent had seen a psychologist or psychiatrist (only 2% of whom recognised it as a physical problem); only one per cent had seen a social worker; 8 per cent had been to a naturopath (2 per cent of whom named the condition correctly); and 29 per cent had tried out other sources of advice and help. Most of the SD people had been referred on to the person who finally diagnosed SD as the condition they had, but 7 per cent had made their own appointment without a referral

and 12 per cent stumbled on the answer from someone by accident or chance (that is, they were there for some other reason and the specialist asked about their voice).

The following quotes indicate the tortured path many SD people experienced on the way to proper diagnosis.

*The psychologist gave me all sorts of crap – It's because you're adopted, etc. (Female, 29 years, 4 years from onset to diagnosis)*

*It emerged gradually over many years. A hypnotherapist gave me relaxation treatment. An acupuncturist gave pressure needles. Then a speech therapist told me to exercise. I saw a TV program and the therapist agreed I might have SD. (Male, 49 years, 25 years from onset to diagnosis)*

*First consulted my GP who was the first in a long line to fob me off with some trumped up diagnosis and he told me to be more conscious of my breathing during speech. Then an ENT specialist diagnosed nodules and told me to rest my voice. The second ENT specialist said the same and suggested speech therapy. Then I saw a psychologist who tried hypnosis and a naturopath who recommended slight dietary modifications. After consulting both ENTs I knew neither of them really knew what the problem was. Understanding was poor, attitude was to baffle me with bullshit and secretly hope my problem would solve itself. So I wouldn't return to them. The psych. and naturopath were interested, attitudes were helpful, but neither of them had encountered this problem previously. (Female, 34 years, 10 months from onset to diagnosis)*

*Saw ear, nose and throat specialists. The first had no idea, the second two said I had somehow 'scrambled' my speech pattern and referred me back to speech therapy. They said it was a speech 'confusion', didn't mention SD. Though one did say the Americans had mentioned a rare problem, but he didn't think it was that! They just shrugged their shoulders as though it would go away with speech therapy. Then at St. Vincent's, they showed a lot of interest, sent me along to the neurologist and I then had a number of tests to exclude other medical explanations, and said it was definitely Spasmodic Dysphonia. (Female, 74 years, 2 years from onset to diagnosis.)*

*The GP told me it was anxiety-produced aphonia, gave me sedatives. The psychiatrist I was referred to didn't know but suggested hypnotherapy. A neurologist didn't know and did various tests including a CAT scan. A speech therapist gave me exercises, an ENT specialist could see no problem. They were all quite understanding, but more a reaction of bewilderment at not being able to diagnose the problem. Then I saw a segment on a current affairs TV show about SD and was greatly relieved. I went to the hospital they mentioned and was diagnosed correctly. (Male, 57 years, 5 years from onset to diagnosis)*

*I saw a GP (nerves), another GP (need speech therapy), and a psychologist (childhood problems and relaxation therapy). I don't think they cared that much, glad to see me walk out the door. The psychologist wanted to put me in hospital as she was concerned that I was close to a breakdown. (Female, 49 years, 35 years from onset to diagnosis)*

*I got eyelid blinking (blephorospasm) in 1975, then my voice broke up when trying to sing a nursery song to my baby grandson 1984. My husband was killed tragically and eighteen months later I was found to be suffering a hyperactive thyroid (had been having trouble several years). At the same time they found the voice problem. A psychologist*

*said it was stress and did hypnosis (no help at all); speech therapy and 9 laser treatments were no help and aggravated the problem; then my GP sent me to a neurologist who diagnosed SD. (Female, aged 75 years, 14 years from onset to diagnosis)*

*My GP didn't know and referred me to ENT. He thought it was psychological and referred me to speech pathology. I did that for a year and then she thought it might be SD and referred me to a neurologist who confirmed it and recommended Botox injections. The GP was OK because nothing was known about SD at that time. The ENT man was ignorant and arrogant, said I just needed to get married and stop worrying so much. The speech therapist didn't know until after a year of trying voice exercises. (Female, 29 years, 2 and a half years before diagnosis)*

*My voice problem started in middle age and I saw a doctor in 1983, but was told no treatment was available. After I had a stroke in 1992, the specialist told me I had SD and could have Botox injections. Very happy with that. (Male, aged 75 years.)*

*I saw an ENT who said it was a virus. I had had a minor operation for stomach ulcer and was told the tube passed down had probably scratched my throat and it would heal itself; I went back to the ENT man who thought I had been lazy trying to use my voice again and sent me for speech therapy. They were not very interested at all, made me feel as if I was going mad instead of having a physical medical problem. Then I had a hysterectomy and an intern asked what was wrong with my voice. He sent another doctor to see me. He came and I explained what had gone on over the years and he sent me to a doctor who referred me to another one who said it was SD. I felt so relieved I wasn't mad when he explained the condition to me. (Female, age 49, 17 years before proper diagnosis)*

### **Lack of medical sympathy**

When asked 'What was the level of interest shown in your voice condition by these specialists? Describe their attitude/ understanding', only 48 per cent of SD patients said the specialists were concerned and helpful and 28 per cent did not know of the existence of Spasmodic Dysphonia. Another 29 per cent of the specialists consulted said they were interested but unable to help, 17 per cent were not the least interested, 18 per cent were downright dismissive of the condition, and 3 per cent told them to go away and relax.

*Some of the otolaryngologists were curious initially but quickly became disinterested, impatient, cursory and rude when it became obvious that the condition was chronic and they were not able to help me. They went from inflamed vocal cords (rest your voice), to possible allergy (prescribed cortisone), to slightly swollen vocal cords (steam inhalations), to depression (due to my crying during the consultation out of sheer frustration, put on valium), to the final speech pathologist who diagnosed SD and reinforced the voice and relaxation exercises I'd found helpful previously.*

*They were keen to help but they made me understand that not much is known about this condition.*

*Mainly concern and support, but it took three years before I found out about SD and that doctor told me very abruptly I was wasting my time and money on psychology and speech therapy.*

*They were confused, little interest shown, not willing to find out more. Attitude was, do more blood tests, urine tests, stools, barium meals, X-rays. They lost interest when they got no results.*

*My local doctor was very caring but really had no idea. He's now very interested in SD. The specialists were understanding and helpful.*

*Showed interest but didn't have a bloody clue. So I became a guinea pig in their experiments. Most frustrating was their reluctance to say they didn't know. I was treated like a bit of a nut case, all in my head. One psychologist saw me for 10 minutes, was more interested in reading his bridge rules, prescribed drugs (diazapan, chlorpromazine, prothaiden, and serapax. I told him we were wasting each other's time, and walked out never to return, and threw away the drugs.*

*Most of them blamed the victim in some way for the problem. I developed a very low opinion of the medical profession over 25 years of looking for an explanation.*

*They thought I was psycho.*

From the start of this search for a diagnosis and explanation to getting a correct diagnosis took up to 2 years for 13 per cent of our SD sample; over 2 years for 8 per cent; and 12 months or less for 78 per cent, a good sign of improved medical awareness of the condition, but still a long time to be kept wondering. Some were given drugs to relax their throat, with only 8 per cent reporting any positive effect. Others were given counseling, and only one per cent regarded this as effective. Speech therapy was effective in only 18 per cent of cases for those who had voice treatment.

In our sample, 72.4 per cent were diagnosed as having the Adductor type of SD (tight, strangled sound), and 27.5 per cent were told they had the Abductor type (breathiness, breaks in the sound of words, as between an initial consonant and the vowels that follow). The figures are roughly the same for both types of SD in terms of who diagnosed the condition: about two-thirds were diagnosed by neurologists or throat specialists, just over 20 per cent by GPs, and only 10 per cent by speech therapists. Only one person said it was diagnosed by a friend or family member. Around 20% could not recall or did not respond to the question 'When were you diagnosed with this condition?'

When first diagnosed?	SD Adductor Type (n = 96)	SD Abductor Type (n = 37)
10+ years ago	21.9%	7.5%
5 to 10 years	26.7%	32.5%
1 to 4 years	18.1%	22.5%
In the past Year	14.3%	17.5%

### **Response to diagnosis of SD**

The patient's response to a diagnosis of Spasmodic Dysphonia and an explanation of what was known about the condition and its possible treatment was very mixed. Most were concerned about finding a cure (69.7%); 13 % were shocked and upset; 7% were

relieved to have a real explanation at last; 12% were depressed and frustrated because there seemed to be no known cure; and 3% were simply confused.

*Happy to hear it had a name! (Female, 71)*

*Relief in one sense, knew it was serious. Immediately assured that I could be helped, but delayed for quite a while, feared Botox. (Male, 80)*

*A little surprised, I had never heard of it. I knew I wasn't nervous, but my voice used to shake. (Female, 45)*

*Relief at having a name put to it finally. (Female, 69)*

*Almost euphoria. Comforting to know the condition was 'real' and was recognised as such, and had a title. (Male, 68)*

*I was stressed to learn there was no apparent cure. (Male, 54)*

*Disbelief. Nice to have a label to put on it, but I refused to accept or hear my voice on tape, refused Botox for some time too. (Female, 49)*

*Absolute relief that there was someone else out there the same, and there was a name for my condition. (Female, 49)*

Recommendations for treatment were equally varied. Some 29 per cent were told to have voice therapy exercises; 5.3 per cent were prescribed drugs; 70 per cent were told about the new treatment of Botulinum Toxin injections, with 12 per cent worried about this and 58 per cent happy to try anything.

## Chapter 2

### Impacts on Self-Image and Lifestyle

Because most of us take our voice for granted, it is difficult to imagine how disabling and handicapping it is not to be able to speak clearly and fluently. The voice is our main instrument of communication, a powerful tool of self-representation, crucial in both our private relationships and in our more public, work-related interactions. Without a voice, we are less able to modify the first impressions others get from our physical appearance, body language and dress. We can't state an opinion or defend it forcefully, we can't break into a group conversation so readily, or modify the way others interpret our silence or embarrassment.

The following quotations from open-ended responses about impacts on SD sufferers' feelings about themselves are grouped into broad age groups.

Older people were less likely to have been diagnosed correctly as having SD because it was not a known medical condition when many of them first experienced voice loss. Some of them were also not in a job (especially the women), so did not experience damage to a career. In contrast, the middle-aged and younger groups more frequently experienced the devastating effects of SD on both their work life and their private relationships. Having Spasmodic Dysphonia emerge early in life, and being told (as many were) that there was no known cure, requires a radical rethinking of one's life prospects, what one can effectively do. And the sudden loss of voice in middle age transforms the way you are perceived by others. It makes you silent where you were once vocal, tentative rather than confident in a range of social situations, resulting in a marked change in personality and social persona.

Overall, their feelings about themselves could be categorised as follows:  
(several responses could be listed, so figures do not add to 100%)

Shattered self-confidence	42.9%
Blamed myself	11.3
Gave up hope	4.5
Determined to get over it	9.8
Withdrew socially	32.3
Depressed/suicidal thoughts	24.1
Other reactions/feelings	51.1

Those medicos and therapists who behaved dismissively might better understand the seriousness of Spasmodic Dysphonia if they read some of the following accounts.

#### **a. Young SD Sufferers**

*I was very vocal before and the problem caused me to withdraw from any difficult situations – public speaking, group discussions, etc. I was less confident to speak out. I felt inadequate and frustrated and this was upsetting. (F, Ab, 34)*

*Huge loss of self-confidence, especially when my voice was required. Loss of sense of control. Initially felt very depressed as time passed and I did not improve, extremely*

*frustrated. Change of self-image – now saw myself as having a disability, though I tried not to let it stop me doing things. (F, Ab, 33)*

*I felt embarrassed and ashamed. It made me more self-conscious and I felt inadequate and alienated. (F, both Add and Ab, 27)*

*I don't like meeting new people and when I do, I'm just waiting for a kick-in-the-guts comment. It's easier to be an anonymous office worker and to just say I've got a cold. All of this has changed my once ambitious and energetic approach to everything I tackled. I don't know what I'm going to do with my life, and I can't talk about it, because I feel nobody understands. (F, both Add and Ab, 30)*

*I just want to hibernate and don't want to mix with people. I feel very lonely even when I'm out with people. I have this constant feeling I'm alone and no-one understands how I feel. (F, both Add and Ab, 43)*

*Dropped the confidence. The misdiagnosis was the worst thing – thinking I was nuts. Since diagnosis I went back to Uni., did BA Hons, a Grad. Dip. and am halfway through a PhD now – bit of a boost! (F, Add, 29)*

*Feelings of hopelessness. (M, Add, 42)*

*Loss of self-confidence. (M, Add, 46)*

*Until I found the disorder was neurological I thought I must be an anxious, nervous and weak person who couldn't handle the everyday stresses of life. Great loss of self-esteem, self-confidence, happiness. Began to talk and participate less, avoided the phone and difficult situations. (F, Add, 41)*

## **b. Middle-aged SD Sufferers**

*I lost all confidence, self-esteem, and felt very self-conscious. I must say, being alone, I felt as if my life was over. I kept thinking why can't I just learn sign language and then people would recognise the problem. (F, Ab, 62)*

*I felt very alone, as I'd always been a very social person. I loved being involved with people and projects and suddenly I had to give all this up. Speech is such an important part of human activity and suddenly I was robbed! I became very withdrawn and frustrated at what was happening to me. For a time I became a workaholic around the house, set about and re-landscaped our section, painted the house and roof over a short time, couldn't just sit down and relax. (M, Ab, 55)*

*Felt worthless, contemplated suicide. Had very low self-esteem, frustrated in not being able to do such a simple thing as to speak. (M, Ab, 52)*

*A realisation that there were now severe constraints on my ability to function normally, which would limit or stop my career. I grew to despise people, although I knew ridicule, etc. was normal human behavior. The anger it generated gave me the strength to push through, although emotion, stress and tiredness make the condition worse. (M, Ab, 57)*

*Kept quiet when out in public. Loss of confidence. Consoled myself by thinking at least it's not life-threatening. (F, both Add and Ab, 58)*

*Enormous grief and distress. I felt I had lost the person who was me. My relationships changed because I could no longer be me. I had been very talkative. I believe it changed my life forever. I took a different path. (F, both Add and Ab, 61)*

*I felt like an alienated freak. My self-esteem was non-existent and I still suffer depression. (F, Add, 49)*

*Depression and fear about the future. I felt guilty that my voice was not under my control. (F, Add, 46)*

*I felt angry, that it wasn't fair. I still had to go on teaching to support my children. Lonely, inadequate, desperate at times. (F, Add, 60)*

