SPASMODIC DYSPHONIA

Information guide for HEALTHCARE PROFESSIONALS

PUBLISHER:

AESDE

Spanish Association of Spasmodic Dysphonia

IN COLLABORATION WITH

Diputación de Cádiz

SPASMODIC DYSPHONIA – INFORMATION GUIDE FOR HEALTHCARE PROFESSIONALS

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IN COLLABORATION WITH:

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subscripcion@visionnet.es

CONTENTS

Authors:

Encarnación Ávalos Serrano
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

María Guadalupe Álvarez-Morujo de Sande
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Andrés Caballero García
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Encarnación Caballero Mateos
President of AESDE

Elvira Cabuchola Fajardo
Medical resident (MIR) at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Ignacio Cobeta Marcos
Chair of Otolaryngology. Universidad de Alcalá. Head of the ENT Department. Hospital Universitario Ramón y Cajal (Madrid, Spain).

Miguel de Mier Morales
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

María Ángeles Dorantes Bellido
Speech therapist. Hospital Universitario Puerta del Mar (Cádiz, Spain).

Raúl Espinosa Rosso;
Specialist at Neurology Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Juan Pedro Fernández de los Ríos
Puerto Sur Medical Centre, El Puerto de Santa María (Cádiz, Spain).

Francisco Javier Fernández Machín
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Lucía Forero Díaz.
Specialist at Neurology Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

María Dolores García Cantos
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Lucía González Caballero
Psychologist

Fiorella Lipari Sebastiani
Medical resident (MIR) at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Ingrid Márquez Estefenn
Medical resident (MIR) at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Antonio J. Martín Mateos
Head of ENT Department at Hospital Universitario Puerta del Mar (Cádiz, Spain).

Emilio Martínez Gutiérrez
Specialist at ENT Department of Hospital Universitario Puerta del Mar (Cádiz, Spain).

Elena Mora Rivas
Specialist at ENT Department of Hospital Universitario Ramón y Cajal (Madrid, Spain).

Marta Rodríguez Cañas de los Reyes
Specialist at Rehabilitation Department. Phoniatrics. Hospital Universitario Puerta del Mar (Cádiz, Spain).

FORWARD

I would like to express how necessary it was to publish this guide, and also how important it is to disseminate it — both to professionals and to those patients already diagnosed with spasmodic dysphonia or about to receive their first botulinum toxin injection. In doing so, I am echoing what Ms. Encarnación Caballero, President of the Spanish Association of Spasmodic Dysphonia (Asociación Española de Disfonía Espasmódica - AESDE) enthusiastically points out in the introduction, and indeed what she has been practising for years. The activity of AESDE patients serves as encouragement for all the professionals treating this disorder.

This guide should be broadly disseminated because we still often see patients coming to our consulting rooms many years after either being diagnosed with a psychological disorder — as spasms frequency happen to increase when patients are nervous — or being told that there is no cure for their disorder. Spasmodic dysphonia is an organic disease. Although its origin remains unknown, there is a reasonably effective treatment for it. The injection of botulinum toxin into the vocal cords is nowadays considered to be the reference treatment, and it is aimed at triggering transitory denervation so as to prevent the spasms which often so mortify patients. In addition to this method, there are other treatments, such as surgery, which, despite having been discontinued some years ago, has now reappeared with the onset of new and more effective surgical techniques.

The diffusion of this guide among patients is also necessary to show them that they are not alone, and that there are cross-disciplinary teams of healthcare professionals (neurologists, otolaryngologists (ENTs), speech-and voice therapists, psychologists, social workers, and so on) working together to help them cope with an illness that has made them feel disabled; to let them know they are not alone. It may also be useful to help healthcare authorities to understand the scale of the problem and provide the resources needed to make it more widely known, improve its diagnosis and make treatment easier.

The way spasmodic dysphonia patients speak (spasms when talking with irregular tension in the larynx sometimes makes speech unintelligible) is so characteristic, that this disease could even be diagnosed with a high degree of certainty over the phone, just by

listening to the patient talking. Admittedly, to be completely sure, diagnosis must be confirmed by means of various other tests, which are clearly explained in this guide. Exaggerated though it may sound, this direct diagnosis method actually works. In fact, on several occasions I have confirmed diagnoses made by colleagues who had recommended the botulinum toxin injection to treat patients after hearing them speaking on the phone. In those cases, I told the patients that a first injection may be used as a very effective diagnostic test: if symptoms improve, we can be sure that it is indeed spasmodic dysphonia, but if they don't, they are probably suffering from a different disorder.

At present, this disorder is considered to be a cervical-facial dystonia, with other well-known kinds of dystonia being blepharospasm (eyelid muscles spasm) or neck dystonia (sternocleidomastoid muscle spasm, causing the neck to twitch). All these symptoms may just be the expression of a still unknown central nervous system disorder located in the basal ganglia, affected by abnormal proteins produced by genes belonging to the DTY group. Until these mechanisms are better understood, and we may act on them — and we are still some way from that — the botulinum toxin injection will continue to be the main treatment and, therefore, ENT specialists and neurologists must keep offering it two or three times a year, as explained in this guide. It is also interesting to note that, according to spasmodic dysphonia records, only in 10% of cases is there a family history of the disorder, that Europeans are the group in which it is most prevalent, and that is scarcely found in Asia and practically unknown in Japan. Its frequency in women is five times higher than in men. It usually starts in the 40s age range. Interestingly, for the purposes of diagnosis it should be noted that spasms rarely occur when patients shout, cry, sing or whisper, but become more evident when they talk on the phone.

With these few lines my intention has been, on the one hand, to highlight the magnificent work of the AESDE and the outstanding professionals involved in preparing this guide (the extraordinary Spasmodic Dysphonia team at Hospital Puerta del Mar, in Cádiz) and, on the other hand, to show patients our commitment to preventing them from feeling alone, helpless or abandoned and let them know that we are at their disposal, particularly for surgical treatment in Madrid, at the ENT Department at Hospital Universitario Ramón y Cajal.

Prof. Ignacio Cobeta
Chair of Otolaryngology. Universidad de Alcalá.
Head of the ENT Department at Hospital Universitario Ramón y Cajal, Madrid

e-mail: ignacio.cobeta@salud.madrid.org

Chapter 1. Reasons for this Guide Patients' needs. AESDE Ms. Encarnación Caballero. President of AESDE.

Ms. Encarnación Caballero. President of AESDE. Ms. Lucía Gónzález. Psychologist.

Reasons for our two guides (Guide for Patients and Guide for Professionals)

Spasmodic dysphonia is a disorder that remains barely known, not just to society in general but also to quite a number of professionals. This leads to delays in diagnosis and adds to the suffering of people afflicted with SD who do not yet know they have it.

After the excellent results of the first edition and the great job done in disseminating it, AESDE decided to update it according to the latest scientific advances on the condition, and to add another, more technical guide aimed at healthcare professionals, hoping to reach to both groups in a clear and understandable way.

This new edition includes a section entitled "Spasmodic Dysphonia from a Psychological Standpoint", an excellent contribution by the psychologist Lucía González Caballero, who kindly joined us as a voluntary collaborator this time around.

These two guides are intended to be one tool among others to overcome the lack of information, help reduce time to diagnosis and generally make life easier to people suffering from this disorder. The idea is to help those who are being treated, not only from a medical point of view, but also from a social perspective. In other words, we hope to reduce the anguish, fear and insecurity that SD causes among its sufferers. Sharing their experiences with other patients is also a part of the psychological therapy they need. Consequently,

these guides include information about the medical and associative resources already available for patients.

These two guides are the first publications in Spanish including both scientific and informative contents about spasmodic dysphonia, addressed to patients and professionals.

Patients' needs.

The most urgent needs for people who suffer this disorder are the following:

- To know what is wrong. Even today, five thousand people are estimated to be suffering from this condition in Spain alone, but most of them have not yet been diagnosed.
- To contact with other patients in order to share experiences and ease their fears and suffering.
- To receive palliative treatments or improve the techniques, drugs and instruments for those who are already being treated.
- More scientific research is needed to improve SD treatments.
- To raise awareness of this disorder among all the professionals in all echelons of Spain's National Health System, for speedier diagnosis, enabling patients to start their treatments without delay.

Spanish Association of Spasmodic Dysphonia — Asociación Española de Disfonía Espasmódica (AESDE): Life experiences and needs

AESDE was founded in El Puerto de Santa María (Cádiz) in September 2005. A group of SD patients in the province of Cádiz decided to help each other and raise awareness among medical professionals and society at large regarding the disorder itself and its treatment. Until then, all of them had experienced the uncertainty and anguish of having a problem that had not been clearly diagnosed, adding to the suffering caused by their losing their voice and ability to communicate.

The members of the association agreed to try to prevent other people from having to go through the same, terrible experience they themselves had endured. That is why one of their first goals was to make this disorder more widely known, through mass media campaigns, by giving speeches and talks in primary medical centres and hospitals, and by participating in seminars and congresses about rare diseases.

The association began operating in the province of Cádiz. Although most of our activity still focuses on this area, we now have members from many different parts of Spain. AESDE belongs to the Spanish Federation of Rare Diseases — Federación Española de Enfermedades Raras (FEDER), an organization that groups together associations representing sufferers of low prevalence diseases from all over the country.

AESDE is always willing to assist, inform and help as far as possible all those people suffering from voice problems who do not yet know what is wrong. Head office address: calle Pedro Muñoz Seca, 9 - El Puerto de Santa María (Cádiz, Spain). Contact telephones: (34) 600 651 062 or (34) 956 857 562 e-mail: asociacióndisfoniaespasmodica.org, website: www.disfoniaespasmodica.org

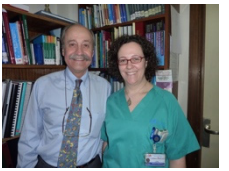
In our head office people affected by this disorder are given information not only about the disease itself but also about the existing treatments, particularly the one offered by the Spasmodic Dysphonia Unit at the ENT Department of both Hospital Puerta del Mar (Cádiz) — which is the reference unit for Andalusia — and Hospital Ramón y Cajal (Madrid). In our office we also provide telephone information services, accompany sufferers to the Spasmodic Dysphonia Unit in the aforementioned hospital in Cádiz for their first visit, and put the new patients in contact with veteran members of the association with whom they may share experiences. Our psychologist, Lucía González Caballero, gives the patients advice on how to cope with everyday life problems. We also organize speech therapy workshops, provide information about scientific advances made in connection with SD, and organize retreats with members, self-confidence and laugh-therapy workshops, and all those activities which may help improve the quality of life of both patients and their families.

