

Meniere's Disease: A Patient-Centered Guide to Decision Making

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We are glad you have sought care with us at UCSF! We have noticed that patient visits are not long enough to thoroughly cover all of the important information about a complicated topic like Meniere's disease. Therefore, we wrote this patient guide, which will hopefully help to fill in the blanks, and give you a detailed information on our approach to management of Meniere's disease.

As you have already realized, there are no quick and easy answers with Meniere's disease. Generally, our treatment approach is "trial and error", where we will initiate a treatment, and see whether or not it works for you before trying other treatment options. Therefore, it's very important that we partner together to figure out a good treatment plan. We are generally less directive with our patients with Meniere's disease toward a particular treatment plan. Instead, we view our job as educating patients about the various treatment options available. Patients will return for a follow up visit, and report back their experience. For example, "The low salt diet worked for a while, but over the last month I've had a couple of bad attacks. Can we try a steroid injection?"

Given our intention of partnership with you, it's important for you to learn about Meniere's disease, about the different treatment options available, and about the risks and benefits of each. A lot of the information provided here is from an article I, Dr. Sharon, wrote a few years ago.¹

What is Meniere's disease?

Meniere's disease is a condition that causes hearing loss, dizziness/vertigo, ear pressure/fullness, and tinnitus (ringing in the ears). We know that these symptoms occur together, oftentimes with this story: someone experiences a sudden attack of vertigo (a sensation of spinning), accompanied by a loss of hearing, an increased volume of tinnitus, and a pressure sensation in an ear. Almost always, patients

with Meniere's disease can point to one ear, and clearly experience either the right ear or the left ear as the problem.

We do not fully understand Meniere's disease. In fact, we don't know what causes it. This makes treatment more difficult, because with our incomplete understanding, we have to make educated guesses. It's important to know that currently, there is no "cure" for Meniere's disease. Instead, the best that we can offer are treatments. The treatments work well for a majority of patients, but it always takes time to figure out which treatments will work for **you**. That's disappointing, because most patients with Meniere's disease are really suffering, and they want the disease gone as quickly as possible. It's our hope that in the future, we will know what causes Meniere's disease and how to cure it! For now, we have to rely on the available treatments. Luckily, through a trial and error approach, we are almost always able to find a good treatment that works for each patient. But we need to prepare ourselves for the reality that this is a long-term (chronic) disease, and it usually takes some time to figure out a treatment regimen that works for **you**.

Of historical interest, Meniere's disease is named after a French neurologist- Prosper Meniere (which can be written Ménière or Menière, the last one likely being the most historically accurate). He published a paper in 1861 showing that the inner ear could cause hearing loss and vertigo. Until that point in time, it was thought that only the brain (cerebellum) caused vertigo.

What causes Meniere's disease?

We don't know.

The inner ear, located deep in the skull, is an intricate and small space, filled with fluid, membranes, and nerves, and includes sensing organs of both hearing and balance.

Various theories have been advocated over the years, arguing that the cause is genetic, autoimmune (when the body's immune system attacks itself, like in rheumatoid arthritis or lupus), vascular (due to a blood supply problem to the ear), infectious (due to a virus that we haven't yet identified), related to otoconia (little crystals in the inner ear that help

the ear sense gravity by being a miniature weight, migraine, or inner ear fluid circulation problems.

What we **do** know is that a certain part of the inner ear, called the endolymphatic space, is almost always abnormal in patients with Meniere's disease. This space is in the central part of the inner ear, and is surrounded by the much larger perilymphatic space. In Meniere's disease, the endolymphatic space is ballooned outward, and is therefore much larger than it should be. This is called **endolymphatic hydrops**. In histologic studies (where the inner ear is examined under a microscope), **all** patients with Meniere's disease symptoms have endolymphatic hydrops. This means that it is a very consistent finding, and is certainly related to Meniere's disease. We don't know if the enlarged space causes Meniere's disease, is caused by Meniere's disease, or is otherwise tangentially related to Meniere's disease. Also, there are some patients with endolymphatic hydrops, who don't have the symptoms of Meniere's disease. This means that there is not a 1:1 correlation between the two conditions. It may be that endolymphatic hydrops can be related to other causes. Or endolymphatic hydrops may not develop Meniere's disease unless an additional problem is present. We just don't know.