*An awful sense of loss. (F, Add, 53)*

*It is very embarrassing in the job that I do. (F, Add, 61)*

*Remarkably, and in spite of my SD and dysfunctional family and three marriages to men like my father, all of which I left, I've always known I am a good person with a great sense of humor and have never had low self-esteem. I learned to be strong at an early age and I think this helped me with the struggles with my voice. (F, Add, 51)*

*My voice was obviously so critical to all parts of my life, so I felt I was finished if someone couldn't give me answers. I felt I was a strong person who would not react this way to 'stress', so kept on seeking answers that were physical, when others lost faith. (F, 55)*

*I feel powerless, and have lost social and work status. I have had to pass up promotion at work because I cannot communicate effectively. I worked very hard at Uni. to get good marks, but it has all been taken away. I cannot describe the loss and sadness I feel. I have not reached my full potential. (F, Add, 55)*

*I began to doubt the effects of my communication, doubts about doing my job effectively. (M, Add, 54)*

*Before diagnosis I felt very low, mainly because of not knowing what was wrong and the prospect of losing my job. (M, Add, 57)*

*Became withdrawn and irritable, particularly with my spouse and parents. (M, Add, 59)*

*I suppose, initially, I wondered if there was something wrong with me that was causing the problem. No-one was able to diagnose it, so you're left in a sort of limbo. I was so keen on my job and disapproved and embarrassed that I wasn't able to perform it at the normal level of quality I'd achieved. (M, Add, 66)*

*No confidence, humiliation, worthlessness, inferiority, hopelessness in never finding a reason or cure for the problem. (M, Add, 67)*

### **c. Older people**

*Self-esteem plummeted, I so enjoyed talking to people. Unable to sing any more is a great grief, but I have many blessings. (F, Add, 84)*

*I lost all my confidence and self-esteem. I felt apologetic all the time and found myself walking behind people I was out with. (F, Add, 73)*

*Distressed that people had a job to understand me, so withdrew from conversations where possible. (M, Add, 74)*

*I went through the 'no confidence' period feeling stupid I couldn't talk properly. I've even shed a few tears, done a lot of praying. Once, when doing deep relaxation, I opened my eyes and spoke – I had a perfect voice. By morning it was gone again. My family heard this miracle. (F, Add, 76)*

*I felt very negative (and guilty) about myself and started to withdraw from social commitments. (F, Add, 72)*

*Very disappointed, for my knowledge was far more comprehensive than I could call forth. (M, Ab, 80)*

*At first I felt like staying at home and avoiding people, but because my family are so caring they help me mix with people. Also my Christian faith helps me a lot. (F, Ab, 75)*

### **Social impact on relationships**

We asked how supportive and understanding other people were when the voice problem started, with the following results:

Spouse/partner	51.1% (were supportive & understanding)
Children	45.9
Other family members	62.4
Boss/workmates	29.3
People in shops	8.3
People on phone	5.3
New people	6.8

The impact on family life was varied, mostly neutral or supportive, but in some cases leading to conflict, resentment, withdrawal of affection and even divorce.

<b>Voice effect on marriage?</b>	<b>(SD n = 133)</b>
Divorced/separated	5.0%
Conflict	6.0
Neutral	47.0
Brought closer together	12.0
Stress	13.0
Communicate less	13.0
Other	4.0

<b>Voice effect on family life?</b>	<b>(SD n = 133)</b>
Hostility	0.8%
Embarrassed	2.3
Neutral	36.1
Closer together	10.5
Can't communicate	18.8
Other	15.8
No response	15.8
Not applicable	0.8

In summary, they were asked what were the worst situations/circumstances for you during this pre-diagnosis period?

Work		23.3%
Social situations	48.9	
Family dynamics		7.5
Personal relationship	7.5	
Phone calling		27.1
Other		8.3
None, it was OK		2.3

From this pattern it is clear that though family life suffered from the trauma, confusion, emotional upset of the SD person and the problem of having no real explanation for why the voice had disappeared, public situations in which the voice has to be projected, and the phone, where the voice is the sole means of communicating, were the worst for most SD sufferers.

## **Chapter 3**

### **Trying to Explain Spasmodic Dysphonia**

Our study aimed at identifying a range of possible conditions that might explain or throw some light on the development of Spasmodic Dysphonia. To this end, the General Health Survey included sections of questions (to both SD patients and to the comparison sample) about their

- occupational experience
- physical/medical history (including parents and siblings)
- diet, eating and drinking habits
- external environmental factors

Causes of any form of dystonia are usually classified into

- primary/ideopathic (where dystonia is the only sign and there is no identifiable cause)
- secondary/symptomatic (where the cause might be drugs, infection or injury)

Research has shown some anti-psychotic drugs can cause tardive dystonia; head trauma can lead to dystonias, but minor injuries are not a factor; there is zero correlation between getting dystonia and smoking; dental surgery can sometimes lead to oromandibular dystonia; and repeated overuse of certain muscles can induce dystonia. (Dr. Tony Lang, Toronto Western Hospital, 1999). Dr. Bressman (Albert Einstein College of Medicine, NY) reports the peak age for most focal dystonias is around 40 years of age, but cervical (neck) dystonia (ST) and spasmodic dysphonia (SD) tend to emerge earlier than dystonias that affect the face (such as blepharospasm or blinking of the eyes, and Meige's Syndrome). Dystonia is not a degenerative disease and there is no loss of brain cells. But Bressman quotes figures showing that 73% (1762 out of 2398 patients) had no known cause for their dystonia. Given the recent estimate that there are 50,000 individuals in North America alone who have Spasmodic Dysphonia, that leaves a lot of people not knowing what has caused their very real social handicap – the inability to speak clearly and consistently.

#### **Possible genetic family links**

Because of the recent discovery of a gene that predisposes some people to Spasmodic Dysphonia, we assumed that it would be a combination of genetic and experiential factors that explained why some people develop the condition while others do not. Genetic predisposition is a necessary but not a sufficient cause for getting most medical conditions (such as a combination with dietary factors in stomach and colon cancer). In this study, only one family reported having another member who also had SD – and that was our own family, where both daughters developed the condition in their early thirties, in different forms. So we were not surprised to find scant evidence of genetic differences between our SD group and the comparison group of ordinary citizens.

Several questions were asked about extended family members and their medical history. We were looking for any link between spasmodic dysphonia and the makeup of the patient's mother, father, siblings, and relatives on either the mother's side or the father's side. The incidence of such medical conditions as Meniere's disease, Huntington's

disease, Cerebral Palsy, Myasthenia Gravia and Frederick's Ataxia was, as expected, too low to make for any meaningful analysis, but a few conditions appeared more frequently on the SD patients' family side than for the control group of non-SD people.

<b>Family member condition</b>	<b>SD Patients</b> (n = 133)	<b>Non-SD group</b> (n = 103)
Asthma - Mother	10.4%	5.8%
- Father	6.0%	4.9%
- Siblings	17.2%	15.5%
- Mo relative	9.0%	5.8%
- Fa relative	3.7%	6.8%
Stutter – Father	2.2%	1.0%
- Sibling	2.2%	1.0%
- Mo relative	3.0%	1.0%
- Fa relative	1.5%	-
Other voice problem – Mo	3.7%	-
- Fa	1.5%	1.9%
- Sibling	3.7%	1.9%
- Mo relative	2.2%	-
- Fa relative	1.5%	-
Shakiness – Mother	8.2%	1.0%
- Father	2.2%	1.9%
- Sibling	4.5%	1.9%
- Mo relative	3.0%	1.9%
- Fa relative	3.7%	1.9%
Cancer – Mother	17.2%	19.4%
- Father	23.9%	17.5%
- Sibling	12.7%	8.7%
- Mo relative	24.6%	19.4%
- Fa relative	14.2%	14.6%
Facial spasm – Mother	2.9%	-
- Father	-	-
- Sibling	4.3%	2.0%
- Mo relative	2.9%	-
- Fa relative	-	1.9%
Arthritis - Mother	33.6%	27.2%
- Father	14.9%	18.4%
- Sibling	13.4%	9.7%
- Mo relative	15.7%	9.7%
- Fa relative	9.7%	11.7%
Spasmodic Dysphonia		
- Mother	2.2%	1.0%
- Father	-	-
- Sibling	2.2%	-
- Mo relative	0.7%	-
- Fa relative	-	-
Aphasia/dyslexia – Mother	1.5%	-
- Father	1.5%	1.9%

- Sibling	1.5%	1.9%
- Mo relative	1.5%	-
- Fa relative	0.7%	-
Neurological	2.2%	1.0%
- Mother		
- Father	1.5%	-
- Sibling	2.2%	1.9%
- Fa relative	1.5%	-

### Neurological comparisons

Nevertheless, some interesting differences emerge between the two groups in terms of what could be related neurological problems. The following table lists the percentages of each group reporting certain medical conditions, either in their childhood or as an adult, or both.

Medical Condition	SD Group - as a child	SD group – as an adult	Non-SD control - as a child	Non-SD control – as an adult
	(SD n =	133)	(Non-SD n =	103)
Ordinary headaches	17.9%	46.3%	11.6%	51.4%
Migraines	9.7%	31.4%	12.6%	26.2%
Meniere's	-	5.2%	-	-
Repeat falls	1.5%	1.5%	-	-
Concussion	5.2%	5.2%	6.8%	2.9%
Epilepsy	0.7%	0.7%	-	1.0%
Fainting fits	3.7%	6.7%	1.9%	-
Twitchy eyes	2.2%	13.4%	2.9%	6.8%
Stammer-ing	3.7%	3.7%	1.9%	1.9%
Shaky writing	6.0%	23.1%	2.0%	4.9%
Trembly hands	-	15.7%	-	8.8%
Numbness	-	14.9%	-	4.9%
Pins & needles	4.4%	24.6%	5.9%	21.4%
Giddiness	2.9%	20.9%	-	16.5%
Arm pain	-	20.9%	1.0%	10.7%
Back pain	5.9%	52.2%	1.0%	47.6%
Action spasms	-	8.9%	1.0%	1.0%
Muscle weakness	2.9%	10.4%	1.0%	4.9%
Abnormal movement	2.2%	12.7%	1.0%	2.9%
Apnoea (snoring)	1.4%	10.4%	-	7.8%

Throat problem	20.9%	34.3%	8.8%	20.4%
Post-nasal drip	6.0%	19.4%	3.8%	12.6%
Tight chest	4.4%	25.3%	5.9%	15.6%
Vascular	-	6.0%	-	-
Cancer	-	13.4%	-	7.8%
Reflux	-	32.0%	-	21.4%
Panic attacks	2.2%	22.3%	-	7.8%
Severe tiredness	1.4%	26.8%	-	15.6%
Thyroid	3.0%	11.9%	2.0%	6.8%
Severe depression	-	23.1%	-	10.7%

As can be seen, there is a consistent pattern (though numbers are too low to be of statistical significance) of SD patients having experienced a range of what could be described as neurologically-related health problems.

On a range of other common illnesses (measles, German measles, mumps, whooping cough, chicken pox, pneumonia, bronchitis, scarlet fever, glandular fever, and ordinary colds, there was no difference whatsoever between the two groups. Nor was there any difference in the numbers who had ever had more extreme illnesses, such as Ischaemic heart, hypertension, low blood pressure, endometriosis, arthritis, aneurisms, hiatus hernias or strokes.

### **Other environmental hypotheses**

We checked other hypotheses about likely causes of SD, but found little of significance.

The notion that early or late onset of puberty/menarche might make a difference was not supported. (Only 2-3% of both groups were early, around 6% late.)

There was no difference in left versus right-handedness, so the idea that being forced to use the right hand for writing might cause later problems was fruitless. (27% of the SD group were naturally left-handed and had been forced to use their right hand, but 37.5% of the control group had been made to do so also.)

Disproven too was a possible link with being taught two languages in the home as a child. As an infant, only 5.2% of the SD group had been taught in both languages, but so were 4% of the control group.

Neither cigarettes nor alcohol intake seem to be related to the incidence of Spasmodic Dysphonia. Just over half of both groups had ever smoked cigarettes, and only 7.5% of the SD people still smoke compared with 15.5% of the control group. There was no

difference in their intake of alcohol, except that 16.4% of SD patients reported that they had increased their intake and drank more spirits and wine, but with few noticeable effects on their health or voice quality.

## Food and nutrition

We asked several questions about diet and nutrition, thinking that certain sorts of foods may exacerbate the SD voice condition. What emerges from the data is an interesting picture of Australian eating habits, but no support for the hypothesis. On most items, both groups say their normal intake is 'average', with over a third eating no Vegemite at all, over 40% eating no cheese, close to half drinking no colored soft drink, over 60% having no fatty milk, 40% no butter or cream and 46% eating no meat. This is a health-conscious sample, whether troubled by SD or not. More of the non-SD group eat 'a lot' of green vegetables, orange vegetables, grains & beans, and avoid Chinese MSG on their takeaway foods. Even with chocolate, only about 5% of both groups eat 'a lot', and round 24% eat none at all. The SD group reports taking more supplementary vitamins (59.7%) than the non-SD group (49.5%); coffee intake is less for the SD group and they use less artificial sweetener in their tea or coffee.

Questions about marked changes in food or drink intake revealed a population across the two groups where over half have, at some time, given up and stopped eating or drinking various types of food, a third reporting better health as a result, but only 2.2% of the SD group noticing any change in their voice.

Water intake was the same for both groups, with 36% drinking 6 or more cups of water per day and about 20% drinking only 1-2 cups per day.

## External environmental factors

Many SD patients in struggling to explain their own voice problems have hypothesised that something in their physical environment - exposure to chemicals, dust, cigarettes, etc. - may have contributed to the deterioration of their voice. Again, the data show no consistent patterns that might support this view. We asked had they ever been exposed to toxic glues, talc, asbestos, cotton or wool fibres, chemicals, drugs, radioactivity, power lines, irradiation, chemotherapy, but found no difference in levels of exposure between the SD group and the comparison group. Only very slight differences show up for the following :

<b>Exposed to</b>	<b>As a -</b>	<b>SD Group (n = 133)</b>	<b>Non-SD group (n = 103)</b>
Pesticides	Child	6.9%	2.0%
	Adult	12.6%	7.9%
Fertiliser	Child	3.7%	-
	Adult	8.2%	6.8%
Wood sawdust	Child	2.2%	3.8%
	Adult	6.0%	2.9%
Paint varnish	Child	2.9%	2.0%
	Adult	11.2%	9.7%
Cold/damp	Child	7.4%	2.0%

	Adult	6.7%	4.9%
Passive smoking	Child	26.1%	21.4%
	Adult	32.1%	28.1%
Antibiotics	Child	7.5%	8.7%
	Adult	12.7%	10.6%
Contraceptive pill ever?	Yes	51.5%	63.2%
	No	48.5%	36.8%

For those who had taken the contraceptive pill, slightly more had experienced dizziness, vascular and vision problems, but numbers are too low to be of significance.