The Association respects the privacy of all persons in contact with, regardless of whether or not they are members, carefully keeps any

information received in the strictest confidence and guarantees its confidentiality.

The Association requires the help of public bodies and private entities to expand its work and be able to offer a better service to both patients and their families. We encourage anyone who may want to help to get in touch, whether you would like to offer financial support as a collaborating member, or as a volunteer of professional services in areas such as IT, speech therapy, social work, physiology or psychology. This guide is intended to provide sufferers with the tools they need to cope with the difficulties caused by SD.

We still have a long way to go until patients can benefit from the policies we are calling for, but this is a hopeful and encouraging beginning which will help improve the quality of life and degree of integration of those who are now suffering from this disorder.



Chapter 2. An Approach to Spasmodic Dysphonia

Dr. Ignacio Cobeta; Dr. Elena Mora

ENT Department. Voice and Functional Larynx Unit. Hospital Universitario Ramón y Cajal. Madrid.

Introduction

Spasmodic Dysphonia has been somewhat stigmatized, as, for a long time, it was considered to have a psychological or sometimes even psychosomatic basis. In any event, it was thought to be caused by an alteration of the personality that was only treatable through psychotherapy. The fact that speech disorders worsen when the patient encounters stressful situations may prevent people from seeing beyond that limited perspective and mistake it for a non-neurological disorder.

It was Robe who, in 1960, first linked spasmodic dysphonia to neurological disorders. He reported some cases of patients suffering not only from SD, but also from other kinds of neurological disorder. A decade later, in 1970, high-speed video laryngoscopy allowed specialists to see that, during speech, the larynx presented small, involuntary muscle contractions, in some cases of the thyroarytenoid, and in some other cases of the posterior cricoarytenoid. This led to the classical division between adductor spasmodic dysphonia (90% of cases) and abductor spasmodic dysphonia (10% of cases). In 1976, spasmodic dysphonia was definitively confirmed as neurological disorder when 34 patients' spasms were successfully treated through recurrent laryngeal nerve section, though their final voice quality was still weak and breathy.

Spasmodic dysphonia is a focal dystonia characterized by involuntary dysrhythmic contractions of the muscles controlling the movement of the vocal cords, altering patients' speech rhythm and their ability to communicate. Patients need to make great breathing efforts, in jumps, to overcome the larynx resistance and generate sufficient air; it is as if

the voice “gets stuck”. This sort of laryngeal dystonia may be associated with other kinds of dystonia in different body areas, mainly in the head and neck. Spasmodic dysphonia occurs when patients are speaking, but not when they are singing or laughing, at least in cases that are not very severe and during the first years of the disorder. This particularity is very helpful for diagnosis. It takes a long time for the patients to be diagnosed because SD is more often linked to a functional or psychiatric disorder than to an organic problem. Diagnosis is mainly based on clinical signs. Spasmodic Dysphonia is a progressive disorder: the initial symptoms are usually mild and linked to emotional stress situations, but over time, both their frequency and intensity gradually increase. It occurs more frequently in women, with a 4:1 female to male ratio. The fibre-optic endoscopy examination does not show any structural lesions in the larynx, but a severe hyperphonation.

Treatment

Although there had been some previous publications about the effect of botulinum toxin (Botox) injection into the thyroarytenoid muscle in spasmodic dysphonia cases, in 1994 Blitzer published several works on the short- and long-term effect of botulinum toxin injection in patients with SD. In the last 20 years, many published works have evidenced the benefits of Botox in treating this disorder, on many different voice parameters (acoustic, aerodynamic and subjective evaluation parameters). The main improvement refers to continuous speech fluency, as there is a decrease in the frequency with which a voice “breaks up” or “gets stuck”. Acoustic analyses also show a notable improvement: a reduction in jitter, shimmer and harmonics-to-noise ratio (HNR), with no variations in fundamental frequency. Other significant improvements after the Botox injection are an increase in reading speed and greater control of voice volume.

To date there is no definitive treatment for spasmodic dysphonia, though since 1987 we have had quite an effective way to control it through successive injections of botulinum toxin into the vocal cords. Once suspected and then diagnosed, the problem is how to reach the vocal cords to inject the toxin. The dose has changed over the course of the years: initially, 15-20 u. were used, but nowadays much smaller doses (3-5u.) have proved to be as effective in controlling the symptoms, with the added benefit of producing fewer side-effects. The

kind of toxin injected is lyophilized botulinum toxin Type A (Botox®). It is important to mention that the benefits obtained through infiltrating only one of the vocal cords are very similar to the ones obtained through injecting both cords.

There are several botulinum toxin injection methods: all of them have advantages and disadvantages.

- EMG-guided botulinum toxin injection: This technique requires mastering larynx EMG exploration and having the necessary equipment. It is mainly performed by neurologists.
- Peroral injection through indirect laryngoscopy: This technique pertains to the realm of ENT. It is performed under local anaesthesia. The vocal cords can be seen on a mirror, though in some cases a fibre-optic endoscope or a video laryngoscope may be also used. It is performed with a curve needle previously filled with toxin. This technique can usually be performed by one practitioner. Its main advantage is that the needle can be easily guided straight to the thyroarytenoid muscle areas that need to be injected and it can also reach the lateral cricoarytenoid muscle. Sometimes, when there is hypertrophy in the muscle bands, access to the cords can be difficult.
- Injection through fibre-optic endoscope with working channel: this technique also pertains to the ENT department. It is performed under local anaesthesia and a mild sedation ((Valium + Atropine). It requires two people, and some quite sophisticated equipment (a video camera with a screen and a fibre-optic endoscope with a working channel through which we introduce the infiltration needle). These needles are provided by the usual endoscopy suppliers. This technique may differ considerably from one patient to another: if they don't swallow, it is quite simple. This technique requires two people and cannot be performed if there is hypertrophy in the muscle bands. Another disadvantage is that there is a tendency to infiltrate more the anterior area as the precise point of injection is not totally controlled.

- Infiltration of the posterior cricoarytenoid muscle in cases of adductor spasmodic dysphonia. This technique is performed in the consulting room with a single channel surface electromyogram. We turn the patient's neck slightly away from the

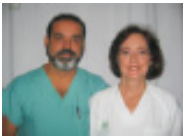
injection area (infiltration can only be done on one side). With one hand we try to turn the larynx so as to expose its posterior section as much as possible and, with the other hand, we inject the neck just in front of the major blood vessels until we locate the cricoarytenoid muscle with the aid of the EMG.

The best results in terms of symptom-free interval are obtained through the bilateral injection on a medium, deep and lateral area of the thyroarytenoid muscle also diffusing through the lateral cricoarytenoid muscle. This technique usually results in a 4-5-month spasm-free interval after the first 24-48 hours. It may produce side-effects such as voice weakness, a breathy voice and mild dysphagia for 7-10 days. When the results are either acceptable or good, patients look forward to having a new injection soon.

Surgery has also been tried so as to reduce the need of repeated injections and advocates of surgery also cite the somewhat random results of the infiltration techniques. To be honest, surgical techniques also have a transitory effect, albeit a much longer-lasting one (about 3 years). The surgical techniques used include:

- Type II Isshiki thyroplasty, which consists of making an incision and vertical section of both sides of the thyroid cartilage and, overlapping the lines of incision, separating the midline vocal cords in order to reduce the contraction effect.
- Myechtomy of thyroarytenoid muscle, a technique usually performed on one side through laser larynx microsurgery and under general anaesthesia. It consists of making a very lateral incision on the epithelium of the superficial side of the vocal cord, above the thyroarytenoid muscle and sectioning or vaporizing some muscular fibres, at no time medial to the vocal ligament.
- Fulguration of the recurrent nerve branch that innerves the thyroarytenoid muscle. This is an approximation technique. As the nerve branch cannot be seen, the surgery remains somewhat uncertain. This larynx microsurgery is done under general anaesthesia. A monopolar electrode is introduced in the area which is lateral to the vocal apophysis at about one centimetre, using punctual coagulation.
- Neurectomy of the recurrent nerve branch that innerves the thyroarytenoid muscle. This technique is performed under general anaesthesia and reaching the thyroid cartilage through a cervical

incision similar to the one performed in Type I thyroplasty. A window is made in the cartilage and the nerve branch is approached through the space between the thyroarytenoid and lateral cricoarytenoid muscles. This procedure yields good results, though its effects decrease partially over time. It is a technically complex procedure.



Chapter 3. Definition, Types and Symptoms of Spasmodic Dysphonia

Dr. Encarnación Ávalos; Dr. Miguel de Mier; Dr. Antonio J. Martín

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

Spasmodic dysphonia is a dystonia

Spasmodic dysphonia belongs to a group of neurological disorders collectively known as dystonia. The term defines a wide variety of disorders causing excessive muscle contraction (spasms) and associated with abnormal movements and postures. Dystonia may be general (affecting the whole body) or focal (affecting a specific part of the body). Spasmodic dysphonia is a focal dystonia.

Other types of focal dystonia include blepharospasm (affecting eyelids), oromandibular dystonia (jaws and tongue), cervical dystonia or spasmodic torticollis (neck) and writer's cramp (hand). These types of dystonia may sometimes be associated with spasmodic dysphonia.

Dystonia disorders are thought to be originated in a brain area called the basal ganglia, involved in muscle movement coordination all over the body.

Spasmodic dysphonia is a neurological disease affecting the voice and manifesting through involuntary "spasms" of the muscles in charge of vocal cord control.

Patients' speech is interrupted, and their voice quality is affected. It is a rare and chronic voice disorder.