Of interest, more and more research is being done with special MRI (Magnetic Resonance Imaging) sequences, which can see the endolymphatic hydrops in a living person. This is exciting, because we don't biopsy the inner ear (which is so small and delicate that a biopsy would destroy it). Therefore, all of the information we have on the microscopic findings in Meniere's disease is based on long term cadaver studies, where there were post-mortem examinations of temporal bones (the part of the skull that contains the inner ear). So, the idea that we are now able to see some of these findings in a living person, without hurting them, is very exciting!

How do I know if I have Meniere's disease?

At the current time, Meniere's disease is a clinical diagnosis. That means that there isn't a laboratory test, or a pathology result, or an imaging finding that can tell you that you have Meniere's disease. Instead, the diagnosis is made by a clinician, after careful consideration

of your symptoms, and reviewing your hearing test (audiogram). There are guidelines for making this diagnosis. Generally, if you meet the criteria in the guidelines (reproduced below), and if you don't have another cause for dizziness as determined by your clinician, then you are determined to have Meniere's disease.

One important point: we routinely see patients who have been diagnosed elsewhere with Meniere's disease, but who do not have hearing loss. While there may be rare variants of Meniere's disease that only affect the vestibular system, this is very uncommon. Instead, most of these patients, with normal hearing, have another cause for their dizziness. That cause is most commonly vestibular migraine, which is the most common cause of dizziness in the United States.

2015 consensus criteria for the diagnosis of Meniere's disease²

Diagnosis	Criteria
Definite Meniere's Disease	<ul style="list-style-type: none">• Two or more spontaneous episodes of vertigo, each lasting 20 min to 12 h• Audiometrically documented low- to midfrequency sensorineural hearing loss in 1 ear, defining the affected ear on at least 1 occasion before, during, or after 1 of the episodes of vertigo• Fluctuating aural symptoms (hearing, tinnitus, or fullness) in the affected ear• Not better accounted for by another vestibular diagnosis
Probable Meniere's Disease	<ul style="list-style-type: none">• Two or more episodes of vertigo or dizziness, each lasting 20 min to 24 h• Fluctuating aural symptoms (hearing, tinnitus, or fullness) in the affected ear• Not better accounted for by another vestibular diagnosis

Do I need any other testing done?

Medical centers across the United States may each have a very different workup for Meniere's disease. Without a national standard, the workup can feel very confusing. Many of the tests that are commonly done, like electrocochleography, vestibular testing, glycerol tests, VEMP tests, and blood tests can sometimes be abnormal. However, none of these are really good tests, meaning that they aren't always abnormal in Meniere's disease, while always normal with other conditions. Therefore, we don't routinely order any of these tests. The bottom line is that we don't find these tests to be particularly helpful, and the results don't change our management of your condition.

Therefore, it's important to know that our philosophy in working up Meniere's disease is to rule out other things that can cause similar symptoms, rather than proving that Meniere's disease is the culprit. This is different than many other conditions, where we use testing to prove the diagnosis. Here we are trying to prove that you don't have other conditions.

The standard of care for anyone with a unilateral (one-sided) sensorineural hearing loss is to have an MRI scan (with contrast). Since Meniere's disease almost always causes one-sided hearing loss, patients with Meniere's disease should always have an MRI done at some point. This is important to make sure that you **don't** have a brain tumor of your symptoms, such as a vestibular schwannoma or an endolymphatic sac tumor. However, please be aware- almost always the MRI is NORMAL in patients with Meniere's disease. Some patients get frustrated with the normal imaging result, because they hope that the MRI will provide their diagnosis, but that was not the goal (or the capability) of the study.

You do need an audiogram (hearing test) to diagnosis Meniere's disease. This is the best test for assessing severity of hearing loss. The audiogram can be used to track and document any changes in hearing. It's also helpful for figuring out if you could be helped by any hearing rehabilitation technologies, like a hearing aid or a cochlear implant.

Sometimes we will order blood work for patients with Meniere's disease. This may be done to check for autoimmune diseases or for syphilis. Autoimmune diseases (like rheumatoid arthritis) are diseases where the body attacks itself. We know that sometimes the inner ear can be a target for these attacks. This can occur exclusively in the inner ear, or may impact more the body as part of another autoimmune condition (such as rheumatoid arthritis, lupus, Sjogren's disease, scleroderma, type 1 diabetes, Cogan's syndrome, Hashimoto's thyroiditis, Graves disease, and others). Typically, autoimmune disease will cause fluctuating hearing loss (hearing loss that gets better and gets worse), in both ears (unlike Meniere's disease), and patients improve with oral steroids. If your symptoms sound similar to that, we will order some tests to evaluate for the presence of autoimmune diseases. These lab tests may include ESR, CRP, ANA, ANCA, SSA/B, and RF.