### Occupational experience and stress

It is logical to assume that the nature of a person's work, both physical and social, might have an impact on health and voice quality. There is plenty of evidence that stress, especially prolonged stress, can be damaging in a variety of ways. So we compared our two groups on several work dimensions.

Firstly, the groups have very similar educational and occupational profiles. The only difference is that more of the SD group had post-graduate qualifications (20.1%) than of the comparison group (12.6%). For both groups, 81% had English as their first language and most had been employed at some time of their lives.

<b>How many paid jobs?</b>	<b>SD group</b> (n = 133)	<b>Non-SD group</b> (n = 103)
Never full-time	3.0%	1.9%
Only 1 job	11.2%	12.6%
2 to 5 jobs	54.5%	51.5%
More than 5 jobs	28.4%	29.1%
Lots of Part-time jobs	2.2%	1.9%
No response	0.7%	2.9%

Their main occupations were also very similar.

<b>Main occupation</b>	<b>SD group</b>	<b>Non-SD group</b>
Manager/administrator	11.9%	13.6%
Professional	29.1%	30.1%
Para-professional	5.2%	4.9%
Clerk, office worker	22.4%	27.2%
Plant/machine operator	3.0%	1.9%
Laborer	2.2%	1.9%
Unpaid housework	12.7%	10.7%
Volunteer	1.5%	1.0%

No response	3.7%	1.0%

### Reliance on voice in their job?

There was no difference between the two groups in terms of business or industry type, but fewer of the SD group worked in the public sector (29.9%) than the comparison group (34.0%) and fewer of the SD group had been teachers (12.7% cf. 17.5%). Nor were the SD group noticeably more reliant on their voice in their job (80.6% said they were totally reliant or relied a lot on their voice, compared with 76.7% of the non-SD group). So our hypothesis that voice strain on the job may have precipitated the onset of SD was not supported. Levels of responsibility were also roughly the same for both groups, about 30% saying they had a great degree of responsibility and another 30% saying it was fairly heavy, not surprising given their age and experience in the workforce.

Both groups reported a high degree of intrinsic satisfaction with their jobs and the SD group worked no more hours on average than the comparison group.

### Job stress

The one difference that does emerge concerns stress, though this is very much a chicken and egg problem. We asked “How stressful is/was your main work (paid or unpaid)?”

Stress in main work?	SD group (n = 133)	Non-SD group (n = 103)
Extremely stressful	14.9%	3.9%
Very stressful	22.4%	27.2%
Moderately	35.8%	46.6%
Not very stressful	19.4%	14.6%

Asked if there was any one job (or type of unpaid activity) that caused them major stress, only slightly more of the SD group said yes (35.8%) than the non-SD group (31.1%), and the reasons suggest it was the actual voice problem that caused the stress rather than the other way around. For those who are now retired, 20.5% of the SD people say it was because of their voice, while only 1.3% of the others gave this as a reason for retirement.

Reasons for stress in job	SD group (n = 133)	Non-SD group (n = 103)
Time pressure	18.8%	3.1%
Boss unsympathetic	12.5%	3.1%
Colleagues conflict	12.5%	12.5%
Voice problems	16.7%	-
Difficult people	4.2%	2.9%
Other	50.0%	25.2%

When we look at the open-ended responses of SD patients to questions about their work, we find several of them do attribute the onset of SD to job-related stress, but a large number had retired by the time they were diagnosed, so had little to say about work impacts which they had simply lived with for several years.

*I was working in a job where I was totally reliant on my voice and the work was quite stressful. (Male, 57)*

*I was under more and more pressure to sell more and more motor cars. I sometimes wonder whether the stress associated with this was the causal factor. (M, 59)*

*My position, which was up-front with people, had to be altered – to the storeroom (my choice). I avoided contact with other members of staff. Lunchtime and breaks I would sit alone or sometimes in my car. I completely alienated myself. Because I could not use the PA system I was running round all the time. Words cannot express how I felt during this time. If I hadn't been needed by my family I would have ended my life. (F, 55)*

*Caused me great stress and frustration, but I always managed my work. Often wondered how long I could go on without having to speak. In later years I had to give up talking on the phone and did mostly admin. and accounting work. Not once did my work mates broach the matter with me. It was almost like discussing sex – it just wasn't done in those days. I always did my work well so I suppose it didn't worry them. (M, 67)*

*Gradually, from about 1974 to the time the (radio station) and I parted company, it saw the end of my original career. Some staff were sympathetic, others not; they'd place me on roster to read the news, which I'd been told I shouldn't and couldn't read. (M, 66)*

*My bosses generally accepted the fact that my voice was defective, but to many of my work mates I was a bit of a joke. As I was a salesman, I eventually had to change my vocation. (M, 59)*

*Very difficult to communicate and it was too much trouble for them to take the time to listen to me. It completely destroyed my ability to earn a living and I was asked to leave. (M, 67)*

*I tried to hide it as much as possible, but it affected my work situation dramatically – it resulted in me losing my job. (M, 57)*

*As it worsened, communication became more difficult. But my staff are very sympathetic, would rather have me there with my voice strained than not at all. (M, 54)*

*I'm respected for the quality and integrity of my work, and my work mates are all very patient and go out of their way to include me in social events. (F, 56)*

*Work was very supportive once they could hear the problem, gave me some months off while keeping the position open if any of the treatments worked. (F, 55)*

*I thought if I forced myself into a situation I would have to speak fluently. So I did a course in shorthand-typing, but I couldn't read the shorthand back. Then I decided to really throw myself in and did an air hostess course, knowing I'd have to speak on the intercom, but it didn't work, though I passed everything else. I suppose it's a bit like a person with no legs applying for a job as a guide on Ayers Rock. (F, 51)*

*I'm always asked don't I feel well, especially on the phone. I have lots of meetings to attend and am embarrassed to speak because I sound as if I'm nervous. (F, 61)*

*Some work mates strained to listen, others couldn't be bothered. It made things difficult if I had to have long discussions of complex problems. Did not enjoy office parties. (F, 58)*

*Some teased and intimidated; made me less outgoing and helpful to others at work. (M, 46)*

*Other teachers asked why I talked like an old woman, thought one injection would fix it. One said he had more complaints about me than anyone else. It became exhausting and very stressful. I was sick a lot. Classroom discipline and control was much more difficult. I dreaded going to work, sometimes started shaking when I went into my classroom. (F, 60)*

*SD made work exhausting and very stressful. Had to rule out promotion. (M, 46)*

*I found it difficult to voice instructions and would resort to notes. I would often be teased or feel degraded if I didn't speak. (F, 49)*

*It didn't affect my ability to work. It affected my enthusiasm to participate in conversation with colleagues. Avoided phone, used fax a lot. (F, 41)*

*I had been a PA/Secretary, but when I returned from overseas with the voice problem, more clerical and less voice-related jobs seemed my only option. (F, 34)*

*I just battled on, but hated the phone. (F, 29)*

### **Stress in relation to onset of SD**

We asked both groups specifically about types of stress they had experienced that might have been related to the onset of voice problems, though it is obvious that many of these stress explanations came from psychologists and other therapists consulted in the long process of seeking an accurate diagnosis. We also asked them what their own personal 'theory' was about the causes of Spasmodic Dysphonia. There is a wide variety of 'theories', none of them tested of course, but since these are the people who suffer SD themselves, they may be of interest to other patients and researchers.

*My fiance was killed in a work-related incident. I noticed subtle voice changes started 2-3 weeks later and gradually worsened over the following couple of months. (F, 34)*

*I was sexually abused as a child. The person who abused me returned to town and the psychologist seemed to think this may have had an influence on my voice. (F, 29)*

*It was a time of great stress and unhappiness. Broke up with my partner who returned from a holiday married to someone else. I had to deal with him bringing her to our squash club. Great degree of emotional trauma, mostly repressed in public. (F, 41)*

*I was a divorced, solo parent, teaching 7-8 year olds in open-plan classrooms which places heavy strain on the vocal cords. I was also taking ditrapan for incontinence and the urologist thinks this may be related to my voice problem. I was exposed daily to chalk dust. Also involved in a family court case after which my family home had to be sold. Four children aged 4-11 years to care for. Stress certainly worsens the SD. (F, 60)*

*Stress caused by lack of public speaking confidence. (M, 46)*

*I came from an abusive family. (F, 51)*

*A few months after my mother died my head began to twitch and I had involuntary hand movements. I was put on serapax which controlled it to a certain extent. Within a year my father passed away. My life fell apart and so did I. I increased the serapax myself, but everything became worse. Then 6 months later, overnight the head and hand movements went away. But immediately my voice problem began. (F, 55)*

*Stress and overwork helped, I'm sure. (F, 84)*

Others explain the onset in purely physical terms:

*Parachuting at the time, landed on my bottom, compressed spine, get a lot of neck pain. (F, 49)*

*Genetic cause relating to brain chemistry. (M, 46)*

*I suffered from a recurrent 'lump in the throat' as a child, medically NAD, but a similar feeling to the feeling of spasm in the throat I now sometimes have. I suffered frequent severe head colds, and my mother was anxious about 'swollen glands'. As a consequence, my childhood was 'throat-focused'. (F, 48)*

*I think it is a sub-conscious, past life condition/pattern, brought out physically via the shock, trauma and accidents. (F, 29)*

*While some symptoms were evident, prior to diagnosis of a tumor, they seemed to escalate after the initial examination with insertion and withdrawal of tubing from the throat. (Right thyroid and a tumor were removed from the windpipe.) But subsequent opinion claimed there was no nerve damage. (F, 63)*

*I have blephorospasm and dystonia and I believe they are connected. (F, 64)*

*I wish I knew, probably hereditary as I think my mother may also have the same problem in a minor way. (M, 56)*

*My husband died at only 51 and I was left with 3 children, so I have always put it down to stress. My father had a catch in his voice and a slight stutter. (F, 73)*

*Recurrent severe throat infections in 1984, and again in 1985. (F, 50)*

*Stress in the workplace. (F, 73)*

*I was in charge of a party of students, teachers and parents on a basketball tour of New Zealand. Over-use and perhaps misuse led to laryngitis, but I tried to coach through the dilemma. I had used spray for my nasal drip, but took myself off it because of its effect on my voice. (M, 54)*

*Maybe coincidence, but it came on after a severe viral infection. (M, 67)*

*Perhaps a combination of an extended period of stress, a virus, and perhaps a pre-disposition towards this disorder. (F, 44)*

*I am now convinced it all has to do with stress. Even going back 20 or so years answering these questions has caused my voice to worsen temporarily. My husband always said I was a born worrier. I think he was probably correct. (F, 74)*

*Husband left, children left, mother died suddenly. Also I shouted a lot! Work increased as I ran a business and husband used to do half. Started on Immigrin to stop migraine headaches. Total emotional trauma because of too many life events happening so close together, no recovery time between. Also wonder if ergotamine (an ingredient of Immigrin medication) has a toxic effect on me? (F, 53)*

*Maybe due to frequent reflux of acid stomach contents. Many episodes of waking with coughing and burning sensation in throat. (M, 66)*

*I've always had a 'little' voice, always been a 'nervous' person. Too much stress at one time appears to have triggered the onset of SD, almost like a nervous breakdown, but in the vocal cords. (F, 61)*

*My body's reaction to repressed stress. I believe a high level of acid contributed to the severity of my condition at the time. (F, 28)*

*I was always a very shallow breather, and only using the top part of my lungs and trying to yell from my throat. Yes, I was a very stressed perfectionist too. I may have had a virus. (F, 51)*

*Extremely stressed at the time, trying to deal with many union meetings over work practices in a large factory, plenty of anger and loud argument over 12 months. Then in my holidays I had to yawn continually to complete my sentences and SD came on suddenly over this 2 week period. (M, 48)*

*When I was 6, I heard how bad my voice was on the tape recorder and tried to avoid speaking whenever possible. My mother had the same, although she denies it. (M, 52)*

*Onset of SD followed two eye operations for cataracts. I had many traumatic experiences in the War (Changi, etc.) and then this. (M, 77)*

*Stress, combined with tinnitus in the ears. (M, 44)*

*I was bashed, and developed the SD 4 months later. (M, 19)*

*I had two major job changes and shifted from the city to the country. I think it is linked to the fact that, since childhood, I have suffered a lot from colds, flues and URT infections. I've also had my share of bronchitis and had pneumonia a couple of times.*

*People try to tell me that SD might be a physical presentation of some deep emotional disturbance, but I'm not convinced. (M, 50)*

*I've had a stressful life and tried to 'bury' it. My husband was a verbally abusive man, and SD came on from that. I'm convinced it's something to do with the central nervous system, brought on by stress. (F, 75)*

*I had a fall when I was 33 years of age and damaged the back of my neck – experienced strange neurological symptoms. At onset, I was pregnant with my third child and looking after my dying father. The voice problem is also related to Meige's Syndrome which I got 12 years ago. (F, 76)*

*In 1977 I suddenly lost my voice. The doctor diagnosed it as 'faryngitis'. He scraped/cleaned the larynx, etc. under anaesthetic. Thereafter I got my voice back, but as time went on the voice kept deteriorating. In 1995, one medical opinion was that this procedure had caused muscle damage, hence deterioration, paralysis of vocal cord, loss of voice, etc. (M, 55)*

*Stress. Started treating physio. patients but worried my voice would give out. I have a phobia about speaking in front of people, especially large groups. (F, 42)*

*I read a lot and knew about basal ganglia problems. I just think I was one of the unlucky ones. (F, 58)*

*Genes plus environmental stress. My mother had writer's cramp which she called 'poor circulation', and told me her father had exactly the same. (F, 55)*

*I was in hospital with pulmonary embolism due to hormone replacement therapy being given to me post-op. (hysterectomy). I was in overload with hormones and fear of dying, my voice just cut out. At the time my husband was not well and teenage children were being very difficult due to a move in house. (F, 56)*

*When I was 6, I was pushed off a fence into a lot of turkeys. I don't know if I was more afraid of the turkeys or the lady owner (she looked like a turkey). That started me stuttering and 10 years ago it was so bad and so interfering with my life I had to do something about it. It was a stressful time in my life then too. (F, 74)*

*When I was young I was a soprano. I was in talent quests, on the radio. But over the years I found it hard to sing, especially the low notes and I was very embarrassed going into shops because I would get a lot of tremor. Maybe I overstrained it. (F, 65)*

*Apart from a nasty flu, there were no unusual circumstances. (F, 69)*

## **\Links between stress and current voice quality**

Whether or not stress was an underlying cause of SD, it is obvious that stressful situations now exacerbate the voice production difficulties of SD sufferers.