Types of spasmodic dysphonia

There are two classical kinds of spasmodic dysphonia: adductor spasmodic dysphonia and abductor spasmodic dysphonia.

In Adductor spasmodic dysphonia muscle spasms cause the vocal folds to slam together (hyperadduction) while speaking. This is the most common type, affecting 80-90% of spasmodic dysphonia patients.

In Abductor spasmodic dysphonia muscle spasms causes the vocal cords to move apart (abduction). This rarer type of spasmodic dysphonia affects about 10-20% of patients.

A combination of the two disorders may occur in the same patient, presenting both adductor and adductor spasms.

Spasmodic dysphonia may also occur with voice tremor which may occasionally be very severe.

Spasmodic dysphonia symptoms

In adductor spasmodic dysphonia, which is the most common type, when patients try to speak, the movement of vocal cords is strained and tense, producing a voice which sounds shaky, trembling, hoarse, tight or faltering. Some spasms or speech interruptions may result in periods with a total lack of sound (aphonia) and periods where voice sounds practically normal.

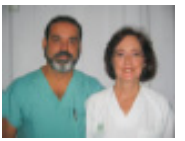
In patients suffering from abductor spasmodic dysphonia, the voice sounds whispery or hushed. The other larynx functions such as breathing or swallowing remain normal.

The first symptoms of spasmodic dysphonia appear more frequently in people aged 30-50. Women are more often affected than men, at a ratio of 4 or 5-to-1. In up to 10% of cases, there may be a family history of dystonia.

Initially, symptoms may be moderate and show up just occasionally; but over time both the severity and frequency of symptoms may increase before eventually stabilizing. Although symptoms sometimes get worse when the person is tired or tense, they may also improve — and even disappear — when patients laugh or sing. The severity of the spasms and the disabling nature of this disorder fluctuate (sometimes decreasing for hours or even days at a time) and vary from one patient to another.

In very severe cases, the patient needs to make such a considerable effort to speak that talking actually becomes a struggle.

Some spasmodic dysphonia patients may also present a related tremor which makes their voice “shaky" or "tremulous”. This disorder is sometimes confirmed by the symptomatic improvement occurring after injection with botulinum toxin.



Chapter 4. When Should Spasmodic Dysphonia be Suspected?

Dr. Encarnación Ávalos; Dr. Miguel de Mier; Dr. M. Dolores García.

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

The voice of a patient with spasmodic dysphonia is so characteristic that its diagnosis may be suspected just by listening to the patient speaking. A series of tests are then performed to confirm this suspicion. To hear some of these voices, visit the AESDE website: http://www.disfoniaespasmodica.org

There is no simple test to confirm spasmodic dysphonia. Diagnosis is based on the presence of its typical characteristics and symptoms reported by the patients and on the absence of those other conditions that might cause similar problems.

The absence of a conclusive test makes spasmodic dysphonia one of the speech disorders which is more frequently misdiagnosed.

Diagnosis is reached after taking a detailed personal clinical history in a warm and gentle atmosphere where patients feel comfortable enough to share all the necessary information (allergies or digestive problems, neurological disorders, surgical or medical treatments as well as ear, breathing or postural problems, etc.). We also evaluate not only patients' general working conditions, but also some more specific aspects such as the use of voice and the time spent speaking at work.

Our aim is to help patients feel free to speak calmly and confidently about their speech problem and the way they perceive it: when and how it started, how long they have been aware of it, factors that make it worse or better, treatments followed and how they worked.

The patients have their voice recorded, usually in conversational, reading and projected voice scenarios. They are then asked to listen to themselves and give an opinion on their own speech.

Patients are asked to take a test (Voice Handicap Inventory/Index – VHI), used as a tool to assess the quality of life related to speech disorders. They are asked to score a series of statements intended to describe their voice and the effects of its alterations on their everyday life, from 0 to 4 on the basis of how far they identify with the statements. There are 30 statements in 3 groups of 10, referring to functional, physical and emotional aspects.

Physical examination starts with a flexible fibre-optic nasopharyngoscopy aiming to evaluate the patients' anatomy concerning both nostrils, the cavum, the soft palate, the root of the tongue, the shape of the epiglottis and the whole voice box. This exploration has a dual purpose: on one hand, it is a basic ENT exploration and, on the other hand, it gives information about the patients' anatomy so that, if spasmodic dysphonia is diagnosed, we would know by then whether there is an anatomical difficulty and we could then tell the patient which nostril would be more adequate for a future treatment with botulinum toxin. This is usually an innocuous exploration and patients tolerate it very well.

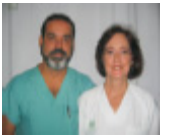
The next examination we perform is a videostroboscopy, introducing either a rigid or flexible laryngoscope through the nose. The purpose of this exploration is to observe the vocal cords in movement during phonation. Sometimes it is possible to see the larynx spasms which are so characteristic in this kind of patients.

Despite all these tests, sometimes it is not possible to reach a definitive diagnosis. Patients are informed that we strongly suspect they have SD, and that this would only be confirmed by the results of injecting botulinum toxin into the vocal cords: if symptoms improve, the diagnosis is correct. In specialized centres where professionals are familiarized with this pathology, there are very few cases of doubtful final diagnosis.

Once the diagnosis is confirmed, patients are informed about their disorder and their options. If they accept the treatment, they are given an informed consent form for the procedure to be used, where both the technique itself and any potential adverse effects of process are explained. Patients are given the chance to have their doubts clarified before signing the consent form.

The best way to evaluate the problem is through a group of professionals working together as a team, including:

- a speech pathologist and a speech therapist to evaluate the patient's voice production and pitch,
- an ENT specialist to explore the vocal cords' structure, function and movement, and
- a neurologist to detect neurological disorder symptoms



Chapter 5: Treatment of Spasmodic Dysphonia

Dr. Miguel de Mier; Dr. Encarnación Ávalos; Dr. Ingrid Márquez

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

Currently there is no cure for spasmodic dysphonia, but there are treatments available to control its symptoms.

Nowadays, the treatment of choice is to inject botulinum toxin into the vocal cords. This is palliative treatment that works for a limited time, so it is not a cure, but it does alleviate the symptoms (larynx spasms) for some time (4-5 months on average). After this period, another injection is necessary. New experimental techniques are also now being used (radiofrequency, super-selective surgery of the laryngeal nerve) which will probably improve on the results achieved so far with botulinum toxin.

Botulinum toxin injection

Here we explain how the intracordal injection of botulinum toxin is performed, as it is the most common and scientifically supported procedure: There are several techniques. All of them are listed, but only the one that our patients find most comfortable and fast is described in more detail.

- Transcutaneous infiltration
- Infiltration by direct laryngoscopy under general anaesthesia.
- Infiltration by indirect laryngoscopy under local anaesthesia.
- Infiltration by flexible fibre-optic nasolaryngoscopy with working channel.

The technique performed in our Unit is the flexible fibre-optic nasolaryngoscopy with working channel under local anaesthesia.

Details of our technique:

We recommend our patients take 1.5 - 3 mg of a Bromazepam-like anxiolytic by mouth both the evening before at home and one hour before the treatment. About half an hour before being treated, the patient will receive an injection of Atropine (0,1mg./10 Kg. weight) in order to reduce salivary secretion and make the procedure easier. Some patients have reported a feeling of dryness in the mouth, which is absolutely normal.

15-20 minutes before the procedure, the patient will be given local anaesthesia by introducing several swabs coated with Lidocaine in the chosen nostril (the one we informed the patient during the diagnosis to be the most suitable).

Patients are in a sitting position with their head comfortably supported and tilted slightly backwards. A flexible fibre-optic laryngoscope is gently introduced through the chosen nostril. Lidocaine 5% is administered through the working channel into the root of the tongue, epiglottis and the surface of both vocal cords. The patients feel the liquid fall into their throat, reporting that this is the worst part of the whole procedure. This phase usually lasts less than a minute, since the effect of the local anaesthetic is almost instantaneous. Once verified that the cough accesses have disappeared and that there is no reflex, i.e. that the surface of the vocal cords do not show any reflex when touched with the fibre-optic endoscope and once confirmed by the patient, who can at any time communicate with the professionals, the needle is introduced through the working channel into the middle third of both vocal cords. Some patients report that they feel the puncture, but no pain at all. This technique usually takes about 5 minutes.

Patients remains sitting for about 30 minutes. No food or drink is allowed for at least one hour. Before leaving, and attached to their discharge report, patients are given a number of safety measures and precautions to be followed as explained below in this guide.

Duration of the effects and check-up

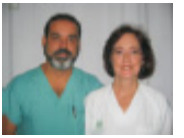
As always, all good things come to an end: depending on the patient, the effect of the treatment may last for up to 5-7 months, although it has been observed that after successive injections, the effect can last for up to one year in some cases.

The first check-up is held one month after the injection. Patients often ask interesting questions or express unexpected feelings, such as: “Can I talk as much as I want?”, “This year I'm going for it at the local fair!” or “I'm paying a fortune for mobile phone calls!” These are incredible milestones for people who had not been able to communicate fluently for up to five years and, worse than that, had lost all hope of ever communicating easily again.

Once again, we are surprised at how the latest technological advances and new therapeutic applications help us improve our patients’ quality of life.

Summary

This technique doesn't require either a hospital stay or general anaesthesia. We introduce a flexible fibre-optic nasolaryngoscope through a working channel. A very small dose of a substance called “botulinum toxin” is injected (that’s right, the same stuff that is used to remove age wrinkles. It has other clinical applications), and patients return home feeling no pain or discomfort at all. During the first week, and depending on each person, patients often have a rather breathy voice which gradually returns to normal.



Chapter 6. Spasmodic Dysphonia at the Andalusian Health Authority's Dysphonia Service.

Dr. Miguel de Mier; Dr. Encarnación Ávalos; Dr. Fiorella Lipari.

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

Introduction

One of the strategic lines established in the Andalusian Regional Government's Quality and Efficiency Plan is the implementation of a project called Management by Health Service Processes in which the Process for Dysphonia (the one this guide is about) is included.