If you have any risk factors for syphilis (a sexually transmitted disease with risk factors of unprotected sex with multiple partners), then it's a good idea to do a blood test to check for syphilis. If this test has never been done, then please let us know, and we can order it for you. Syphilis is a treatable disease, with proper antibiotics.

Finally, in endemic areas, sometimes we will check for Lyme disease. Lyme disease is not endemic in California. It begins with a tick bite, that then causes a red rash that spreads outward, looking like an expanding circle (or target). In its later stages, Lyme disease can cause joint pains, fatigue, heart problems, facial palsy, and nerve pain. If this is suspected at all, then we will send you to an infectious disease doctor for further workup. This is because there are a lot of nuances in testing for Lyme disease, and it is common to have "false positive" results (test suggests a diagnosis of Lyme disease, when that is not the case).

What other diseases can be confused with Meniere's disease, and how do you tell them apart?

Disease	Typical Symptoms	How do you tell it apart from Meniere's disease?
Vestibular Migraine	Dizziness, which can last for seconds to years. Migraine can also cause light/sound sensitivity, visual disturbances, headaches, head pressure, ear pressure, tinnitus, and facial pressure. One big clue is a personal or family history of migraine, but this is not always the case.	Vestibular migraine is VERY common- MUCH more common than Meniere's. It can cause similar symptoms, like tinnitus, ear fullness, dizziness, and sound sensitivity. However, hearing is usually unaffected. And the patient will usually have a history of migraines AND/OR migraine symptoms (light/sound sensitivity, or headaches) closely timed with attacks of dizziness.
Autoimmune Hearing Loss	Fluctuating (meaning frequently changing for better or worse) sensorineural (inner ear) hearing loss, usually in both ears, that gets better with oral steroids (like prednisone)	Autoimmune hearing loss usually involves both ears. Many patients have already been diagnosed with another autoimmune disease. Finally, the hearing usually improves with oral steroids, like prednisone.
BPPV (Benign Paroxysmal Positional Vertigo)	Intense dizziness lasting seconds to 1 minute, that is triggered by positional changes (usually rolling over in bed)	BPPV doesn't cause hearing loss. This type of dizziness is caused by specific movements (looking up or rolling over in bed).

Temporal Bone Tumors	Usually just cause one-sided hearing loss, and/or tinnitus, but can cause dizziness	MRI can effectively rule out the possibility of a temporal bone tumor.
Otosyphilis	Otosyphilis can cause similar symptoms to Meniere's disease, including hearing loss and dizziness.	It's a sexually transmitted disease, so it's very unlikely to occur without any behavior that puts someone at risk of an STD. In those patients, a blood test can effectively rule out the possibility of otosyphilis.
Lyme Disease	Commonly causes a spreading target-shaped rash, followed years later by joint pains, heart problems, and nerve damage. This nerve damage can present in variable ways, including hearing and balance symptoms.	Since it's transmitted by a tick bite, it's unlikely to happen without that history. It's also unlikely to occur in places where Lyme isn't endemic. This can be worked up with a blood test.
Multiple Sclerosis	Causes nerve problems, like numbness, weakness, blurry vision/blindness, and trouble with coordination/walking.	Multiple sclerosis usually affects the whole body, not just the hearing and balance mechanisms. If it is suspected, then further workup is done by a neurologist. Also, certain findings on MRI of the brain, which is done as part of the workup of Meneire's, will usually show abnormalities with multiple sclerosis (white matter plaques).
Perilymphatic Fistula	A perilymphatic fistula (PLF) refers to a drainage of inner ear fluid into the middle ear. This can occur (rarely) after head trauma, such as a skull fracture, or surgery (typically stapes surgery). Some	Perilymph fistula can be suspected if there is an inciting event, such as a skull fracture or a stapes surgery, which causes hearing loss and vertigo. There is no test that can