In describing what happens when workplace stress affects their voice, 11.9% of the SD group said the voice simply stops, 8.2% said it shakes, 23.1% said the voice worsens in

quality. And asked the more general question about whether emotional stress causes any sort of voice difficulties, significantly more of the SD people said it does.

<b>Emotional stress &amp; voice?</b>	<b>SD group</b> (n = 133)	<b>Non-SD group</b> (n = 103)
Often causes voice problems	40.3%	3.9%
Sometimes	45.5%	25.2%
Never	11.9%	66.0%

### **Other life traumas**

Several other possible life experiences were compared, revealing few differences between the two groups.

<b>Ever experienced?</b>	<b>SD group</b> (n = 133)	<b>Non-SD group</b> (n = 103)
Physical trauma	47.8%	28.2%
Intubation of throat	35.8%	30.1%
Diet changes	14.9%	9.7%
Serious injury	14.9%	10.7%
Family violence	17.2%	11.7%
Change of living	30.6%	21.4%
Vasectomy/tubal ligation	19.4%	19.4%
Stressful periods	78.4%	68.9%
Severe depression	33.6%	16.5%
Dental anaesthesia	47.0%	49.5%
Voice therapy	85.8%	3.9%

Obviously, some of the above can be attributed to the onset of the SD voice problem, such as depression, and the high frequency of voice therapy simply reflects the need for treatment. But we also explored for both groups, their general experience of voice problems and found a much higher experience for SD people, as would be expected.

<b>Specific vocal symptoms ever experienced?</b>	<b>SD group</b> (n = 133)	<b>Non-SD group</b> (n = 103)
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Loss of pitch - Often	47.8%	1.0%
- Occasionally	23.1%	9.7%
Hoarseness - Often	59.7%	1.9%
- Occasionally	23.1%	46.6%
Volume control – Often	51.5%	8.7%
- Occasionally	28.4%	-
Throat pain - Often	24.6%	2.9%
- Occasionally	31.3%	35.0%
Growth on vocal cords	0.7%	-
Paralysis	14.2%	-
Stoppages in speech – Often	32.1%	1.0%
- Occasionally	18.7%	14.6%
Effortful speaking – Often	74.6%	2.9%
Occasionally	17.2%	11.7%
Breathiness - Often	47.8%	3.9%
Occasionally	15.7%	11.7%
Trouble getting sound out		
- Often	47.0%	2.9%
Occasionally	13.4%	1.0%
Concerned about style		
- Often	8.2%	3.9%
- Occasionally	9.7%	1.9%

Moreover, there are more associated eating/swallowing problems for the SD group than for the others without this condition.

<b>Eating problems, ever had?</b>	<b>SD group</b> (n = 133)	<b>Non-SD group</b> (n = 103)
Swallowing solids	32.8%	21.3%
Swallowing liquids	31.3%	7.8%
Choked while eating	41.0%	14.6%
Choked while drinking	33.6%	16.5%
Choked on spicy foods	18.7%	12.6%
Acid burping	51.8%	52.4%
Diagnosed reflux	28.3%	32.1%



## **Chapter 4**

### **Male-Female Differences in the Experience of SD**

It is well known that men have different health histories from women, related as much to their attitudes towards illness as to their differing exposure to risk and their genetic makeup. Men are slower to recognise they have a health problem, less likely to visit a doctor or have tests, and less consistent in their use of prescribed treatment. As a result, the morbidity and mortality rates for men are higher than for women with diseases that affect both sexes equally.

In the current sample, of the 133 spasmodic dysphonia patients who completed the questionnaire, only 37 (27.8%) are men, and 96 (72.2%) are women. They are not significantly different in age range, however, so the men in this sample probably represent those who have been willing to identify their problem and come to terms with it. Close to 20% of the SD women first became aware of their voice difficulty in early adulthood, compared with only 5.4% of the men. The bulk of the men (59.5%) became aware in middle age (compared with 41.7% of the women) and more of the women (26%) than the men (16.2%) developed SD in later life.

Comparatively few had it as a child (5.4% men, 2.1% women) and about 8% of both sexes developed SD during the teenage years. More of the men (38%) than the women (25%) say the problem of SD emerged over a period of years, whereas 44% of the women and 24% of the men say it happened over a period of a few months. Some 12% of women and 8% of men report a sudden loss of voice, inexplicable to them at the time, and 18% of men, 17% of women say it took only weeks for the voice problem to develop to a severe state.

Some interesting sex differences emerge from the data. More of the SD women (72.2%) than the SD men (27.8%) report having Generalised (ITD) Dystonia, a form of dystonia that affects all or most of the body. Only one male and one female have secondary dystonia or damage to the basal ganglia. 8% of the women but no males have Blepharospasm (blinking eyelids); 6.3% of the women but no males have Cervical Torticollis (neck and shoulder muscle spasms); 4.2% of the women but no males have Oromandibular or lower face spasms (sometimes called Meige's Syndrome); and there is no difference in numbers reporting writer's cramp (just over 10% of both sexes with SD).

The female SD sample (n = 96) has the Adductor type of spasmodic dystonia more (83.3%) than the male SD sample (n = 37) (67.6%), that is, where the vocal cords spasm together, causing tight, squeezed, strangled sounds and very effortful speech. And 29.2% of the women, 32.4% of the men, have the Abductor type of SD (where the vocal cords spasm apart, causing sound separation, often between a first consonant and the next syllable, intermittent breathiness and a dropping out of the voice in mid sentence. The numbers for women add to more than 100%, because some of them have been diagnosed differently at different times, and the symptoms are often hard to distinguish. This difference in SD types led us to do some comparisons between the two groups in terms of how their lives are affected and how well treatments such as Botox work on the two groups. (See Chapter 5)

It follows that women are more likely than men to describe their condition in terms of being 'strangled' and 'shaky' or 'tremulous', whereas the men say they simply 'could not speak', or 'be understood'. 27% of men for example say they have trouble with 'some sounds', whereas 23% of women describe it in more general terms as sounding 'strangled'.

When asked whether any other crisis or life situation was apparently associated with the onset of dysphonia, more women report 'family problems (35% of the 96 SD women cf. 24% of the 37 SD men), a death (24% cf. 11%), general life stress (26% cf. 19%). But quite a few of both sexes associate onset with an illness or operation (28% of the SD sample of 133), an accident (5%) or job problems preceding voice difficulties (27% of the 37 SD men, 23% of the 96 SD women). Their own theories about what might have caused Spasmodic Dysphonia differ little by gender. Round 15% attribute it to genetic weakness, 31% to stress, 6% to environmental factors, 7% to overuse of their voice and 33% see it as a straightforward medical condition. None of the men, but 10% of the women feel it might be psychological and only 3% of the men attribute it to having a high public profile.

These responses were obviously influenced by the pattern of diagnosis experienced differently by men and women. 29% of both men and women were told the explanation for getting spasmodic dysphonia was 'stress and emotional problems'. But 28% of women and only 13.5% of men were told directly it was 'imagined and psychological'. They were also asked 'What was the level of interest shown in your voice condition by the specialists you consulted?' Men fared better than women again. 54% of men but only 46% of women found doctors were concerned and helpful; 40.5% of men but only 25% of women said they were interested in the problem but unable to help; 20% of women and only 10% of men thought the doctor was not at all interested; and 3% of women were told simply to 'go away and relax'.

Worst of all, 24% of the SD women compared with only 3% of the SD men found these medicos totally dismissive and uninterested in pursuing diagnosis further. At least 32% of the men and 26% of the women found their doctors honest enough to acknowledge that they knew nothing about voice problems and many of them were referred on to other specialists (81% of men and 74% of women). Close to 16% of the women said they discovered the cause purely by accident or chance.

Nonetheless, 73% of both men and women were diagnosed correctly in less than 12 months; for 8% of men and 13% of women it took between 13 and 24 months; and for a sad 5% of both sexes their search for an explanation took over two years, one man suffering for 4 years and one woman for 5 years before anyone correctly diagnosed Spasmodic Dysphonia and offered appropriate treatment.

Reactions to diagnosis were pretty much the same, the women more likely to be shocked and upset, the men more concerned about whether there was a cure for the condition. Only 7% state they felt a sense of relief, and 12% were depressed and frustrated that there seemed to be no satisfactory cure. (Botulinum Toxin is a palliative rather than a permanent cure.) For those told to try Botox, 58% were happy to try it, with at least 12% of both sexes openly worried about possible side-effects.

Women again suffered more in terms of the reactions of their friends and family to having Spasmodic Dysphonia. Whereas 75% of the men said their partner/spouse was sympathetic and supportive through the difficult period of trying to find an explanation,

only 42% of women found their partners understanding. More of them report their spouse as being upset, confused, ignoring the problem or thinking they were just being emotional, not willing to accept the condition as truly medical, and being embarrassed, impatient or intolerant. These negative spousal responses add up to 40.3% for what women report, and only 12.5% for the men.

Even children were more sympathetic to their fathers (57%) than to their mothers (42%); other family members were on the whole supportive but also more negative to the women with SD; friends were more helpful to the men; and at work, more of the men found colleagues helpful and supportive (67.9%) than did the women (50.8%). People in shops were the least sympathetic (11% for men, 7% for women), 7% being quite intolerant of the person with speech difficulty, and 18% of SD sufferers being treated 'like fools' by the person serving them over the counter.

As a consequence, the life impacts of Spasmodic Dysphonia for women are worse than they are for men. 44% of women report a shattering loss of self-confidence, though so too do 38% of the men, since the condition has a major impact on social interaction and communication. More women blamed themselves for the condition (12.5%) and gave up hope (5%); 25% became depressed and had suicidal thoughts (so did 19% of the SD men); and 34% of the women, 27% of the men withdrew socially.

During the period they spent searching for a correct medical diagnosis, close to 70% of both sexes tried to pretend to others there was nothing really wrong ("just a cold, sore throat", etc.); more women (63.6%) than men (56.7%) reacted angrily to their mistreatment; over 90% started to avoid situations where their voice might get them into difficulties; over two-thirds started to think it must be caused by their own tension (a chicken-and-egg problem, since the condition itself and their anticipation of voice production difficulty makes them tense in social situations and exacerbates the level of vocal disability and apparent stress).

The good thing is that only about a third began to think they were 'psychologically disturbed' (as many doctors and family members had suggested), with 51% of men and 54% of women totally rejecting this suggestion. Family members and friends often report that SD patients become very aggressive, self-defensive, angry and 'in denial' of their condition, and it is difficult for them to make the distinction between accepting that there is a physiologically-based voice condition and the apparent accusation of 'weakness' or being 'unnecessarily distressed about it'. Only the SD patient can understand how distressing, embarrassing, awkward and frustrating it is to be unable to express words one has used for a lifetime, get out sounds that have been natural and fluent since childhood, communicate clearly what one wants, thinks or is trying to say.

During the period before a correct diagnosis was made, about 70% of both men and women tried to pretend nothing was wrong, over a third felt ashamed and two-thirds tried to avoid potentially embarrassing situations. More women than men reacted angrily to questions about what was wrong with their voice, about 20% of both sexes thought tension must be the cause (but 24% refused to accept this accusation), and over a half say they never accepted the suggestion that their condition was psychological.

In every social situation – family and work life, social gatherings, groups meetings, and marital relationships, it was the inability to communicate clearly that frustrated them most. Close to 60% of both men and women felt withdrawn, 12% became badly depressed, 24% of the women and 19% of the men felt isolated. Most of them claim the

time before onset of SD was either very happy or quite content, around 27% of both sexes agreeing it was an unhappy time in their lives, not strong enough to suggest a causal connection. Laughter clearly helps the voice condition somehow (48% of men and 56% of women claim an improvement in their voice quality after laughing).

At the time of the survey, SD sufferers claimed their condition, at its worst, was as follows:

<b>Voice now, at its worst?</b>	<b>SD Males</b> (n = 37)	<b>SD Females</b> (n = 96)
Can't communicate clearly	8.1%	3.1%
Bad with some words	13.5	16.7
Difficult, but can cope	45.9	52.1
A bit of a croak	16.2	18.8
Like having a cold	8.1	7.3

This is largely because 73% of the SD sample have been having Botulinum injections and have experienced improvements in voice quality. This issue is examined in the next chapter, where again some differences are noted between males and females and their reactions to the treatment.

## **Chapter 5**

### **The Impact of Botox Injections**

Botulinum toxin is produced by the bacteria *Clostridium botulinum*. In medical use, it is heavily diluted and administered in very small doses by injecting it into one or other, or both, of the vocal cords. The effect is to paralyse the muscle, thus preventing the spasm that makes the voice 'spasmodic'.

Some more recent uses of Botox include injections into 'worry lines' on people's foreheads, mouth sag, and stammering.

In our sample of 133 SD sufferers, 113 (84.9%) reported that they had tried Botox injections; 16 (14.2%) had not, and 4 (3%) did not respond to the question. The following data refer to the two main groups, Botox and Non-Botox patients. Some slight anomalies appear because a few of the Non-Botox group respond to some items as though they have tried Botox once and given it up as unsuitable for them, but the findings are not affected in any serious way.

Fewer of those diagnosed as having the Abductor type of dysphonia have been given Botox injections than those with the Adductor type (30.1% cf. 81.4%).

More of those for whom the onset of SD came in early adulthood have had no Botox injections (31.3%), probably because the treatment was unavailable then; but also fewer of those whose SD developed in later life have had injections, perhaps because they dislike the idea or feel treatment for them is too late and not worth the pain. More of those who report having had family problems, a death of a friend or family member, a severe illness or operation, or an accident, have gone on to have Botox injections.

In contrast, more of those whose personal explanation for getting SD is psychological, or stress-based, have resisted having the Botox treatment. This reflects the initial diagnostic problems experienced by them, because if they were told it was 'imagined', 'nerves', 'psychological', or 'stress-related', they are more likely to be in the Non-Botox group. If the doctor seemed interested but unable to help, 44% did not go on to Botox treatment, whereas those treated dismissively by their initial doctor seem to have defied their response and are more likely to have tried the injections.

The earlier SD was detected, the more likely they are to have tried Botox injections (80.5%) and they are more likely to have had this treatment if SD was diagnosed by an Otolaryngologist (32%), a Speech Therapist (34.5%), or a Neurologist (26%), than if they were seen by a GP (12.5%), though 56.3% of the Non-Botox group had been diagnosed by a Speech Therapist who may have recommended voice exercises in preference to Botox injections.