The goals of the Andalusian Public Health System when broaching health service processes in a comprehensive way are as follows:

- To guarantee continuity of service.
- To adapt the departments' functional structure to citizens' needs and requirements.
- To link the work of professionals to the ultimate goal, sharing risks and results.
- To place resources in the most appropriate location.

Process management methodology boosts efficiency by optimizing the coordination between departments and units, engaging professionals in the achievement of targets, eliminating delays or unnecessary expenses, and encouraging a global vision of patients, which will increase their levels of satisfaction.

We are aware of the difficulty which implementing any health service process, and ours in particular, may entail, but we are also convinced of the need and advisability of making an effort to put them into practice, with the aim of:

- Rationalizing the healthcare provided to patients suffering from dysphonia at the Andalusian Public Health Service.

- Organizing healthcare provided to dysphonia patients at the Andalusian Public Health Service, establishing quality parameters concerning patients' referral, waiting and treatment times, guaranteeing the continuity of the healthcare process in all levels of the system.

Spasmodic dysphonia is included in the dysphonia healthcare process, and it is treated at specialized centres by injecting the botulinum toxin into the patient's vocal cords.

The healthcare process at the Voice Unit of the ENT Department of Hospital Universitario Puerta del Mar.

The Health Department recently designated Voice Unit of our hospital as the Reference Unit for spasmodic dysphonia. For more than 11 years, a great number of patients suffering from this disorder — not only from Andalusia but also from other regions — have been treated in our Unit.

Due to the fact that this disorder requires regular treatment (every 6 months on average at the Unit), we have gradually acquired more than just a simple doctor/patient relationship with those affected, sharing with them all their joys and sorrows in parallel with their condition.

Thank to this trust, patients have felt free to suggest ways to improve their healthcare and quality of life which have been used to keep adapting the diagnosis and treatment circuit. To ensure our patients' comfort when they come to receive treatment, we make a room available to them where they can meet other members of the association. We also make appointment times as flexible as possible, considering the distance between their homes and the hospital, and we have introduced other improvements aimed at increasing their well-being.

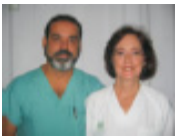
The personal commitment of the President of AESDE has been a source of encouragement for all of us at the Unit in introducing these improvements and seeking solutions to the problems identified by our patients.

We think it is worth updating this edition of our guide with some of the data compiled over the course of these 11 years of work. From the

outset, our goals have been to achieve an accurate diagnosis of the disorder, to obtain a 100% response to treatment and to tailor the best individual dose to each patient. Over the years, we have also managed to reduce the duration of the adverse effects (breathy voice and difficulty swallowing liquids) to the point of eliminating them.

Neurologists from the various provinces of the region of Andalusia tend to be the specialists who suspect the presence of SD and refer the patients to the ENT Department. But thanks to the work done by the Association, the number of GPs who first suspect the illness and refer the patients to the Department is gradually increasing.

A few months ago, the Department developed an application together with Hospital Ramón y Cajal and Hospital Central de Asturias, called "Take care of your voice", available on the Play Store, where samples of the typical voice of patients suffering from Adductor Spasmodic Dysphonia can be heard. We believe that this tool could help improve diagnosis, reducing the delay in treating these patients.



Chapter 7. Care Procedures for Spasmodic Dysphonia Patients at the Voice Unit of the ENT Department

Dr. Miguel de Mier; Dr. Encarnación Ávalos; Dr. Antonio J. Martín.

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

Purpose

Single-visit care for patients affected by spasmodic dysphonia.

Fundamentals

- Currently, the botulinum toxin injection seems to be the most efficient treatment of spasmodic dysphonia.
- This technique may be performed by infiltration under endoscopy and local anaesthesia and does not require hospitalization.
- The patients come from different areas all around the region, so both examination and injection times must be adapted to enable them to come to the hospital, be treated and return home the same day.

Scope of application

Functional Voice Pathology Unit of the ENT Department

Appointments

First visit:

Patients suspected of suffering from spasmodic dysphonia and referred from Central Services or from other centres via the Citizen service Centre will be contacted by phone by the Department

secretary in order to arrange an appointment for a morning consultation. Patients are informed that they will be given a preliminary examination and, if appropriate, they can have the treatment done the same day.

Patients belonging to the same health area follow the same procedure.

Follow-up visits:

For follow-up consultations, the patients will contact the professionals by whom they were first treated to arrange an appointment in relation to their symptoms. That is why it is essential that the patient and the doctor programme the check-up session together.

Reception:

New patients:

New patients go straight to the voice pathology consultation. If they need an injection, they are then referred to the Admissions Service to attend the Surgery Day Hospital of the ENT Department, located on the sixth floor. These patients are given the chance to contact AESDE on the same day at the Department Information Room, which is adapted every Friday for use by these patients. There they can get personalized information from members of AESDE staff. Several informative brochures about both the disorder and the association are available. Many of these patients have often previously contacted AESDE, enabling them to be accompanied throughout the process.

Re-injections:

Patients go to the Admissions Service to be admitted to the Surgery Day Hospital of the ENT Department, on the sixth floor. They may wait at the information room if they wish.

Evaluation and conclusions

Clinical anamnesis

General ENT examination

Clinical voice examination

- Subjective evaluation by the patients themselves. Voice Handicap Index (VHI) – perceptual exploration of the voice GRABS Index – examination by videolaryngostroboscopy.
- Aerodynamic examination. Maximum phonation time. Phonatory quotient s/z ratio.
- Acoustic analysis. The study of the acoustic signal provides information about voice quality through the study of the various acoustic parameters of which it is comprised. Fundamental frequency, intensity, jitter, shimmer, harmonics-to-noise ratio, blocks – spectrographic analysis.

If the patients need an injection so wish, they are informed about the technique and given the consent form.

Patients go to the Admissions Service to be admitted to the Surgery Day Hospital of the ENT Department, on the same floor as the consultation.

Procedure

The procedure is performed under local anaesthesia in the available operating room at the Surgery Day Hospital.

Botulinum toxin is injected into both vocal cords using a needle through the working channel of the flexible fibre-optic laryngoscope

Post-operative period

Observation by the Day Hospital staff.

Discharge

The discharge report given to patients includes:

- A clinical report
- Voice care tips

- Possible side effects or complications
- Telephone numbers and data of the doctors who have treated them

Check-up

Patients are monitored by phone.

If necessary, subject to prior consent, their voice is recorded.

For follow-up consultations, the patients will contact the professionals by whom they were first treated to arrange an appointment in relation to their symptoms. That is why it is essential that the patient and the doctor programme the check-up session together.

Quality assessment indicators

- Number of days of unwanted side-effects. Breathy voice and/or dysphagia to liquids
- Voice quality (VHI).
- Duration of the effect.

Chapter 8. The Delay in Spasmodic Dysphonia Diagnosis and Treatment

Dr. Antonio J. Martín; Dr. Andrés Caballero; Dr. M. Dolores García

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

We wish to highlight a number of characteristics and factors that often mean that spasmodic dysphonia patients wait for too long before being diagnosed and properly treated.

They commonly tell us about the anguish they felt before being diagnosed and treated properly. In this connection, AESDE must be thanked for raising awareness of this disorder.

Spasmodic dysphonia is a rare disorder that is often debilitating and probably underdiagnosed.

Due to the lack of awareness among professionals and the absence of well-defined diagnostic criteria, the journey for spasmodic dysphonia patients before being properly treated is too often extremely hard.

Patients' journeys comprise two stages, the first lasts until diagnosis, and the second begins when they are offered the right treatment.

First stage: from the first symptoms to diagnosis.

It is still common for us to receive patients who have been diagnosed and treated solely for a psychological disorder: a diagnosis they willingly accept, since they usually observe that under stress the frequency and intensity of their spasms normally increases.

The length of this first stage depends both on the patients and on the doctor´s inability to recognize the symptoms.

Initially, the patients occasionally suffer from voice spasms alternating with normal voice. As they usually attribute it to stressful situations or

previous infections, they don't find it necessary to consult a doctor about their voice problem.

Once they decide to consult a professional, their doctors fail to recognize the symptoms, thereby delaying diagnosis further. They are seen by a GP, a psychologist or psychiatrist, a neurologist, an ENT specialist, etc.

The average time-to-diagnosis as reported in scientific articles is about 4-5 years from the time the patients first see a doctor to discuss their voice problems. At the Department we have treated patients from our region who have waited up to 11 years from the onset of symptoms to the diagnosis.

Patients are previously examined and are often treated by 3 to 5 doctors who prescribe drugs other than the botulinum toxin.

The voice of a patient with spasmodic dysphonia is so characteristic that it is possible to make a diagnosis just by listening to the patient speaking. Despite knowing the answer, the professionals who treat these patients still wonder: "if our secretary at the Department can diagnose this disorder over the phone, why are all these doctors unable to do so? Their voice is practically unmistakable."

The answer is easy: SD is a rare disorder, they have never got to know specifically what patients' voices sound like, and they tend to associate the problem with other conditions.

Second stage: from diagnosis to treatment

Currently, patients suffering from spasmodic dysphonia are rarely offered treatment with the botulinum toxin injection from day one. Instead, they are prescribed anti-inflammatory or anxiolytic drugs. Sometimes they are even told that there is no cure for their illness and that it is not worth treating.

But even when by any chance patients are offered the botulinum toxin, they are not given the possibility to have it injected under local anaesthesia, which has important advantages compared with general anaesthesia.

Both the patients and the professionals treating them must know that spasmodic dysphonia patients must be assessed by a team, usually

including an otolaryngologist (ENT specialist), a speech pathologist, a speech therapist and a neurologist.

The ENT specialist examines the vocal cords searching for other possible causes for the voice disorder using fibre-optic laryngoscopy or videostroboscopy, which show the vocal cord vibrations in slow movement.

The speech and language pathologist evaluates both the characteristics and quality of the patient's voice.

The neurologist evaluates the patient for signs of other kinds of movement disorders.