	<p>physicians believe that the membranes that separate the inner and middle ear (the round and oval windows) can spontaneously rupture, causing symptoms of vertigo, hearing loss, and ear pressure. However, this is very controversial (meaning many physicians don't believe that this can occur).</p>	<p>diagnosis this condition. Generally, the vertigo should occur with middle ear pressure changes, such as occur with coughing, sneezing, or straining. If suspicion exists, then we can perform a fistula test, where we put air pressure against the eardrum, and look for eye movement that indicate that the middle ear pressure changes are being transmitted to the inner ear.</p>
<p>Superior Semicircular Canal Dehiscence (SCD)</p>	<p>SCD is a rare disease that results from absent bone over part of the inner ear. This causes several symptoms, including autophony (hearing your own voice abnormally loudly), hearing other bodily sounds that you shouldn't hear (like hearing your eyeballs move), hearing your heartbeat in your ears, and dizziness that is provoked by loud sounds, or coughing/sneezing/straining.</p>	<p>SCD causes a slightly different set of symptoms than Meniere's disease, so usually they can be distinguished. Further workup of SCD involves a VEMP test (done by a balance audiologist), and a CT scan of the temporal bones.</p>
<p>Vestibular Paroxysmia</p>	<p>This is a rare disease, that can cause brief intense feelings of vertigo, that can be triggered by head movements or exercise.</p>	<p>Vestibular Paroxysmia is very rare. In addition, it does not usually cause hearing loss, and the dizziness lasts a few seconds, not minutes to hours, which is typical for Meniere's disease.</p>
<p>Vestibular Neuritis</p>	<p>This refers to an inflammation of the balance nerve, which causes a very intense feeling of spinning that usually lasts at least a</p>	<p>Vestibular neuritis is typically a one-time event, whereas Meniere's disease causes recurrent symptoms</p>

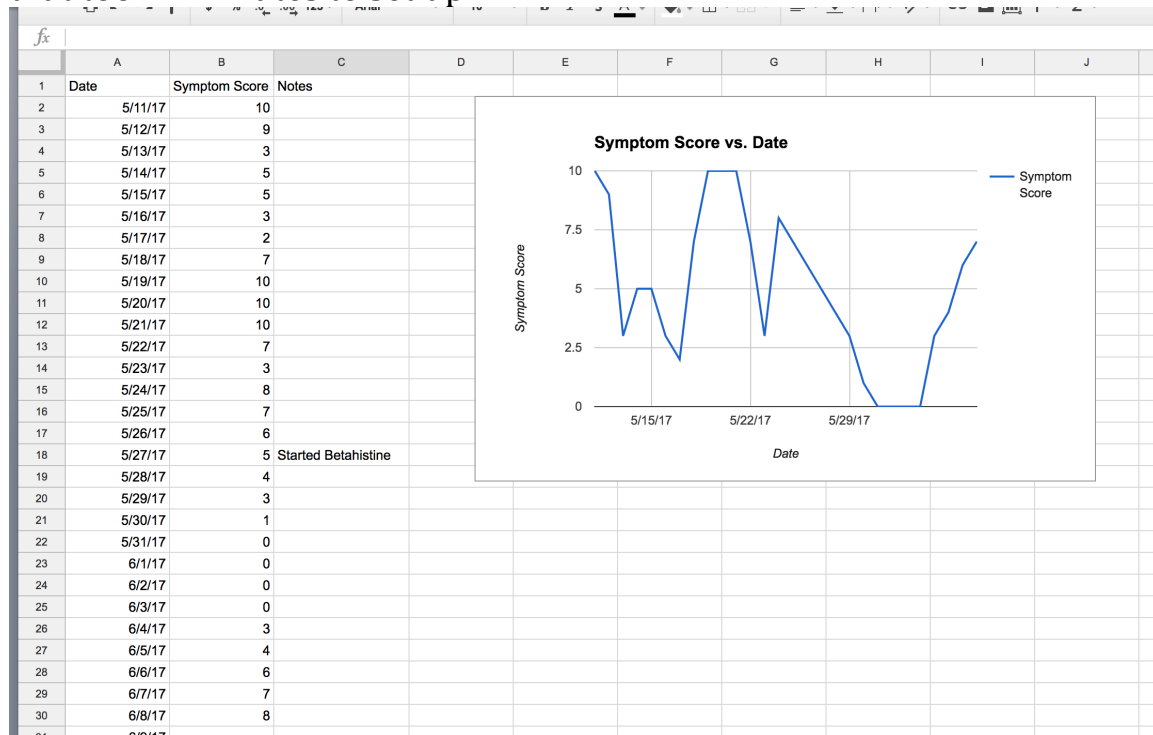
	day, if not longer. There is no hearing loss. Most patients will just have the one episode of vertigo, but will then have some dizziness with rapid head motions that occur until the brain compensates for the damage that was done.	over many years. Also, there is no hearing loss with vestibular neuritis. Finally, a physical exam usually shows a typical finding (positive head impulse test) with vestibular neuritis.
Labyrinthitis	Labyrinthitis refers to an infection of the inner ear. This starts abruptly with dizziness that lasts several days, in addition to profound hearing loss. The dizziness then gets better over time as the brain compensates for the hearing loss.	Labyrinthitis is a one-time event where typically all hearing and balance function is lost at once, whereas Meniere's disease causes recurrent symptoms for years.
Patulous Eustachian Tube (PET)	PET is the rare condition of having a Eustachian tube that is abnormally open (usually it's closed all the time, and just opens when you swallow). This causes a feeling of ear fullness, but you also hear your own voice and breathing abnormally, like you are in a barrel where sounds echo or reverberate around in your head.	PET does not cause hearing loss or vertigo, just ear pressure.