On diagnosis of SD, more of those who were shocked, confused and upset, or concerned about a cure, never offered themselves for Botox injections. More of the Botox group were happy at the prospect of a cure, while more of the Non-Botox group were happy with speech exercises as a remedy.

Social support from others is also clearly a factor in deciding in favor of what must be a frightening experience for many people. More of the Non-Botox group say their spouse

was unsupportive and unsympathetic, upset, ignored the problem and accused them of being emotional than those in the Botox group. More of the Non-Botox group blamed themselves for the condition (25% cf. 8%), but more of them were determined to get over it (19% cf. 9%), suggesting a will to cure themselves without potentially painful and possibly ineffective injections.

This pattern is echoed in how they describe their pre-diagnosis reactions. More of the Non-Botox group refused to pretend there was nothing wrong (31.3% cf. 18.6%); more of them were angry at the lack of a satisfactory explanation (31.3% cf. 19.5%); but more of those who went on to have Botox rejected the suggestion that the cause was their being 'psychologically disturbed' (56.6% cf. 37.5%). The Non-Botox group was more likely to find social situations, the workplace, family dynamics, and telephone conversations difficult, and they describe their general life situation before diagnosis as less happy than those who tried Botox injections later on.

Certainly, those who have had Botox injections report a more active approach to solving the problem than those who have not, suggesting perhaps a more fatalistic attitude on the part of the Non-Botox group. When asked what other things they are trying to improve their voice, 75% of the Non-Botox group say, 'Nothing'. Some 12.5% are trying voice exercises (cf. only 3.5% of the Botox group), and 18.8% have tried Yoga and other relaxation techniques (cf. only 9.7% of the Botox group), but more (11.5%) of the Botox group have had voice therapy than the Non-Botox group (6.3%).

## Reactions to Botox

The reactions of people to Botox injections are of great interest in this study. The effects on improving voice quality were immediate and dramatic for 19.5%. For another 30.1% their voice improved over a short period of 2 to 3 weeks, and for another 31% it took a longer period of several weeks for them to notice any improvement. So Botox is not a magic fix for everyone. However, 59.3% claim that Botox returned their voice to 'normal', with 17.7% saying it brought about only a slight improvement, and 8.8% saying it did nothing at all. Men seem to respond better to Botox treatment than women, though only slightly, and men have had more injections, over a longer period of time, than the women in the sample.

For 68.1% the improvement in voice production lasted for only a period of between 0 – 10 weeks; for 28.3% it lasted between 11 – 40 weeks; and for a lucky 3.5% their voice quality was improved for between 41 – 99 weeks. Most of them (68.8%) experienced a gradual fading off in voice quality rather than a sudden deterioration (13.4%), but obviously Botox is not a permanent fix, and repeat injections are necessary for most SD sufferers.

In this sample (and their diagnosis varies from between a month and several years), the number of Botox injections varies widely.

1 injection	10.6%
2 injections	16.8%
3-5 “	23.0%
6-12 “	23.1%

13-20 “	14.9%
20-30 “	4.5%

The time period over which Botox injections have been given also varies, some having had repeated injections for over five years.

1 month or less	15.9%
1-6 months	34.8%
7-12 months	12.4%
13-24 months	11.6%
24-36 months	6.2%
37-60 months	4.5%
5+ years	12.6%

The effects of Botox injections are, however, not miraculous for everyone, or consistently positive. Patients report how they rated their voice quality after having had the injections.

As good as pre-diagnosis	25.7%
Useable	43.4%
Still an effort	17.7%
No better	9.7%

Some 67.3% report there are negative side-effects. There are no apparent differences between those who have Adductor Type SD and those who have the Abductor Type.

We can group such side-effects into

- i. voice quality changes
- ii other physical symptoms
- iii personal reactions

**i. voice quality changes – mostly breathiness following injection. e.g.**

*Breathiness. (F, 29)*

*Breathy voice following injection – as we affectionately call it, the midnight to dawn voice. (F, 49)*

*The usual – two weeks of whispers, difficulty drinking fluids. (M, 54)*

*Nothing except for notable breathiness, which isn't a side-effect, but the main effect. (M, 46)*

*I lost volume and was very breathy. (F, 60)*

*Breathiness, some choking, high pitched voice. (F, 55)*

**ii. other physical symptoms, mostly difficulty in swallowing fluids**

*Difficulty in swallowing liquids for first two weeks following injection. (F, 34)*

*Sore throat for many weeks. Felt tired/unwell for a day or two afterwards. (F, 41)*

*Voice softened next day and became hoarse. Maybe loss of muscle control. (F, 49)*

*A little breathlessness in first few post-injection days. Tend to have trouble taking fluids first week and causes a bit of coughing. (F, 49)*

*Some difficulty in swallowing liquids. Feel I sound a little garbled in the first week or so. (F, 53)*

*Nausea; voice worsening to a whisper. (M, 46)*

*In the beginning I had trouble swallowing fluids – they used to go down my windpipe, causing violent coughing. This very rarely happens now. Initially, injections lasted 3-4 months, now they last 9-12 months. (F, 58)*

*After the injections I felt pain in the muscles in my throat when I talked. It was as though the muscles had to strain even more to work the vocal cords. I felt quite traumatised. The neurologist's reason as to why Botox didn't work for me was that I must have a natural immunity to Botox. I find this explanation unacceptable. (F, 56)*

*Have to watch how I swallow for a week after injection. (M, 67)*

*Some congestion in throat with the need to clear it. Weakness in voice, voice tone change to higher register. Since Dr. X has got the correct dosage settled I don't encounter these problems. (M, 67)*

*For the first 4-6 weeks I have a very breathy voice, but the longer I have this, the longer the injection lasts. Sometimes have difficulty swallowing on or around the 9<sup>th</sup> day after. (F, 55)*

*I had one very bad reaction when the dosage was increased to 2 units in each cord. I completely lost my voice for three weeks. Couldn't manage a whisper. Felt very nauseated and tingly and peculiar and shaky for several days. (F, 69)*

*On the third day I feel slightly feverish and generally miserable for several days. (F, 76)*

*Runny nose, stiff, sore neck. Dry, scratchy throat, coughing, increased mucous. (F, 72)*

*Slackness of eyelids, slackness in upper and lower lips, dribbly. (F, 84)*

*Very weak eyes, very tired and sometimes flu-like symptoms, headache, choking. Then for the first to second week, very breathy, and with swallowing problems – tablets, orange juice, etc. - but not with eating. Also seem to swallow a lot of mucous down my throat. (F, 76)*

*Through it all I find that face muscle, lips and jaw have become very tense and I'm now trying to relax them. Since the Botox injection one person has remarked that my facial expression is different. (F, 76)*

*In the early days of injections I had difficulty swallowing for a week or so. Sore at actual spot where injected. Slight cough. Now I don't seem to have any side-effects. I also used to have a high-pitched sound after (like Daffy Duck) for a week or so. (F, 58)*

### **iii. Personal reactions**

*I was petrified whilst having it done and chose not to have any more injections in my throat. (F, 70)*

*First injection was rather frightening, had very little voice for 6 weeks, then improved. The second one was even worse, could not swallow liquids at all, developed a bad cough and was diagnosed as having pneumonia in the right lobe, so did not have another injection for 12 months. (F, 71)*

*I reject the medical model that says Botox is the only helpful treatment because this has not been my experience and I know how limited the medical model can be. There are days when I would dearly love to have a 'magic injection' which restored my voice, but my concerns about Botox are two-fold. One concern is that I cannot afford to have even a temporary aggravation (for a few days) after each injection because my work relies heavily on my voice. The other is that any possible long-term side effects are not yet known, so I view the treatment as still being experimental. (F, 33)*

*Botox injection was recommended and I was nervous about it and knowing that I would have to have this regularly was most upsetting— voice returned to normal after Botox. (F, 50)*

*The first time I lost my voice for one and a half weeks. The next two times there were no real problems, apart from a bit of breathiness. This last time, it's been more than two weeks and I still don't have a voice! I've also had some choking while swallowing. (F, 30)*

### **Reactions of family and others to post-Botox voice**

The reactions of others to the voice improvements produced by Botox injections are clear and generally positive.

Pleased/amazed at the improvement	58.4%
Accept that it's a physical problem	2.7%
Anxious about a relapse	4.4%
Relief it's over	7.1%
Other	21.2%

*Extremely pleased, felt it was a miracle. (M, 80)*

*Simply amazed. (F, 34)*

*Mostly great relief for me to be able to talk normally again. Positive comments on how well I'm speaking. Some people are suddenly taken by surprise when they realise after quite some time how well I'm speaking again. (M, 55)*

*My friends say my voice has improved 100% (F, 62)*

*Very happy with the results. (F, 60)*

*Hey, your voice sounds great! (F, 57)*

*Surprised and happy for me. (F,27)*

*Amazement, tears! The first time I came home, and with a saucepan for a microphone, I stood on our coffee table and belted out a Jimmy Barnes song, for my then 12 and 16 year old sons, who had tears in their eyes. It was wonderful. The first time, I phoned everyone I'd ever known in my life nearly, and no-one believed it was me, even when I said 'But remember I told you on Saturday we shampooed Albert, our dog. Even after that, they didn't believe me, because I didn't sound like me. (F, 51)*

*Pre-Botox there was a lot of stress. My husband believed my voice was worse when I spoke to him as well! He cried when my voice returned after the first Botox injection. (F, 74)*

*Encouragement, enthusiasm, optimism. (F, 30)*

*Absolute amazement. Thrilled. My grandchildren had never heard me speak normally and my children had forgotten how I sounded. I would go shopping just to talk to people and to see their reactions, phone people and say 'Guess who this is?' (F, 58)*

*They say I should have had Botox long ago. (F, 73)*

*They all say it is a miracle. They can't believe it. So many people rang me that I began to go a bit hoarse from talking too much. (F, 73)*

*Pleasure for me. Some friends do not recognise me on the phone. (F, 69)*

*Excellent, because I am so much more relaxed. My posture actually changes. (F, 29)*

*All so thrilled, found it difficult to understand the fact that I could now communicate without great difficulty. (M, 67)*

*Said I was like my old self. (M, 67)*

For some, however, the reactions of others reflect their own disappointment with Botox treatment.

*Very disappointed that it didn't work for me. (F, 56)*

*Mixed reactions – they expect me to be right once I have an injection. (F, 43)*

*My family were very pleased after the first injection settled down, but not too pleased with the second injection. (F, 71)*

*They are concerned that I had to have the injection. My youngest son always says, 'Why do you put yourself through this? Well, it's stress to have it done, but I'm always happy with the results. And if I dropped out (of the Botox program), as I may have to as I get older, then I wouldn't be able to get back in, as they have so many waiting for the injection. I feel so sorry for young people for their long road ahead. (F, 76)*

*They notice only a slight improvement. (F, 66)*

*No effect – all disappointed. (F, 55)*

*They understand that I sound odd after for a week or so, depending on dose. (F, 55)*

*Nothing was noticed until about 10-12 weeks after the injection. Then comments were 'your voice sounds better.' Only lasted 4 weeks. (F, 61)*

*They felt my voice was 'better', but it didn't last. They were glad for me though. (F, 60)*

*They notice the breathiness. Many think it is worse. Some subconsciously imitate it! (M, 46)*

*After 24 years of therapy, etc., my voice was usable. The first Botox injection produced only a small improvement, probably only noticeable to me. The second made no improvement, so no-one commented, sorry for me. (M, 57)*

*Nobody really comments that it has improved. (F, 41)*

### **Botox and other efforts to improve voice quality**

One interesting consequence of the Botox treatment is that it may have cut off further efforts in the area of voice therapy and speech exercise. Once 'cured' by the injection, patients seem to feel they don't need to try anything else; they'll just go and have another injection when the voice quality deteriorates again. The following table lists a range of alternative ways of assisting the voice, as used by Botox and Non-Botox respondents. We have taken out those respondents who do not use these 'techniques', so the percentages show the effects, good and bad, for those who try other modes of voice improvement.

<b>Other things help?</b>		<b>Botox</b> (n = 113)	<b>Non-Botox</b> (n = 16)
Smooth speech	Good effect	17.7%	50%
	Irregular	38.7	33.0
	No effect	43.5	16.6
Breathing	Good effect	23.2%	37.5%

focus			
	Irregular	46.3	37.5
	No effect	40.8	14.3
Alcohol	Good effect	30.9	57.0
	Irregular	22.5	14.3
	No effect	40.8	14.3
Speech therapy	Good effect	13.7	20.0
	Irregular	34.2	40.0
	No effect	46.6	40.0
Own voice exercises	Good effect	24.6	50.0
	Irregular	29.5	16.7
	No effect	45.9	33.3
Change pitch	Good effect	24.6	50.0
	Irregular	44.6	33.3
	No effect	30.8	16.7
Talk quietly	Good effect	57.3	40.0
	Irregular	55.9	40.0
	No effect	11.8	20.0
Mimicking sounds	Good effect	21.1	40.0
	Irregular	34.0	40.0
	No effect	44.7	20.0
Substitute words	Good effect	41.5	72.7
	Irregular	44.6	18.2
	No effect	13.8	9.1
Talk slowly	Good effect	46.2	60.0
	Irregular	36.3	40.0
	No effect	18.7	-
Reduce stress	Good effect	50.6	61.5
	Irregular	30.3	38.5
	No effect	19.1	-
Shorter sentences	Good effect	47.8	44.4
	Irregular	34.8	44.4
	No effect	17.4	11.1
Laughing	Good effect	67.4	54.5
	Irregular	20.9	27.3
	No effect	11.6	18.2
Singing	Good effect	46.1	50.0
	Irregular	18.5	25.0
	No effect	35.4	25.0
Inspiration speech	Good effect	23.2	16.7
	Irregular	30.4	50.0
	No effect	46.4	33.3
Say "Ah" to start	Good effect	35.6	33.3
	Irregular	28.8	33.3

	No effect	36.6	33.3
Maintain fitness	Good effect	61.1	55.6
	Irregular	23.6	1.1
	No effect	50.9	33.3
Avoid noisy rooms	Good effect	58.8	75.0
	Irregular	22.3	12.5
	No effect	18.8	12.5

Clearly, the most effective techniques seem to be laughter, singing, talking more slowly or quietly, reducing stress and avoiding noisy rooms where their voice has to strain to be heard.