Measures to be taken

There is an important component relating to medical education and training. Despite living in the era of the Internet, websites, mobile apps and social networks, a disorder that could easily be diagnosed, at least tentatively, just by hearing the patient's voice is still underdiagnosed. We need to harness all this technology to make SD more widely known.

Experts in voice pathology at two Spanish university hospitals (Hospital Universitario Ramón y Cajal in Madrid and Hospital central de Asturias in Oviedo) have developed a mobile application called "Take care of your voice" whose main aim is to give users detailed information and advice about how to look after their voice, as well as written and multimedia information on different pathologies, including spasmodic dysphonia.

In addition, a mobile app for spasmodic dysphonia will be soon launched.

Conclusions

Objective criteria for spasmodic dysphonia diagnosis as well as a better clinical training for doctors on this matter are necessary to reduce delays in diagnosis.

Such delays have a negative psychological effect on patients as they do not know what is wrong or think that they cannot be cured.

Furthermore, they have to cope with significant expenses related to consultations, useless treatments or sick leave due to the condition itself or the psychological impact it may cause them.

We, the professionals treating these patients, are aware of the need for these people to be heard.

Chapter 9. Spasmodic Dysphonia and Psychology.

Ms. Lucía Gónzález Caballero. Psychologist.

How to cope with stress

Each person is unique and there are many ways to cope with a diagnosis. In many cases the knowledge of the definitive diagnosis turns out to be a relief compared with the uncertainty of not knowing what is going on. For others, it may be difficult to assimilate.
Patients may pass through different phases such as:

- **Initial shock,** characterized by a feeling of fragility and vulnerability, confusion, insecurity or loss that may last from several days to a few weeks.
- **Denial, incredulity** ("this is not possible, they must be wrong.")
- **Sadness, depression, weeping, helplessness, fear**…
- **Acceptance:** this tends to coincide with the treatment and the relief that fighting the illness usually entails.

These stages are very typical when patients are diagnosed with either a chronic disease or one that has an unpredictable prognosis. They do not always occur and, if they do, they might not follow this order. We insist on the fact that each person is unique.

How to cope with stress

Experiencing negative feelings is something natural when people are faced with a situation they cannot control, as is the case in spasmodic dysphonia.
This particular disorder prevents us from communicating in a natural way. Feeling stress at times is therefore not unusual at all.

What does stress really mean?

When an external situation (**an environmental stimulus**) triggers a strong physical reaction in us (**physiological reaction**), which is very often related to anxiety, we tend to see it as something bad (**negative thoughts**) and of course we end up feeling bad (**painful emotion**). If this pattern occurs repeatedly, we will end up being exhausted and downhearted, and it is then we will start to experience stress.

It is always a good idea to know how to cope with this reaction, in order not to be controlled by it.
To start with, we must clearly identify what our **stress triggers** are; in other words, which situations cause us stress in our daily lives.
For example, a very common stress trigger might be those situations in which we must socialize and talk to other people. This is something that occurs many times a day and cannot be avoided.

Once these stress triggers are identified, we must know how to differentiate between thoughts, emotions and physiological feelings.
A *thought* might be: "I cannot communicate with the other people".
An *emotion* is: "I feel sad", "I feel anxious".
A *physiological* feeling is: "I have tachycardia", "I need more air", "I have a headache".

And now, what can I do?

What is really important in identifying thoughts is to be able to classify them as real/false and positive/negative. For example:

"I cannot communicate with other people". How real is this thought? It may not be entirely true. I certainly do have a difficulty, but it doesn't prevent me from communicating. Hence, this thought turns to be FALSE.

Concerning emotions, we must know what we really feel, trying at least to give it a name in order to understand ourselves a little better. For example:

"I feel sad and anxious because I think that I cannot communicate with the others." It is normal to feel like that if I think that "I cannot communicate with other people," but now I know that this is FALSE so I can start to feel differently about it.

Physiological reactions are easy to see and should be controlled in spasmodic dysphonia since they have a direct influence on the person's voice. For example:

"I sweat more than usual; my pulse is accelerated; I breath quickly; I am nervous." I can start simple relaxation techniques such as deep breathing, muscle relaxation… in order to ease these disagreeable physical sensations

Finally, we have to make it clear that these tips seem easy at a first glance, but it actually takes a long time to assimilate these concepts and, in the event of any problem related to stress, anxiety or depression, the patient must **ALWAYS** go to a specialist.

Personal relationships: how to improve them and get support.

From the onset of spasmodic dysphonia symptoms until we receive a diagnosis, weeks or even years may elapse. Due to the characteristics of this disorder it is normal that our personal relationships may deteriorate slightly.

We may follow some easy steps to try to improve our social situation and even get more support, as this is important for anybody in this situation.

Exercise ASSERTIVENESS

Assertiveness consists of placing yourself at the half-way point between two opposite poles:

- *Passivity*: which is letting other people decide for us or indeed simply ignore our opinion, interest or well-being.
- *Aggressiveness*: which emerges when we are not able to be objective and respect other people's opinions.

In order to be more assertive, we must take an intermediate position where we can express our needs while respecting and understanding others. It is also assertive to say "no" to certain situations which may damage our health, but which are socially accepted, and which may be tempting because of a desire to conform socially.
In short, we can always try to better explain how we feel and the reasons for the decisions we make. Besides, this way our family and friends will glean a much better understanding of their own situation and how important their support is.

Another way to receive more support is to meet our 'peers', other people with spasmodic dysphonia who can consequently understand our situation, tell us about their experience and give us advice.
This is the founding purpose of AESDE: through the Association we can contact other sufferers and professionals who are familiar with this disorder.

lucia.goncaballero@gmail.com

Chapter 10. Frequently-Asked Questions by Patients to their GP.

Dr. Juan Pedro Fernández de los Ríos. GP at the Puerto Sur primary medical centre in El Puerto de Santa María (Cádiz).

Spasmodic dysphonia is classified as a "rare" disease since it affects quite a small population, although the number of people affected is increasing, probably due to improvements in its diagnosis.

As soon as patients are given the diagnosis at their local medical centre, they naturally ask doctors all kind of questions about the disorder, and it is precisely these questions that we wish to address in this Guide:

Can this kind of dysphonia be cured?

In principle, and in line with the therapeutic standards indicated in the **Voice Unit**, although we cannot claim that there is a complete cure, we may say patients can expect an acceptable improvement, particularly after cyclical treatment with botulinum toxin.

Of course, unless the doctors at the Unit say otherwise, what patients MUST NOT do is to remain totally silent, since this can actually make the disorder worse.

Are GPs trained to give a diagnosis?

Your GP has rotated through different medical specialties and is prepared to establish an ***approximate*** clinical judgement regarding your illness, and the definitive diagnosis must be performed by an ENT specialist, with necessary specific medical devices.

The approximate clinical judgement is based on the way the patient speaks, as it is characteristic of this kind of disorder: a faltering, forced voice with difficulty in pronouncing specific letters and words, etc.

In any event, unfortunately, many doctors have never had the chance to hear a person with spasmodic dysphonia speak, making it very difficult for them to reach a diagnosis. However, the Dysphonia Procedure is a tool that has been available to us since May 2009 to help doctors refer patients more quickly and efficiently to the ENT specialist, and the latter to refer them to Hospital Puerta del Mar Voice Unit.

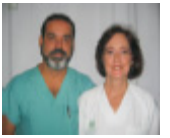
For check-ups with the specialist, do I need to go back to my doctor?

Once you have visited the ENT specialist and until you have been medically discharged, appointments will be arranged directly by the specialist and patients will not have to ask their GP for any kind of referral note.

This is one of the advantages we have in Andalusia, thanks to the implementation of the Procedures Programme for certain illnesses (including SD), as patients are fast-tracked to the various specialists they need to see. This way, the specialist and GP both have access to the same medical history. This makes the process much more fluid.

When I start treatment, if I need to take leave from work, who should I ask?

Temporary leave or transitory incapacity to work (doctor's certificates) are documents that must be issued by your GP based on a report from the specialist, including the approximate duration and the diagnosis. If you need to take more than three days' leave, you will have need to ask your doctor for a certificate: the first one after three days and after that one every week.



Chapter 11. Frequently-Asked Questions by Patients to their ENT Specialist.

Dr. Miguel de Mier; Dr. Encarnación Ávalos; Dr. M. Dolores García

Why do the effects of the injection last seven or eight months in some patients, while in my case they only last four?

The duration of the effects of the botulinum toxin remains uncertain, as there are no published studies on this matter. The patient's weight, severity of symptoms and the dose administered are among the many factors that may influence this issue. Also, the higher the dose of toxin, the more the side-effects, making specific research more difficult to perform.

Will there be new techniques in the short or long term?

Yes, there will; in fact, some of them are already starting to be introduced, but there are not yet significant sample data.

After the injection, if I talk a lot will I shorten the duration of the toxin's effects?

Studies have been published to the effect that, if a series of voice hygiene measures are taken (as explained in the guide) the effect can actually last longer.

Does speaking loudly damage my voice?

No, it doesn't; but patients need to learn speech techniques to avoid damaging the vocal cords, even when speaking loudly.

Will the botulinum toxin injection be less effective over time?

Our experience over these 11 years coincides with the published research: the effect of the treatment does not change over time. In fact, we have several patients who have been having the injections for more than 14 years and the results have always remained the same.

When I have the injection, will I be able to eat the same day?

This guide includes the measures to be followed after the toxin injection.

Is it a good idea to rest my voice after the injection?

We recommend a resting your voice during the first 24 hours after the injection. Avoid forcing your voice and having long conversations. See the answer in the guide.

Why do I feel dizzy if I try to speak when my vocal cords are weak?

During the first 48 hours after the injection your vocal cords will be flaccid and, since they cannot close completely, air will escape as you speak. You may then hyperventilate and feel a little dizzy, but this will end as soon as you stop talking and relax. See the answer in the guide.

What do I have to do not avoid choking on liquids when I get injected?

The guide shows some postural measures and aids such as straws.

After a time, will I become immune to the toxin?

This shouldn't happen. In our experience, none of our patients have developed antibodies against the toxin.

Why do I sometimes bleed after the injection?

When there are concomitant conditions like allergic rhinitis, the endoscope may occasionally tear nasal mucous membrane that is already a little inflamed because of the allergy, causing a little bleeding that stops spontaneously. In these cases, we recommend the use of a nasal vasoconstrictor for a day or two before the infiltration.

Are there contraindications to the botulinum toxin injection?

It is only contraindicated during pregnancy and in some neurological diseases.

What is the botulinum toxin and how does it act?

The botulinum toxin is produced by a bacterium called Clostridium Botulinum. It is a strong neurotoxin which acts at the neuromuscular junction to inhibit the release of acetylcholine at the synaptic terminal of motor neurons, preventing the transmission of the nervous impulse and producing a paresis or temporary paralysis of the injected muscle (Langeveld, 1998; Blitzer 2001). We use the type A toxin.

Chapter 12 Guidelines for Spasmodic Dysphonia Patients

Dr. Raúl Espinosa Rosso; Dr. Lucía Forero Díaz. Department of Neurology at Hospital Universitario Puerta del Mar (Cádiz, Spain).

Can craniofacial dystonia and spasmodic dystonia occur simultaneously?

Dystonia is a movement disorder which induces abnormal positions or postures in the affected area of the body. If just one area is affected, such as jaw or eyelids, the dystonia is said to be "focal". If a whole area is affected (such as an arm), and another adjacent one is also affected (such as the head), it is called “multifocal dystonia”. And if it affects several areas, it is called “generalized dystonia”. This last type of dystonia is the rarest one and is most often congenital, i.e., appearing at birth. A case of **isolated spasmodic dystonia** should be considered a focal dystonia.

In some patients, several kinds of dystonia occur in the same area: for example, blepharospasm, (involving eyelid muscles) and spasmodic torticollis (involving the neck muscles). This would be classified as **craniofacial dystonia**. The same is true of spasmodic dystonia: it may be associated with other types of dystonia in the same area. However, this kind of dystonia is usually isolated and affects only one muscle group.

I have been diagnosed with spasmodic dystonia and treated with botulinum toxin for many years now. Might I develop cervicofacial dystonia?

In adults, dystonia that is localized from the onset usually has an unknown cause and is called “idiopathic dystonia”. This kind of disorder does not usually spread to other areas of the body. In children or young people in whom dystonia started in a particular area of the body, the disorder may spread to other nearby areas overtime.

This process is called “overflow”. This possibility is much rarer in adults. In some cases, in which dystonia is due to chronic treatment with certain kinds of drugs such as those taken to treat heavy digestions or flatulence, dystonia may be spread to other areas if the patient continues to take drug that caused the problem. **It is important to let your doctor know about any drugs you are being or have been prescribed.**

I have had botulinum toxin injected to treat my blepharospasm; but I also have an associated spasmodic dystonia. Is there any risk if have the toxin injected in both areas together?

Botulinum toxin is a safe drug, as it produces very few severe side-effects even when used at high doses. It is administered via intramuscular injections. The most frequent side-effect is weakness of the muscle injected. Nevertheless, bear in mind that these side-effects are **transitory** in any case. The toxin is eliminated by the organism, making the effect transitory and the treatment must be repeated periodically. In order to avoid these side-effects, ultrasound-guided injection is highly recommended. This technique enables the doctor to view the muscle via ultrasound and place the injection directly in the muscle affected, preventing the toxin from reaching nearby muscles which do not need to be treated.

The organism reacts against the toxin and gradually weakens its effect. As its name suggests, these poisonous substances cannot be recognized by the organism, which therefore reacts against them producing antibodies. This phenomenon is called **toxin resistance**. In isolated spasmodic dysphonia, this occurs very rarely since very low doses are used and the area injected is very localized. When there is more than one kind of dystonia a higher amount of toxin (measured in Units) is required. Currently there are several kinds of botulinum toxin available in the market: type A (Botox, Xeomin and Dysport), which is the most commonly used, and type B (Neurobloc). There are subtle differences among the A-type toxins which are important when selecting a particular one. Xeomin, for example, allows more flexible dose intervals (it may be used every 6 weeks) and higher doses since there is less risk of inducing the antibodies which would neutralize its effect. Botox is indicated for most of the problems that may be treated with botulinum toxin, including the treatment of chronic migraine.

Dysport is a more concentrated toxin, so numbers of Units may be used with the same volume, making it possible to treat larger muscles. This is useful, for example, in the treatment of spasticity. The doctor will choose from among all the different kinds of toxins the one which best suits each patient's case.

Can neurologists inject the larynx in spasmodic dystonia cases?

Currently the technique of choice for the treatment of spasmodic dysphonia with botulinum toxin is the transoral or direct technique: a flexible laryngoscope allows access to the larynx and the toxin is injected into the vocal cords under direct vision. This technique requires knowing how to access the larynx using a flexible laryngoscope. That is why it is performed by ENT specialists.

Injection under direct view or ultrasound-guided techniques increase efficacy of the treatment and reduce side-effects.

Are the drugs used in dystonia treatments useful in the treatment of spasmodic dysphonia?

The botulinum toxin is the only drug supported by scientific evidence in the treatment of dystonia. Some supporting therapies such as muscle relaxants and physiotherapy techniques may be used to improve the effect of the toxin.

The botulinum toxin acts a pain-killer. People suffering from dystonia usually experience some pain due to the contraction of the muscles affected. This is one of the main symptoms the toxin can improve.

Chapter 13 What Patients Usually Ask their Speech Therapist.

Ms. M. Ángeles Dorante Bellido*; Dr. Marta Rodríguez**

*Speech-therapist. Rehabilitation Service. Hospital Universitario Puerta del Mar (Cádiz, Spain).

** Rehabilitation Service. Phoniatrics. Hospital Universitario Puerta del Mar (Cádiz, Spain).

What to do during the first few the days after the botulinum toxin injection.

Week one

After the botulinum toxin injection, the vocal cords need some time to recover from this minor procedure and assimilate the change that has occurred in the larynx. That is why any irritation of the vocal cords should be avoided.

Recommendations:

- Avoid dusty environments.
- Do not use toxic products (bleach, ammonia, paint)
- Avoid exposure to smoke

The day after the operation you will notice that your voice is breathy, and you may even get a bit dizzy when speaking.

Do not worry at all. These are common effects produced by the toxin. It is absolutely normal.

Your vocal cords are not closing fully, and air is escaping as you talk. This problem may cause hyperventilation, making you feel dizzy.

The escaping air makes it very tiring to speak. It is advisable not to force your vocal cords and let your voice rest, relatively.

Recommendations:

- If you get dizzy when speaking, stop, sit down and breathe. Once you have recovered, you may go on talking.
- Do not shout.
- Avoid talking in noisy places.
- Avoid talking on the phone.
- Avoid talking in meetings.
- Keep your conversations short.
- Be as close as possible to the people you are talking to.
- Speak quietly, calmly and without forcing.
- If your job requires frequent talking, it is a good idea for you to take a few days off under medical prescription.

Week two

After the first week, the voice is often still breathy. If so, you will do a series of exercises which will improve the vocal cords' muscle tone so that they close fully and no air escapes. The idea is to make a productive voice.

Exercises to improve subglottal pressure (repeat 5 times)

Exercise (repeat 5 times)

1. Take in air through your nose
2. Blow air out through the mouth making an ‘sssss’ sound.

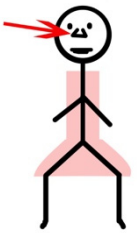
Exercises to give the vocal cords the proper correct tone (do this for 7 days until you achieve the correct tone)

Cough loudly (repeat 3 times).

Sitting on a straight-backed chair with your feet on the floor (repeat each of the following exercises 5 times):

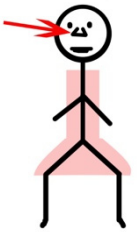
Exercise 1:

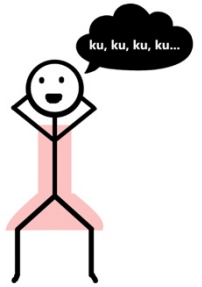
1. Take in air through your nose
2. Press the nape of your neck with your hands as you say: "kee, kee, kee, kee"



Exercise 2:

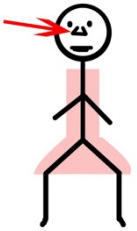
1. Take in air through your nose
2. Press the nape of your neck with your hands as you say: 'Koo, koo, koo, koo'.

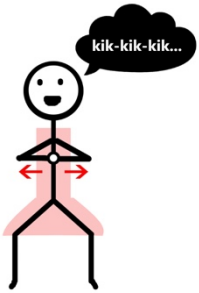




Exercise 3:

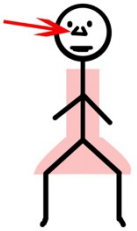
1. Take in air through your nose
2. Interlace your fingers in front of your chest. Pull each hand to one side and say: "Keek, keek, keek, keek".

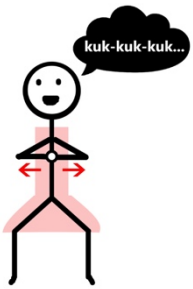




Exercise 4:

1. Take in air through your nose
2. Interlace your fingers in front of your chest. Pull each hand to one side and say: “Kook, kook, kook, kook”.