But the Non-Botox group does better on all of these techniques, plus gaining more benefit from a greater focus on their breathing, smooth speech, changing the pitch of their voice, substituting words that are too difficult to say, and from their own personally-devised voice exercises. The low level of positive response to voice therapy needs to be seen in light of the fact that many SD patients (both Botox and Non-Botox) do actually try techniques that have probably been suggested by speech therapists.

It may be of interest to note some of the techniques SD people use to improve voice quality and their personal techniques of coping now. (Q.113). Individual and idiosyncratic methods may well work for other SD patients if they try them out.

Some are general attitudinal and style responses, more frequently with older patients. e.g.

*Keep your sense of humor. There's no pain to SD and I could be a lot worse off. It doesn't help to be angry. (F, 73)*

*Since Botox, I don't have to use any special 'tricks'. I just say I have a speech problem and always seem to get that out OK; people readily accept the situation. (M, 67)*

*I would say be brave and bold. Go out there and make yourself understood. Listen to music tapes; those 'Tightening your muscles' tapes are not really relaxing. Go dancing, play indoor bowls, let it take you on a journey through it to some place else. (F, 76)*

*I avoid long conversations and use short sentences and alternative words where possible. If there's background noise I just withdraw. (F, 72)*

*I just try to forget about it, since I've had Botox. (F, 71)*

*Good night's sleep. (F, 41)*

*Speak with my hands, laugh, make a joke of it. (F, 49)*

*I just tell new people it is stress of work. (F, 61)*

*I use a card describing the problem. (F, 66)*

*I would rather talk to someone about the condition than have them wonder what is wrong with me. I hate to think that people feel sorry for me. (F, 73)*

*Do playful acts. Avoid talking whenever possible. (F, 84)*

*I wear a badge with 'Voice Impaired' and my name – helps when shopping. (F, 57)*

*Just be myself, learn to laugh at myself. (F, 71)*

*I just apologise and explain the condition. (F, 81)*

*No tricks. I just try and talk. (F, 71)*

*Use my hands as well as my voice when speaking. Botox gave me more confidence, so on the odd occasion it breaks up it seems easier to explain why. (F, 62)*

*Use my hands as well as my voice when speaking. Botox gave me more confidence, so on the odd occasion it breaks up it seems easier to explain why. (F, 62)*

Others are more specific about voice production techniques they have found to be helpful:

*Practising what I'm going to say just before I say it e.g. before using the phone. Seeing people in person, trying to choose the time and place for a conversation so the surroundings are quiet. (M, 46)*

*When I go to the shops I write a note saying what I need. I make excuses. I use short sentences. (M, 42)*

*Going through the mental process of trying to speak and using words that come out more easily. Laughing at myself, humor, explaining the condition, repeating myself more slowly. (F, 60)*

*I try to make my voice soft and clear, avoiding background noise. I probably use more hand gestures now than before. I always explain my condition. (F, 53)*

*I use shorter sentences and avoid talking whenever possible. (F, 58)*

*After doing extremely vigorous exercise I noticed a definite improvement for a couple of hours. If I go out on a date, or have to talk to someone, if possible, I push myself to walk or jog or bike ride hard, for perhaps 2 to 3 hours. It definitely helps fluency for a few hours after. (F, 51)*

*When talking on the telephone I find it easier to speak if I put my head back. When speaking to someone and sitting down, I put my hands behind my head. (M, 57)*

*Whispering helps. I find it easier to talk to someone who knows me and understands my situation. I tell new people that I have a voice problem, and ask would they be patient and bear with me. Use shorter sentences, and speak in a very quiet voice. (M, 59)*

*I used to teach communication, body language, speech techniques at university level, with TV and radio presenters. SD ended that career, but propelled me into learning more about delivery of messages person to person and a whole new career. (M, 66)*

*I found standing close to people they could lip read. Have a typed note ready in case I can't be understood. I try to use shorter sentences. (F, 68)*

*At first I found if I laid flat on my back it helped, but only for a short time. Now nothing works. (F, 55)*

*I tried 'Rivotril' for 7 weeks; it really helped. I do voice exercises and a very dedicated, positive attitude. Use opening words that do not cause straining (glottal stops). (M, 57)*

*I think of what I'm going to say before I open my mouth. Quite often by the time I say it, it's not relevant. I'm quite open about my disability and don't feel embarrassed as I did in the early days. (F, 69)*

*Opening the muscles in the throat, holding my neck sometimes helps. (F, 70)*

*Talking softly, making my voice higher, taking a deep breath before I speak, breathing out when I speak, calming myself down, visualising that I can speak smoothly. (F Ab, 34)*

*Avoidance of caffiene. I warn people in lectures that my voice may fade in and out, try to use a microphone to take the pressure off a bit. Warm up with voice exercises like humming, sirening and 'horse blows'. I also avoid difficult sounds. (F Ab, 34)*

*Avoid the telephone. Give doctors information about SD. Luckily I'm a listener by nature. F, 55)*

*Keep in eye contact with the person you're talking to. I avoid using words that develop in the back of the throat; letters and words spoken off the lips come a lot easier. (M, 55)*

*Sing 'Good morning' to get the voice started. Start with m...mn.. and roll into slurred continuous speech, then back off to acceptable level. Never let the voice fall down and back. Lift up and forward to back of nose and seek resonance, with perhaps raised pitch. Visualise the whole operation and continually experiment with bio-feedback to optimise and maintain improvements. The voice can get on a roll with reasonably quiet, lengthy talk. Forcing will cause deterioration. (M Ab, 57)*

*Laughing works best; not sure whether it actually improves my voice or just takes my mind off it. I try to focus on the other person and ignore my problem. (F, 27)*

*My best coping technique is an attitude of getting on with things. I try to prevent the doubt and the frustration creeping in and I try to forget I even have SD. At the same time, I'll try whatever the experts suggest and I'll try to hang in there during the treatment. I won't stop talking and I won't stop going out. (F, 30)*

*Taking 'Inderel' (a Beta-blocker) before public speaking helps. So does a small amount of alcohol. Reading out loud first thing in the morning to steady the voice, and singing. Speaking briefly is best, and substituting words. (F, 61)*

Interestingly, men seem more willing than women to try techniques that might help with vocal quality, apart from botox injections, though not all are necessarily of benefit.

**“What other things help you in the use of your voice?”**

Figures in the following table are again percentages only for those who said they have tried a particular form of assistance. The remaining percentages out of 100% (not shown) are those for whom the method had no effect at all.

What helps?	Good effects Male (n = 37)	Good effects Female (n = 96)	Irregular but helps – Male (37)	Irregular but helps – Female (96)
Smooth speech	35%	14.2%	40%	36.7%
Breathing focus	31.8	24.3	40.9	45.7
Alcohol	28.0	35.2	20.0	24.1
Beta blockers	-	17.6	16.9	17.6
Relaxing drugs	-	33.3	58.3	20.0
Speech therapy	18.2	14.8	45.5	33.3
Own voice exercises	36.8	22.0	36.8	26.0
Change of pitch	31.6	24.5	15.2	45.3
Talking quietly	44.0	42.7	44.0	42.7
Mimicking sounds	23.1	22.5	30.7	35.0
Avoid noisy rooms	62.3	56.3	22.2	21.1
Substitute word	56.0	39.6	40.0	41.5
Talk slowly	64.0	41.2	32.0	36.8
Reduce stress	55.2	50.7	31.0	30.7
Phone modulator	11.1	26.3	-	21.0
Shorter sentences	43.5	47.4	34.8	35.1
Laughing	65.2	65.3	26.1	21.3
Singing a lot	61.1	40.4	16.7	19.2
Inspiration speech	40.0	18.4	20.0	36.7
Say “Ah” before speaking	45.0	29.8	30.0	27.6
Maintain physical fitness	56.0	40.9	21.4	16.4

Those who have had Botox injections clearly experience an improvement overall in their voice quality and in their perceptions of difficult situations. The following table shows responses for the whole SD sample to the question “What have been the most difficult things for you to handle?” The last column gives percentages only for those who have had Botox treatment and indicate a marked drop in difficulty overall for them.

Most difficult to handle? (n = 133)	Pre-diagnosis	Post-diagnosis	Both pre- and post-diagnosis	All times	After Botox
Telephone	33.6%	8.0%	33.6%	16.8%	1.8%
Public presentation	15.9	5.3	16.8	15.9	1.8
Group conversation	24.8	8.8	24.8	15.9	3.5
Unpredictability	26.5	7.1	16.8	16.8	6.2
Starting a sentence	21.2	6.2	23.0	11.5	.9
Vowel sounds	17.7	3.5	22.1	12.5	2.7
Consonants	10.6	3.5	22.1	12.5	2.7
High pitch	6.2	4.4	12.4	4.4	5.3
Lower sounds	11.5	4.4	9.7	3.5	.9
Singing a song		7.1	15.0	8.8	3.5

Moreover, more of the Non-Botox group say that their current voice condition is “Worse than ever” (19% cf. 9%), and more of the Botox group say it is “Bearable” now (35.4% cf. 25%, and “Better than at first” (28.3% cf. 6.3%). Oddly, however, 18.8% of the Non-Botox group claim their voice is “Better than ever” than do those who have had Botox injections (10.6%).

### Other symptoms of dystonia?

We asked all SD people whether they had noticed any other symptoms of dystonia since being diagnosed as having the Spasmodic Dysphonia form. There are few differences between the Botox and the Non-Botox group, but it is of interest that quite a few overall have developed or noticed other symptoms. As well, more of the women have developed such symptoms than the men.

Other symptoms noticed	Botox Group (n = 113)	Non-Botox Group (n = 16)
Shaky hands	15.0%	18.8%
Body tremor	8.0	6.3
Head twitch	13.3	-
Eye blinking	13.3	12.5
Neck strain	33.6	37.5

Worst times for voice use seem to vary inconsistently across the two groups, though later in the day, tiredness affects more of them overall. The only gender difference is that 33% of the women say their voice is worse in the morning compared with 11% of the men, and more of the women say the more they talk the more effortful their speech becomes (39.6% cf. 27.0% for the men).

Times of day		Botox Group (n = 113)	Non-Botox Group (n = 16)
Early morning	Worse	29.2%	12.5%
	Same	28.3	37.5
	Better	32.7	25.0
Middle day	Worse	5.3	6.3
	Same	60.2	43.8
	Better	11.5	12.5
Late in day	Worse	41.6	56.3
	Same	34.5	25.0
	Better	12.4	6.3

For a large number, the more people talk, the more effortful their speech is, but for a few it improves with use and many say this happens only if they overdo the use of their voice.

More talk, more effortful?	Botox Group (n = 113)	Non-Botox Group (n = 16)
Yes, usually	35.4%	43.8%
Only if overdo	34.5	37.5
No, it improves	10.6	-
It varies	16.8	18.8

**Chapter 6**  
**Overall Life Impacts of SD**

We have already described how SD sufferers felt about themselves and how it impacted on their work and social relationships. But at the end of the survey questionnaire, we offered them a chance to comment in general on the impact Spasmodic Dysphonia has had on their life overall. The following categories were coded, but their own words are much more graphic. Males differ somewhat from females in that they claim less of an impact on communication processes. And those who have had Botox treatment seem to have different responses from those who have not had these injections, being less depressed because the injections have rescued their ability to communicate at least to some extent.

<b>Overall life impact of SD</b>	<b>Male (n = 37)</b>	<b>Female (n = 96)</b>
Personality change	27.8%	30.2%
Loss of communication/interaction	22.2	32.6
Depression	5.6	8.4
Ruined/hurt career	27.0	21.3
Ruined family/social life	29.7	32.6
Learn to live with it	44.4	33.7

<b>Overall life impact of SD</b>	<b>Botox (n = 113)</b>	<b>Non-Botox (n = 16)</b>
Personality change	32.1%	18.8%
Loss of communication/interaction	29.5	37.5
Depression	6.3	18.8
Ruined/hurt career	25.2	12.5
Ruined family/social life	29.5	50.0
Learn to live with it	39.8	18.8

**a. Older people:**

Several are philosophical about their fate and have adjusted to dealing with their disability. e.g.

*Frustrating when I could not get help for what was wrong, but since my husband's stroke and I have to care for him, I realise my voice problem is not so bad after all. (F, Add, Botox, 71)*

*Well, I look on it that I'm in very good health for my age, having played tennis to the age of 70. I have not been happy having SD but if I didn't have this what else might I have had? I just keep on believing my voice must get better now (hate the Botox injections and their after-effects), so for now I must be patient and keep hoping. (F, Add, Botox, 76)*

*I am supported and involved in the SD Support Group and will do anything I can to help SD sufferers. (F, Add, Botox, 73)*

*SD has made my life difficult, but I have battled along and manage to do most things. Exhaustion overtakes me and I long to escape. I do get complimented on how I manage. (F, Add, Botox, 84)*

Others describe the effects on their life as devastating:

*SD has had a devastating effect on my life for the last 21 years, robbing me of my confidence and self-esteem and preventing me from doing all the things my husband and I had planned to do when he retired. I have three grandchildren and until I had the Botox injection they had never heard me speak in my normal voice. I had the injection on 21 Nov. and Xmas time was the most wonderful I have ever spent. We all celebrated. I wish my husband had been here, but he died in 1989. I feel as though I have been in prison and just been released. (F, Add, Botox, 73)*

*I have been devastated by this disorder, and having both a throat problem and eye and face problem makes my life very difficult. And I am now having eating problems; although I can swallow I can't chew very well, so avoid going out for meals, which I always loved to do, and my husband finds this difficult to cope with. (F, Add, Botox, 76)*

*I suppose the biggest change in my life is not being able to express myself as I would wish, not able to chit chat. Thinking it was just me that could not speak properly until diagnosed and treated. (F, Add, Botox, 70)*

*It has spoiled my enjoyment of life, my interaction with family and friends. However, I keep a positive attitude and battle on. I'm just grateful that I was afflicted at the latter stage of my life and have the utmost sympathy for younger people. (F, Add, Botox, 69)*

*It has completely changed the direction of my life. I was about to do 'my own thing' i.e. acting, once the family left home, but that was no longer possible when the voice cracked up. I have now got involved with a 'Singing for Seniors' group. (F, Add, Botox, 74)*

*I go out when I feel like it as it is easy for me to talk after my injection. Before Botox, I would only go out when I had to as I felt people just stared at you and made you feel embarrassed. (F, Add, Botox, 65)*

*Not a great deal except when I am at worst and in need of an injection. (F, Ab, Botox, 75)*

*I do not participate in any organisations now. I do have many friends who understand. I was fortunate in my early 60s when it started to be noticed more, so I count my blessings, being a lover of the outdoors. (F, Ab, Non-Botox, 71)*

*It has minimal impact on me, I just carry on as usual and don't worry about it. (M, Ab, Non-Botox, 75)*

*By having the condition whilst so young it prevented me from mixing socially and consequently I do not have a large network of friends. I didn't mix because I felt*

*embarrassed and 'of no consequence', no-one would want me as a friend. I feel that I missed out on my teens/20s years. I would still love to mix more but just do not have the confidence to do so, still have the feeling of yesteryears of being inadequate and having nothing to give. (M, Add, Botox, 67)*

*Spasmodic Dysphonia caused me to lose a highly paid and satisfying job. We had to make adjustments after having to retire early. But now I am very happy with my lot and my wife and I can go wherever we want when we want. So perhaps in getting SD in the first place and getting Botox to cure it, my life could have been extended by many years as I have avoided the pressures of work. (M, Add, Botox, 67)*

*Ruined it (my life) but as time passes I am becoming more tolerant of myself. I hate imperfection, so find SD hard to accept. If Botox had not come along for us, I feel suicide would have become an option. I can't expect other people to understand, as when my voice is 'normal' I feel myself it will never return to being 'spastic', but, sadly, it does. I feel that when I have my spastic voice my whole personality has changed. I am normally a happy and outgoing person who loves people and communicating with them. This person disappears with my confidence. (F, Add, Botox, 61)*

#### **b. Middle-aged people**

*The loss of satisfactory communication undoubtedly has a devastating effect on those afflicted and the people around them. Like many other disabilities, the human animal learns to adjust and cope, and a positive outlook and good sense of humor are vital to achieve this. But there is no doubt such disabilities reduce personal development potential despite a good attitude and have a huge effect. (M, Ab, Botox, 57)*

*Socially it has restricted me. I need to carry a water bottle with me at all times (talking gives me a sore throat). I get frustrated at having to repeat things several times (husband is a bit deaf), but I have been able to adapt my lifestyle. My husband is my support. I do not dwell on negative aspects. (F, Ab, Non\_Botox, 55)*

*Devastating – had to relinquish a very satisfying and rewarding position which I had been transferred to as I was unable to use the phone. Feel socially isolated. (F, Ab, Botox, 57)*

*Having SD has made me want to isolate myself. I was quite outgoing and enjoyed being with other people, but I now prefer to be with just one or two people on my own. (F, Ab, Botox, 50)*

*SD changed my life. I minimized the extent to which I had to use my voice in public. (F, Both Add & Ab, Non-Botox, 61)*

*Before SD I was very outgoing, sang in choirs and enjoyed life generally. I then became quiet and withdrawn. When we had an evening out I would come home exhausted from trying to make myself heard. Now after Botox, I am enjoying life again and can speak with anyone, have my confidence back. (F, both Add & Ab, Botox, 58)*

*I lead a very lonely, isolated life now because I lost contact with friends when I first started having voice problems (e.g. never returning their phone calls). Because of the unpredictability of my voice I lack the confidence to go and meet new people. But the*

*four months after my first Botox injection, I was a totally different person, full of confidence, enjoyed life, even enjoyed my work. Botox changed my life. (F, both Add & Ab, Botox, 49)*

*It has effectively curbed my chance of promotion, it constrains some of my more ambitious career aspirations. It worries me that my offspring may have SD in store for them. In many ways it has made me a more competitive person and a better listener, made me re-direct my energies into contributing even more with my current priorities. (M, Add, Botox, 54)*

*Made me more difficult to get on with. Makes me tend to be withdrawn and anti-social, able no longer to be a good mixer. (M, Ab, Botox, 56)*

*I think pretty dramatic. I'm very well qualified and others say I have been good at my job. I reached the level of Manager Grade 2 and my supervisor was seriously talking to me about going to a higher manager grade or applying for a position in the Senior Executive Service. But I was always so conscious of the voice thing. Then my marriage broke up. (My wife tried very hard to be supportive. She has told me since that I seemed to push her away. I felt a bit like a wounded animal and just wanted to crawl away into a cave to try and recover.) And I had a complete health breakdown, forcing me out of the workforce altogether. (M, Add, Non-Botox, 50)*

*Gone from outgoing and talkative to introverted and non-communicative, thinking of injuring persons who look at me as if I'm a cretin – having done martial arts for 20 years I am quite capable. Thoughts of suicide and a reassessment of what I can offer my family and friends. I don't want sympathy! (M, Ab, Botox, 44)*

*Feels like a huge anchor on my career ambitions. Hated having to accept that a physical disability could cause me to change careers from a large business to a small business. Probably not a bad thing in hindsight, however I still have a niggle about how far I might have gone. I stopped enjoying life because it had become a mysterious, constant battle. My first wife died 6 months before I had Botox – twinges of guilt that maybe she 'left' me to have a rest from the shared burden of the then unknown SD. (M, Add, Botox, 48)*

*It has devastated my life, simple as that. I am now a very lonely person, even if there is a room full of people. (F, both Add & Ab, Botox, 43)*

*At times, I have become suicidal. Before Botox I had become almost a recluse, not socialising, no communicating on the phone. Working was an embarrassing nightmare. I would break out in a nervous rash, just praying that no-one would speak to me, so I would not have to answer. I would almost push my husband ahead of me when entering a store. Then, I would become upset if he didn't say word for word what I wanted him to say to the salesperson for me. (F, Add, Botox, 55)*

*I find I lack tolerance of other people's annoying habits. I tend to hold grudges and overall am a more irritable person than I used to be. (M, Add, Botox, 59)*

*It has forced me into early retirement from the workforce. Also I am not as outgoing as I was before. (M, Add, Botox, 57)*

*I am in a high communication job – school principal. Even though the teachers, children and parents are very supportive, it has brought on a new stress to a sometimes stressful job. At times it is physically and emotionally exhausting. (M, Add, Botox, 54)*

*SD has isolated me socially. My husband had a stroke and is living in a nursing home, all my children have left home. I now live alone, with no social life. I fear the future as I often feel terribly lonely. Sometimes I just want to die and leave all the embarrassment behind. The only good thing is that I discovered I can paint, I spend my isolation using and developing my newly discovered artistic talents. Whilst this gives me some joy, I still feel very isolated. (F, Add, Botox, 56)*

*Decisions about holidays etc. all revolve around what part of the cycle my voice is in. I spend many times embarrassed by sounding like Minnie Mouse. It's financially a drain as I had to travel interstate to get results. I have lost a fuller lifestyle by the three years' withdrawal. I'm OK now, but not the same. (F, Add, Botox, 55)*

*It has limited my opportunities considerably, although I do have a very happy life now (divorced). But I am reclusive because of SD, don't go to singles do's, pubs, clubs or parties, prefer picnics where there is no noise. If I want to learn something, where normally I would do a course with other people, I get library books and do it at home, where I don't have to speak to people. But continuing motivation is a problem. (F, Add, Botox, 51)*

*While it is a deep sadness at losing something so personal as your voice, my life has been enriched in many ways, having to give up my profession as an occupational therapist I started my own business. I was embarrassed by SD but have many new friends because of it. What I seem to have lost completely is an ability to sing, which is hard. (F, Add, Botox, 53)*

*Dreadful impact on my whole life. I have had to change my entire personality to cope. I work my butt off from early in the morning till late at night doing a job most men find too difficult to do, but I am good at it and people admire and respect me for doing it and this is one of the few things that make me feel good about myself. (M, Add, Botox, 49)  
Career – it has affected my 'drive' and prevented me from realising my true potential. Personal – for a long while I believed no-one would ever want me because of this dud voice. Social – frustrating that I can't be the person I feel to be on the inside. Within myself – a humbling experience. I think I have a greater sensitivity and respect for other disabled groups, or people in marginal categories of any type. (F, Add, Botox, 41)*

*The most negative aspect is that it has stopped me being articulate when I know what I want to say but can't because my mind is so busy thinking of alternative words and sentence structures that I lose the fluency of normal speech and thus lose control of the conversation. I haven't sought higher, managerial positions, though whether this is SD, as I've never had the ambition to aspire to such positions? (F, Add, Botox, 58)*

*I feel my future has been completely ruined by Retrocollis. Dysphonia is a nuisance, but I can live with that. (M, Add, plus Retrocollis, plus Ballismus from birth, 54)*

*For a long time I suffered major impact – increased anxiety and depressed outlook, much reduced social activity. Very difficult to maintain communication with my family, parenting made difficult, hard to be able to be a role model for children. Major impact too on my work performance. Even with Botox I may need to change my job to feel more*

*comfortable. My work involves full-on talking. Unable to pursue a hobby. Had major problems in everyday activities, shopping, using the phone, all those tasks that involved talking. (M, Add, Botox, 47)*

*It has changed me from being very outgoing and confident (sometimes the life of the party) to taking a back seat in most things, although I will make a stand when I need to. I don't listen to people as well as I used to either, maybe because I feel I can't be bothered commenting on what's being said. (F, Add, Botox, 41)*

*I felt I had lost my identity as the only thing of interest I had to anyone was my voice disorder. No longer in control of my destiny. (F, Add, Botox, 53)*

*My life became my voice. I refuse to believe the condition is permanent and believe the old me will re-emerge. (F, Add, Botox, 54)*

*Career in the public service is fairly competitive and with a 'normal' voice I would have done much better. Though I've had full support and understanding from my family, I cannot help but feel that in some way I've 'let the side down'. Social contact has reduced, but I still enjoy activities that do not involve talking – arts, films, reading, golf! (M, both Add & Ab, Botox, 55)*

*It was the hardest period of my life, and almost cost me my marriage. I used it as a turning point – have retrained and am looking forward to entering the workforce again. I'm more contented and self-aware than I have ever been in my life. (M, Add, Botox, 59)*

### **c. Younger people**

*At first I saw it as a devastating force on my existence, but now I see it as something which has helped me become a much better and very focused person. It's brought me closer to God, taught me compassion and made me determined to do something special with my life. (F, both Add & Ab, Botox, 33)*

*SD has wrecked my social life. I avoid talking situations all the time. I've had Botox injections twice, but they didn't work on me. I am thinking of going back once more because I am desperate to get a better voice. (M, Add, Botox, 42)*

*I think the biggest problem is people's fear of developing other dystonias – especially on the Internet where people often have more than one. I have had SD for 12 years and nothing else, and I am constantly being worried that I could get something else. So, my eye twitches like everyone's do, and I rush to the doctor! Stupid! (F, Add, Botox, 29)*

*Sometimes things happen in order for us to change and learn. I have now accepted that I wasn't meant to continue a singing career, and my daughters have come into my life, who enjoy my voice more than anyone would have ever appreciated it. (F, Ab, Non-Botox, 28)*

*SD has had an enormous impact on all aspects of my life – self-esteem, personality, relationships, confidence, social interaction, and even changed my career path and uni. Studies (from journalism to video and film in order to avoid situations where I would have to speak a lot. I felt no-one would want to be really close to me, I felt like some sort of freak, and had constant feelings of inadequacy in my personal and professional lives. Many of these feelings persist ... and I continue to berate myself for having the condition in the first place, and for failing to control it all the time. (F, Add, Non-Botox, 31)*

*It has been the single most difficult thing I have ever had to deal with. It has severely restricted or limited my ability and willingness to do things (social and work-related) which rely on using my voice. Pre-diagnosis I had to deal with the uncertainty of what was happening to me and post-diagnosis have had to live with the prognosis, which suggests there is no cure other than Botox and that SD is often degenerative. I now live with it, but not particularly comfortably... Having SD has forced me to confront situations and face challenges I would otherwise not have had to face. One could assume that this has been 'character-building', but in fact many aspects of having SD have been limiting and very demoralising. However, it has pushed me along the path of pursuing meditation, which has been enormously beneficial in all sorts of ways. It has also given me an increased empathy with people suffering from chronic illness or with disabilities.*

*(F, Ab, Botox, 33)*

*I have been pregnant for 4 months. During this time, my voice has been worse than it ever has been, I think it is directly related to the pregnancy. Normally my voice does not cause me concern as I can manage it and it is not a bad or obvious problem. It used to only get bad when I am tired or stressed. It will be interesting to see if it improves when I have had the baby. (F, Ab, Non-Botox, 34)*

*Six or seven years ago, I was ambitious, successful and on my way up in the cut-throat world of radio. I've still managed to achieve a great deal, but my throat and voice problems have made it a struggle. Now, I'm having to reassess my future and my priorities. I'm too young to give up on having a career, but I'm too old and I have too many commitments to start all over again. (F, both Add & Ab, Botox, 30)*

*I have never been a very social person, but sometimes I think it would be nice to have that special someone in my life. But what's the use as I can't even get to first base, can't even get out a 'Hello'. So life is pretty lonely. When I do talk I end up thoroughly embarrassed and I spend the rest of the day feeling like a fool. Very often I think is it all worth it, as I feel suffocated by this condition, physically and emotionally. (F, both Add & Ab, Botox, 36)*

*Absolute hell. Miss out on enjoying what life has to offer. Depressed and frustrated. Think about it all the time, wish I was someone else, worried if my kids will get it. (F, Add, Botox, 25)*

## **Chapter 7** **SD Support Groups and the Future**

We are very grateful to the Spasmodic Dysphonia Support Groups which now operate in several states, because without their help this survey would not have been possible. The only way to obtain a sample of SD sufferers was through the hospitals that deal with them, and we received excellent cooperation from the SD Support Groups in Sydney, Melbourne, Brisbane, Perth, Adelaide and also from New Zealand. At the end of this report we list the actual names and contact details for each group, plus some of the web sites and other literature that people may find useful.

Here we report on their answers to some questions about whether or not they have found the Support Groups helpful and any constructive suggestions they had to offer. Obviously, some people do not like to be labelled or treated as part of any 'disabled' group, others prefer to cope alone and not have to attend meetings of like sufferers, and our sample lacks SD patients who have chosen not to join any support group. But the neurology and speech therapy specialists who treat SD now ensure that all their patients know about the existence of SD Support Groups and make their literature available to them.

*(One wrote, 'I receive newsletters monthly and am pleased to know my feelings/frustrations, etc. are shared by others with the same problem.'* (F, 34)

On the other hand, one SD person wrote, '*Didn't know there was one!*', and another said, '*As I'm not in the area where there is one, I can't participate.*' (F, 69)

Not everyone chose to comment, so we presume what follows represents mostly those who were happy with their Support Group or who had some complaint. As well, because numbers were too small, and in order to preserve full confidentiality, we do not disclose which SD Support Group they belong to.

We do provide the age and sex, so that leaders of SD Support Groups may take from the comments whatever lessons they can about how best to cater for a diversity of SD patients and perhaps attract higher membership.