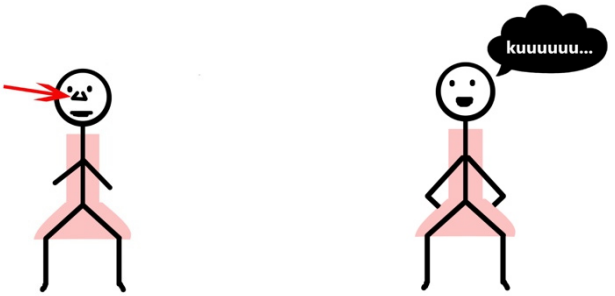


Exercise 5:

1. Take in air through your nose
2. Put your hands under the seat of your chair and say, pull upwards and say: “Keeeee”

Exercise 6:

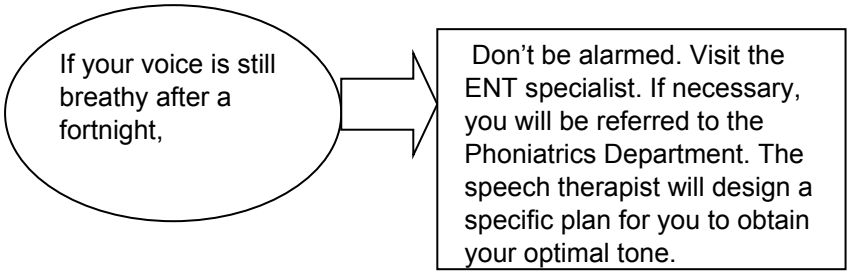
1. Take in air through your nose
2. Put your hands under the seat of your chair and say, pull upwards and say: "Kooooo...."

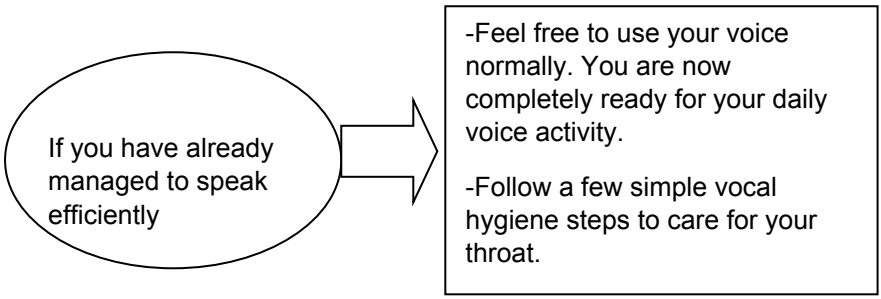


As soon as you recover your normal tone of voice, you should stop resting your voice and doing the exercises. You will notice that you no longer get tired or dizzy when speaking. This means that your voice is ready to be used in any situation; you can go back to your usual activities. Don't worry.

Not all patients need the same time before recovering their normal voice. In fact, it varies a lot. Don't be disappointed or anxious if you haven't achieved it yet. It takes longer in some patients than in others.

Week three





Current literature suggests that following these routines may make the effect of botulinum toxin last longer, although there are no actual studies to prove this.

In case of doubt, do not hesitate to consult your medical team.

Chapter 14: Vocal Hygiene

Dr. Marta Rodríguez Cañas de los Reyes*; Ms. M. Ángeles Dorantes Bellido**

*Rehabilitation Service. Phoniatrics. Hospital Universitario Puerta del Mar. (Cádiz, Spain).

**Speech therapist. Rehabilitation Service. Hospital Universitario Puerta del Mar. (Cádiz, Spain).

Once spasmodic dysphonia patients have been injected with botulinum toxin and have acquired their optimal tone, which usually occurs 7-14 days after the treatment, they are advised to follow a suitable vocal hygiene programme. There is not enough scientific evidence on hand, but the few studies available do show that, if patients follow a series of vocal hygiene standards after the botulinum toxin injection, its effects last longer.

A vital requirement for good vocal rehabilitation in spasmodic dysphonia patients is a vocal hygiene programme since, apart from being essential both before and after the voice re-education period, it is actually the basis of the treatment itself.

The first goal of this programme is to identify and eliminate any factor causing damage to the voice box. Having eliminated any harmful voice habits, the second goal is to identify and incorporate healthy habits in patients' daily life.

Vocal hygiene standards are the group of measures aimed at having a healthy voice, free of vocal effort and muscular tension, enhancing its performance and avoiding injuring the larynx.

The following tips are key:

Avoid forcing your voice to make yourself heard in noisy surroundings.

- Avoid overusing your voice by shouting, screaming, laughing too loudly or changing your voice (imitating other voices).
- Control your voice volume in any ambience, trying not to speak over the surrounding noise (avoid talking in discotheques, in places where traffic is very intense, in airports, in places where machinery is working, etc.).
- In a conversation, place yourself in the middle of the group. Rest your voice as you listen (do not agree with or confirm what is being said).
- Control your speaking speed, pausing between sentences.

- Do not sing without knowing proper vocal technique.
- Keep telephone conversations as short as possible.

Avoid larynx-irritating agents and damaging environments.

- Avoid tobacco, alcohol and caffeine.

- Avoid excessively cold or hot drinks and food, as well as spicy food.
- Avoid damaging environments: dry, very cold or hot atmospheres, sudden sharp changes of temperature, places full of smoke or dust, over-heated or air-conditioned places, and gases produced by irritant chemicals (cleaning products, paint, etc.).
- Avoid air-conditioned environments as much as possible.
- Avoid heavy evening meals and wait two hours before going to bed.

Keep your larynx well hydrated.

- It is highly recommended you increase your liquid intake to 2 litres per day.
- Avoid mint or menthol sweets as they tend to dry vocal mucous membrane.
- Use a humidifier or place a container full of water in the room if either the heater or the air conditioning is on.
- Always breathe through your nose.

Avoid unproductive coughing and throat clearing.

- Tips to avoid this: swallow saliva, drink small sips of water or perform a silent cough technique.
- If your larynx is dry, breathe in eucalyptus steam and gargle with lemon juice, honey and rosemary.

Do not force your voice.

- Avoid speaking while exercising or while lifting or pushing heavy objects.
- Learn to recognize and avoid the feeling of forcing your voice: signs of it include neck tension or lack of air when speaking.
- Control the tone of your voice by relaxing your neck and shoulders to avoid tension in your larynx. Do not raise you head when speaking.
- Do not whisper. Even if you wish to speak in a low voice, make sure you use your voice.

Reduce the time you spend speaking:

When you get a cold or throat infection (pharyngitis, laryngitis, tonsillitis), moderate the intensity of your voice.

Treat infections and/or inflammation of the upper and lower airways properly.

- Do not self-medicate — go to the doctor's. 
- Do not rest your voice except under prescription. 

Try and keep an orderly routine:

Have an orderly schedule, sleep at least 7-8 hours every night, practice sport and avoid stressful situations.

Below are some good and bad vocal habits patients should take into account in order to achieve maximum vocal efficiency with a minimum effort.

Bad habits

The idea is to eliminate those habits which negatively affect our vocal performance, such as:

- Breathing through your mouth.
- Having alcoholic drinks.
- Smoking
- Coughing or clearing your throat with effort.
- Having mint sweets when you have a sore throat.
- Eating spicy food.
- Using your voice for a long time after a heavy meal.
- Having very hot or very cold drinks.

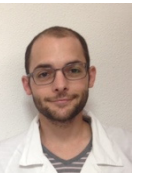
- Speaking in a noisy environment.
- Speaking while making a physical effort.
- Sleeping too little.
- Being exposed to dusty or toxic environments.
- Being exposed to excessively heated or air-conditioned environments.
- Shouting or speaking loudly.
- Talking on the phone for a long time.
- Talking loudly.
- Whispering.
- Talking when you are physically tired.
- Talking for a long time.
- Talking for a long time when you have a cold or throat infection.
- Self-medicating

Good habits

The idea is to interiorize and reinforce those habits which benefit our voice quality, such as:

- Gargling with honey, lemon juice and rosemary, breathing eucalyptus steam and washing out your nose with physiological serum.
- Protect your neck with a scarf in cold or wet environments.
- Drink plenty of water: 2 litres per day.
- Keep the right posture when you talk.
- Do relaxation and breathing exercises
- Talk in quiet environments.
- Use a mask if you are in contact with toxic products.

- Use sweets to soften your throat (liquorice, honey and lemon).
- Rest your voice.
- Keep your voice volume moderate.
- Sleep 7-8 hours per night.
- Be as close as possible to the people you are talking to.
- Do physical exercise regularly
- Make sure your diet is rich in vitamins.



Chapter 15. Drugs that Could Adversely Affect your Voice.

Dr. Andrés Caballero; Dr. M Guadalupe Álvarez-Morujo; Dr. Emilio Martínez

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

The larynx is the part of the respiratory tract or tree where the vibration producing the voice is originated. That is why any factor affecting the mucous membrane and consequently the vibration will affect the sound it generates, particularly in those patients who already suffer from this disorder.

Drugs may affect the larynx in different ways:

- A direct effect on the mucous membrane
- Systemic effects.

A direct effect on the mucous membrane	Systemic effects.
Inhaled drugs: -Inhaled corticosteroids -Inhaled bronchodilators Topical medication -Nasal corticosteroids	Antiplatelet and anticoagulant drugs Bisphosphonates ACE inhibitors Antihistamine drugs Diuretic drugs Anticholinergics Hormone treatments Antipsychotic drugs Tricyclic antidepressants Angiogenesis inhibitors Phosphodiesterase-5 inhibitors

Inhalers normally used in Asthma or bronchopulmonary therapy may produce dysphonia as they irritate the mucous membrane (a dose-dependent side-effect). In the case of corticosteroid inhalers, it is known that 5%-58% of users may present dysphonia because of the effect of the active ingredient on the mucous membrane or due to myopathy; they may also cause dysphonia since they sometimes cause fungal infections of the larynx.

Topical nasal corticosteroids are used to treat allergic rhinitis. It is suspected they may produce in rare cases, although there are no studies confirming this theory (5). Anticoagulant or antiplatelet drugs such as Aspirin®, Symtrom®, Plavix® and some NSAIDs like Ibuprofen increase the incidence of bleeding, which can lead to haematomas on vocal cords.

Bisphosphonates, a drug used to avoid weakening and bone deterioration in osteoporosis may irritate mucous membrane and consequently may trigger dysphonia due to chemical laryngitis.

ACE (Angiotensin-Converting Enzyme) Inhibitors are widely used to treat high blood pressure and heart failure. A side-effect which may occur with this medication is cough and subsequent vocal cord trauma.

Antihistamines are used to treat allergies and may also be found in cold and flu treatments. They may cause dryness of the pharyngeal and laryngeal mucous membrane, inducing dysphonia.

Diuretics are drugs very commonly used to treat high blood pressure, heart failure, kidney or liver diseases and other disorders associated with liquid retention (oedema). These drugs promote diuresis, increasing urine secretion and excretion, which increases body liquid loss. Accordingly, they may dry the mucous membrane of the larynx, causing dysphonia.

Anticholinergics are smooth muscle relaxants. They are used at peripheral nervous system level in asthma treatment (Ipratropium Bromide), although they may also be used to treat intestinal or biliary colic, ophthalmic disorders (mydriasis and cycloplegia), and to control nausea and vomiting (marketed in Spain as Biodramina®) which, despite being an antihistamine, has anticholinergic effects. In anaesthesia it is used to avoid vagal reflex bradycardia and to reduce

secretions (nose, saliva and gastric secretions). They are also used in the central nervous system to reduce tremor in Parkinson's Disease. One side-effect of this group of drugs is the reduction of saliva secretion, with the subsequent dryness in pharynx and larynx, which in turn may lead to dysphonia.

Sexual hormones considerable influence on the voice; in fact, they are responsible for the changes that occur in the larynx during puberty. In this case, women are more sensitive to dysphonia from a physiological point of view due to the cyclical changes produced by female hormones. It is known that about 3 days before menstruation and for 5-6 days there are changes in voice tone due to a reduction of follicle-stimulating hormone (FSH). With menopause, oestrogen levels drop, sometime causing a woman's voice to deepen. When hormones are administrated as medicines there is also a risk of voice changes, as in the following cases:

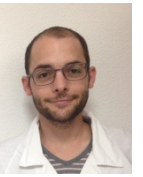
- Danazol: a drug used to treat endometriosis and benign fibrocystic mastopathy treatment. It is also used in the treatment of hereditary angioedema. As it is an androgen, it tends to make women's voices deeper.
- Oral contraceptives with a high dose of progesterone may deepen women's voices.
- Diethylstilboestrol is an antiandrogen drug used exceptionally in some cases of prostate and breast carcinoma. In men it may produce a higher voice.

Antipsychotics may cause larynx dystonia (involuntary muscle contractions) and subsequently, dysphonia.

Tricyclic antidepressants may cause tremor and dryness of respiratory mucous membrane, both of which can lead to dysphonia.

Angiogenic inhibitors are drugs which inhibit the production of new blood vessels. They are used in monotherapy or associated to drugs used in chemotherapy for the treatment of certain cancers. The mechanism through which they cause dysphonia remains unknown, but is quite a common side-effect in patients treated with this kind of medication, particularly in those who receive Axitinib, Aflibercept and Regorafenib.

As vasodilators, 5 Phosphodiesterase Inhibitors (Vardenafil-Levitra®) are used to treat erectile dysfunction. Among their reported side-effects are the following: epistaxis, varicose vein haemorrhage, intracranial haemorrhage and haemorrhoidal haemorrhage. It is suspected they may cause dysphonia by causing vocal cord haemorrhage.



Chapter 16. Speech Impairment and Quality of Life

Dr. Andrés Caballero; Dr. M. Guadalupe Álvarez-Morujo; E. Cabuchola.

ENT Department, Hospital Universitario Puerta del Mar (Cádiz).

The voice is the main instrument used by humans to connect with the people around them. It is also characteristic to each of us and easily recognizable by relatives and friends, even when the speaker is not visible. That is why, when patients go to the doctor's office, apart from taking their clinical history—including all their medical and surgery records, usual treatments, unhealthy habits, profession and examination, doctors must ascertain not only how patients perceive their own voice but also how far this disorder may affect their quality of life. The tools to make this assessment focus mainly on ascertaining the patients' the subjective feelings about their own voice (which is very important for the successful outcome of therapy) and evaluating the disability or functional issues that may be attributed to their speech disorder. All this information will help the ENT specialist evaluate the situation and choose the most appropriate solution for each patient: medical treatment, surgery, speech therapy or a combination of these.

The assessment of patients' quality of life uses consistently reliable and valid questionnaires with high levels of statistical sensitivity. These surveys may be either general and therefore not focused on a specific problem (Health-Related Quality of Life – HRQOL) or focused on gaining awareness on a particular issue – in this case concerning the voice (Voice-Disordered Quality of Life – VDQOL). There are many assessment tools to measure vocal quality of life, as summarized in the table below:

VDQOL: Voice-Disordered Quality of Life

VHI (Voice Handicap Index)	One of the most often used (translated and approved in Spanish for use in Spain).
VHI-10 (Voice Handicap Index – 10)	Abbreviated version of the previous questionnaire
VHI-P (Voice Handicap Index - Partner)	Derived from VHI. This questionnaire evaluates how people living with the patient perceive the patient's voice.
PVHI (Paediatric Voice Handicap Index)	Extension of VHI for dysphonic patients' parents.
SVHI (Singing Voice Handicap Index)	Similar to VHI but aimed at singers.
VPQ (Vocal Performance Questionnaire)	Similar validity to VHI-10
VoiSS (Voice Symptom Scale)	Considered the most robust self-evaluation test
VAPP (Voice Activity and Participation Profile)	This test evaluates the perception of the voice problem, limitations and restrictions using the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH)
V-RQOL (Voice-Related Quality of Life)	Highly correlated with VHI.
PVRQOL (Paediatric Voice-Related Quality of Life)	Adaptation of the previous questionnaire for paediatric use. To be completed by the patient's parents.
VOS (Voice Outcome Survey)	For patients suffering from unilateral voice paralysis.
PVOS (Paediatric Voice Outcomes Survey)	VOS adaptation for paediatric use. To be completed by the patient's parents.

Table 1 : VDQOL

VHI (voice Handicap Index) and its abbreviated version VHI – 10 are two of the most commonly used questionnaires to evaluate how patients perceive their vocal disorder, the physical handicap it causes and the emotions caused by dysphonia. VHI comprises 30 statements, divided into three groups of 10: functional, physical and emotional. Each statement receives a score from 0 to 4, where 0 means 'never', 1 means 'hardly ever', 2 means 'sometimes', 3 means 'nearly always' and 4 means 'always'. The maximum score would be 120. That would correspond to a severe case. A score of up to 10 would be considered normal. VHI-10 includes the VIH ten most robust statements from VIH and has been proven to be equally valid. Consequently, it can save valuable time during the consult.

VHI-10 (Voice Handicap Index – 10)					
My voice makes it difficult for people to hear me	0	1	2	3	4
People have difficulty understanding me in a noisy room	0	1	2	3	4
My voice difficulties restrict my personal and social life	0	1	2	3	4
I feel left out of the conversations because of my voice	0	1	2	3	4
My voice problem affects my performance at work	0	1	2	3	4
I feel as though I have to strain to speak	0	1	2	3	4
The clarity of my voice is unpredictable	0	1	2	3	4
My voice problem upsets me	0	1	2	3	4
My voice makes me feel handicapped	0	1	2	3	4
People ask me: What's wrong with your voice?	0	1	2	3	4

Table 2. VHI -10 (3)

VoiSS (Voice Symptoms Score) is an easy 30-stage questionnaire that is simple for patients to complete and easy to score. It comprises

30 questions divided into three categories: voice impairment, emotional factors and related physical symptoms. It is sensitive enough so as to reflect both physical and emotional symptoms in dysphonic adults. From a psychometric point of view, it is the most robust subjective voice evaluation self-report available.

VAPP is the only self-assessment protocol that uses the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH). It is a 28-stage questionnaire which was initially classified into five areas: self-perception of the severity of the vocal problem, effects on job, effects on daily communication, effect on social communication and emotional effects. Two more categories were later added: limitation on activity and constraints on involvement. The scores for these two additional aspects are obtained by adding the score obtained in certain selected questions from the five original sections. It is considered to be a reliable tool for assessing the effects of voice disorders like spasmodic dysphonia on the quality of both work and daily life.

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Lucía González Caballero, psychologist.

María Ángeles Dorantes Bellido, speech therapist at Hospital Universitario Puerta del Mar (Cádiz).

Ignacio Cobeta Marco, Chair of Otolaryngology. Universidad de Alcalá. Head of the ENT Department. Hospital Universitario Ramón y Cajal (Madrid, Spain).

Antonio J. Martín Mateos, Head of ENT Department at Hospital Universitario Puerta del Mar (Cádiz).

A SPECIAL MENTION IS GIVEN TO PROVINCIAL GOVERNMENT OF CADIZ FOR THEIR COLLABORATION AND SUPPORT IN IMPLEMENTING THIS PROJECT.

Encarnación Caballero Mateos
Presidenta AESDE

Your voice, forever a part of my voice, now diminished

Now just a memory in songs, sometimes perhaps loud for those who never knew it both soft and at once strong; the sound of softly murmured advice. How could it deserve such a fate?

Nobody understood what was happening: ignorance, tears and a permanent lack of information; a heart trapped by a mute cry, fear of not being able to nurture all those things you used to tell me, which were so numerous and so beautiful they needed to be heard.

At last, after so much effort, so many journeys to specialists and doctors, your courage and temperament, the need to know why, as it prevented you from sleeping. These are the lights that dysphonia could not darken, and a reason for many to keep fighting, every day.

Juan Carlos González Caballero, Nurse (University Diploma in Nursing)
Spasmodic dysphonia patient's relative

The Spasmodic Dysphonia Unit of the ENT Department at Hospital Universitario Puerta del Mar is considered to be a reference centre for the entire region of Andalusia. It is coordinated by Dr. Miguel de Mier Morales and Dr. Encarna Ávalos Serrano.

Spanish Association of Spasmodic Dysphonia — Asociación Española de Disfonía Espasmódica (AESDE):
C/ Crucero Baleares, Nº 54-6ºA
11500-El Puerto de Santa María (Cádiz)
C.I.F. : G72008329

Sede C/Pedro Muñoz Seca 9, 1º planta
11500 El Puerto de Santa María (Cádiz)
Tel/: 956 85 75 62
Mobile phone: 600 651 062

aesde@disfoniaespasmodica.org
www.disfoniaespasmodica.org