### **Are you a member of a SD Support Group and, if so, how helpful do you think this has been? (n = 133)**

I am not a member	12.8%
Very helpful	44.4
Helps somewhat	16.5
Not very helpful	5.3
No response	21.0

### **Positive comments on SD Support Groups**

For those who were members, we then coded their responses to the question: What aspects of the SD Support Group have been most helpful?

<b>What aspects of SD Support Group Help?</b>	<b>Yes</b>	<b>No</b>
Knowing others have it	48.9%	5.7%
Support in dealing with SD	9.1	
Information provided	19.3	5.7
All of the above	9.1	1.1

*Knowing there are other people with the same disorder (I used to think I was the only person in the world). Being able to talk to people who have a real understanding. Seeing how supportive the partners are. (F, 41)*

*Knowing there is someone else with this problem – you are not alone. (F, 49)*

*Meeting others who speak the same way and understanding I am not alone. (M, 46)*

*Just knowing other people with the same problem, sharing coping strategies. One thing that has always stayed with me, a strange intuitive thing – our first meeting with the Support Group, I just had the feeling that we were all so similar, not only physically but in our makeup. All of us are either teachers, hospital workers, constantly being with the public, but have since discovered most of us have an artistic streak. (F, 53)*

*I used to write a Newsletter for a Support Group, Learned a lot from America and the UK. The response showed that it helped many other sufferers to understand and accept their problem. (F, 58)*

*Seeing common problems, realising I am luckier than some others there. (F, 55)*

*The literature and medical advice we get. (F, 56)*

*Talking to people who have a worse dose and who have been coping for years. (M, 54)*

*Just being able to talk to people with the same problem and realising I am not the only person in the world with this problem. (M, 57)*

*Since Botox, my life has returned to normal. I feel that I can give others good support, people less fortunate than me. (M, 67)*

*Meeting and not being embarrassed, to talk to people who are similarly affected. (M, 59)*

*The Newsletter from America, talking between ourselves. (F, 57)*

*Learning how others cope and what research is being done. (F, 76)*

*It's great to speak to these people, to hear them talk of the same feeling of despair I have had, all they have been through. I too have been there and done that. (F, 84)*

*See how other people cope, compare results after injections. They're all good company. (F, 73)*

*The friendships we have made, hearing if there are any great leaps forward. And I have a speech therapy session after it. But I find it very distressing if it coincides with the morning of the injections, which take a lot out of me with nerves, even though I take two Diazapan on the morning of the injection. (F, 76)*

*I am not a member but have the notes of each meeting sent to me, as with my husband's health, I find it impossible to get to these meetings. (F, 71)*

*It's great to talk to other people in the same boat. You all understand the hassles of having a voice problem. You can relax and talk freely, without worrying about your voice. If there are any developments in treatment, you can hear about them from the Support Group. (F, 27)*

*I've just started, but am very hopeful. Even the information implied in the questions on these pages has pointed out things to me. (F, 76)*

*I have only attended one meeting. It was interesting to see the latest video (on SD) and to meet other sufferers. (F, 49)*

*Regularity of meetings helps. Variety of speakers, input from all members, social events twice a year, and the head speech pathologist usually attends. (F, 55)*

*Meeting similar folk and accepting it is a recognised condition which can hopefully be researched for a better understanding and eventual cure. Helps to increase medical and community awareness. (M, 57)*

*Up-to-date reporting on research progress. (F, 63)*

*The personal contacts it has provided; the information provided has been fantastic as it is up to date. I never feel frightened or alone any more. (F, 44)*

*As I'm closely involved, it has helped me to overcome a lot of the frustration and sense of helplessness. (F, 74)*

*The first time I spoke to a fellow SD sufferer, I cried tears of joy because she was so understanding. I don't get so depressed now. Only problem is my distance from the group meeting place. (F, 33)*

*Sharing experiences with other members helps give me confidence and reassurance about the disorder. I feel less isolated. Makes me feel like I am not 'crazy' or a 'nervous wreck'. A lot of helpful and up-to-date scientific info. is disseminated through the group. (M, 47)*

### **Negative comments on SD Support Groups**

For the small number who made negative comments (21 in all, so the percentages refer only to this small number, not to the total sample of SD patients), we coded their responses as follows:

Has become too intellectual/not suitable to my needs	19.0%
Divorces you from normality/realty	19.0

Should provide more/reassure people they can cry together/offer more empathy	10.0
Location/time of meetings unsuitable	19.0
Need more structure to meetings (talks, formal Introduction, inviting medical experts to speak)	14.3
Other reasons not help	14.3

*The lady who runs the Support Group in (our State) fills the Newsletter with her personal health problems, with no relevance to Spasmodic Dysphonia. I would like any information you have about our condition. (F, 51)*

*I developed SD when I was in X Hospital. The Support Group meets in the hospital. I get stressed going back to that hospital. I also do not like the medical model approach. I object to feeling like a victim and meeting in a hospital. I would prefer the Support Group concentrated on wellness and in normal type surroundings. (F, 56)*

*Having had the condition for so long and having avoided contact with people over this long period, I find it still an ordeal to meet with people, even knowing they have the same problem. I think the group is very good for some, but having had to solve my own life problems since being a teenager, and never confiding in anyone about these matters, I suppose I have become detached from people. Even in my early days of marriage I found it difficult to 'open up' and discuss things. (M, 67)*

*It is good to know that someone cares. But unless someone can find a cure, I don't want to talk about it. After I've had my Botox injection and my voice becomes normal, I don't want to know anything about SD, I am a normal person again. So I don't want to talk about it. Even completing this questionnaire is uncomfortable for me. At the moment, SD does not exist for me, so I don't need support. (F, 55)*

*Not offering anything new. (F, 57)*

*I am a member of the Support Group in (State), but unable to attend any meetings, being too far away and meetings are always held at 6 p.m.. I get the Newsletters. If the time of meeting could be changed to midday (even sometimes), but considering my age I guess it would not be practicable for them. (F, 84)*

*I think they are a good thing, but there should be more leaning to some relaxation period that would unwind the patient, particularly if they have just had their injection. I hope to start a group with this in mind in the eastern suburbs, I can also refer people to the right help. (F, 76)*

*Access to information is good, and to remind me that I'm not alone. Unfortunately, I also feel guilty that I'm getting treatment and I'm so distressed, when many people are so much worse than me! (F, 30)*

*I don't like or need support groups. (F, 61)*

*One thing that truly frustrates me is the lack of knowledge of general practitioners on the subject of Spasmodic Dysphonia. I typed up a two-page newsletter giving as many details as I could, to send to every GP in (State). The (GPs organisation) was most unhelpful, wouldn't accept my article because I was not a doctor. The (State) branch of*

*the AMA informed me there were at least 4,500 GPs in this State and, since I financed the Newsletter myself, I couldn't afford the postage, so my bright idea came to an abrupt halt! (F, 58)*

*I don't like to think of myself as a 'patient', and think that to focus too much on my SD will make it too large a part of my life. (F, 48)*

*Basically, I don't need the support because I have access to health professionals easily and I understand the genesis of the problem. (M, 66)*

*I feel it has become too intellectual. Tea, sympathy and a good chat to compare injections, problems, humorous situations, etc. I feel would have been of more benefit to most of us. (F, 61)*

*One difficulty is that you sometimes feel your 'normality' back in the workplace has been suspended for the duration of the meeting. This is nobody's fault, just a psychological reaction. (M, 54)*

*I think people need to feel they can cry together and really express the emotional effects of this condition without feeling they are complaining or not coping. Empathy is all important, and a stiff upper lip approach is not helpful to many, I believe. (F, 54)*

*At first it was enormously helpful as far as emotional support, knowing that I am not alone. But it has also been a somewhat painful experience attending meetings and hearing the effortful speech of others, since it brings back memories of when my voice was at its worst and the anguish that this caused. I would like to see more medical specialists giving talks – and perhaps a structure where each person is more actively involved – a quick intro. by each person at the opening of the meeting, or perhaps a different topic each time. e.g. what is your most embarrassing moment with SD? or something like that, light and informal. Also, my group has very few younger people in attendance; at 31, I often feel a little incongruous – it would be nice to see more younger SD sufferers become involved. (F, 31)*

Clearly, many people benefit from meeting with others who understand their voice problem and from the additional information they receive on the likely causes and treatments of Spasmodic Dysphonia.

## **Conclusion**

Though some readers may be disappointed that the findings of this Survey reveal no significant differences between the SD patients and the comparison sample, it is hoped that the first-hand descriptions of the onset of SD, its (often faulty and delayed) diagnosis by medical professionals, and, in particular, of the social difficulties caused by the loss of voice – that most vital form of human communication – will be of assistance both to the sufferers of Spasmodic Dysphonia and to those professionals who are trying to treat them sympathetically.

It is important that people who have been properly diagnosed become active in publicising this condition, so that others still going through the agony of not knowing there is a physiological cause, still hiding their embarrassment and confusion, are given some hope. Botox injections may not be everyone's choice, but they clearly give relief – a sort of short-term miracle cure – to many SD sufferers. The medical profession is becoming more aware of Spasmodic Dysphonia and the research on genetic causes seems promising.

Whenever someone asks, 'What's wrong with your voice?' the answer should be, 'It's a spasm in the vocal cords called Spasmodic Dysphonia. It has no cure as yet, but injections can help and the research is starting to look promising.'

Good luck to all of you.

## **SD Contacts & Support Groups**

### **New South Wales                      Sydney**

St. Vincent's Hospital, Darlinghurst, NSW 2010  
Dr. Paul Darveniza, Neurologist - Tel: 02 9332 6739  
Dr. Ian Cole, Otolaryngologist – Tel: 02 9252 8168  
Helen Brake, Speech Pathologist – Tel: 02 8382 3372  
(Voice Clinics on alternate Mondays and Wednesdays)

Royal North Shore Hospital, St. Leonards, NSW 2065  
Mary Wagg, Speech Pathologist – Tel: 02 9926 7741

Support Group  
Cynthia Turner – Tel: 61 2 9411 2424 ([dennist@agsm.unsw.edu.au](mailto:dennist@agsm.unsw.edu.au))

Newcastle – John Hunter Hospital  
Dr. Jeff Blackie, Director Neurophysiology Dept.  
Tel: 0249 213 490

### **Queensland                      Brisbane**

Princess Alexandra Hospital, Ipswich Rd., Woolloongabba 4102  
Prof. Gerard McCafferty, Otolaryngologist – Tel: 07 3839 3940  
Dr. Rick Boyle, Neurophysician  
Kelli Hancock, Speech Pathologist – Tel: 07 3240 2314  
(for Voice Clinics alternative Thursdays and Botox appointments)

Support Group  
Contact Kelli Hancock at princess Alexandra, as above)

### **South Australia                      Adelaide**

Queen Elizabeth Hospital, 28 Woodville Rd., Woodville, SA 5011  
Mr. Neville Minnis, ENT Surgeon – Tel: 08 8272 4688  
Dr. Joseph Frasca, Neurologist – Tel: 08 8222 6431  
Johanna Flavell, Speech Pathologist – Tel: 08 8222 6723  
([johanna.flavell@nwahs.sa.gov.au](mailto:johanna.flavell@nwahs.sa.gov.au))

Support Group (See Sydney)

### **Victoria                      Melbourne**

Royal Victorian Eye and Ear Hospital, 13 Gisborne St., East Melbourne 3002  
Dr. Malcolm Baxter, ENT Surgeon – Tel: 03 9783 7511  
Dr. Andrew Hughes, Neurologist – Tel: Austin & Repatriation Medical Centre, 03  
9496 2845; or John Fawkner Hospital, 03 9383 2744

Jenni Oates, Speech Pathologist – Tel: 03 9479 1939  
Anne Yorston, Speech Pathologist – Tel: 03 9929 8223  
([ayorston@rveeh.vic.gov.au](mailto:ayorston@rveeh.vic.gov.au))

Support Group

Contact Anne Yorston, as above. Ask for their pamphlet on SD)

**Western Australia**

**Perth**

Royal Perth Hospital, PO Box X2213, Perth WA 6001  
Dr. John Dunne, Neurologist – Tel: 08 9224 2593  
Melita Brown, Speech Pathologist – Tel: 08 9224 2197/1097

Support Group

Helen Sjardin ([hsjardin@smartchat.net.au](mailto:hsjardin@smartchat.net.au))

**Tasmania**

Royal Hobart Hospital, GPO Box 623, Tasmania 7001  
Marjorie Conroy, Speech Pathology Dept.

Support Group

Tricia Brown, 96 Molle St., West Hobart, Tasmania 7000  
Tel: 03 6331 1266 or Mobile 0411 696 213  
([madiarare@tassie.net.au](mailto:madiarare@tassie.net.au))

**New Zealand**

Support Group

David Barton, 15 Pluto Place, North Shore City, NZ 1310  
Tel: 64 9482 1567

David runs an On-Line Dystonia Support service - [dsbarton@ihug.co.nz](mailto:dsbarton@ihug.co.nz) - and is conducting a similar study on Spasmodic Dystonia.

**Other useful sources of information:**

USA – National Spasmodic Dysphonia Association – has a Newsletter and runs national symposiums and conferences.

NSDA, 1 East Wacker Drive, Suite 2430, Chicago, Illinois 60601-1905. Tel:  
800-795-6732. Fax: 312 803 0138  
([dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org))

Several publications are available through their catalogue:

*Questions & Answers About Dystonia* (DMRF)  
*Dystonia: the Disease that Distorts*, by Eugene Smith  
*Thank You for Asking*, by Valerie F. Levitan

*Holding the Hope, A Parents' Guide to Living With Dystonia*, by Karen K. Ross  
*Dystonia is ... A Personal Poem*, by Beka Serdans  
*8 to 18: A Guidebook for Young People*, by Meryl Kasden  
*Annie's Book*, by Emily Blum

In the USA, a national 'Dystonia Awareness Week' is held (October 12-19 in 1999, for example) and a major study is being conducted by Lisa Orloff University of California in San Diego, entitled: *Laryngeal Dystonia: Economic and Functional Outcomes*.

Other SD Resource Pages on the www include:

Wake Forest Voice Center ([www.bgsm.edu/voice](http://www.bgsm.edu/voice))

National Center for Voice and Speech ([http://forte.shc.uiowa.edu/ncvs\\_home.html](http://forte.shc.uiowa.edu/ncvs_home.html))

American Speech, Language and Hearing Association (ASHA) ([www.asha.org](http://www.asha.org))

Pacific Voice & Speech Association ([www.pvsf.org](http://www.pvsf.org))