What should I be doing to keep track of symptoms?

I recommend that all patients with Meniere's disease keep track of their symptoms with a diary. Since all treatments are trial and error, it's important to have your careful observations as feedback to tell whether or not a treatment is helpful. In other words, since we aren't sure ahead of time if a particular treatment is going to be beneficial, we need to have a record that summarizes your symptoms both before and after treatment.

The details of the symptom diary are really up to you. The simplest way to keep track of symptoms is just to sum up all your symptoms (ear pressure, vertigo, dizziness, tinnitus, hearing loss) each

day into a number from 0 to 10, with 0 indicating “no symptoms”, and 10 indicating “the worse possible symptoms”. Then, record your “number” each day. We recommend doing this in Google Sheets. It’s free, secure, and easy. Below is a screenshot of a sample symptom diary that took 2 minutes to set up.



All you need to do is open a new spreadsheet. Then create 3 columns: one column for date, one for the symptom score, and one for notes. If you input the current date into a cell, you can just drag that one cell down, and Google will fill in new dates for you, sequentially from your starting date. In effect, this means that each row will represent one day. Once you have some data, you can highlight that data, and then click “insert” and “chart”, and you will be able to see a graph detailing your symptoms. For notes, we suggest that you mark down when you start and stop a new treatment, or anything else that seems relevant.

If you prefer to record more data, that is totally fine. Create a category for each symptom that you get from Meniere’s disease. In addition, you can create “composite score”, which is a calculated value that is the average of all the individual symptom scores. You can weight each symptom differently if you feel that some influence the impact of your disease on the quality of your life more than others.

If you aren't computer savvy- don't worry. Just use the simplest diary that works for you, which can even be just marking a number from 1-10 each day to represent your symptoms on a calendar.

Why are my treatment options?

There are quite a few treatment options in Meniere's disease. In fact, the number of different options can be overwhelming! This can make it difficult to figure out which treatment is right for you, which treatments you should try, and in what order. Before we start getting into details, it's important to realize the success of each treatment is measured by the reduction in frequency of vertigo attacks. That means that someone feeling less dizzy indicates a treatment success.

Many new patients ask if anything can be done to change the course of the disease, which damages balance and hearing over time. The sad answer is "no", there is no therapy that currently exists that has been shown in a study to alter the "natural history" of Meniere's disease. That means that the medical profession currently doesn't have a way to prevent damage to the inner ear caused by Meniere's disease. However, there are effective ways to treat the hearing loss and balance problems caused by Meniere's disease. Also, keep in mind, most people say that the worst part of Meniere's disease is not the hearing loss, but instead the attacks of vertigo, and the randomness and severity of those attacks, which most affect quality of life. For preventing attacks of vertigo, there are several effective treatments.

To simplify things, we can consider 4 categories of treatment:

Treatment Category	Details
Treatments that aren't harmful (most of the time), and seem to be helpful for some people	<p>This category covers the majority of treatments for Meniere's disease. The evidence for each is reviewed below. The "standard" treatments, at least in the United States, fall into this category</p> <ul style="list-style-type: none"> - Low salt diet - Water pill (diuretic) - Steroids (usually injected into the ear) <p>In addition, there are numerous other therapies that don't appear to be harmful, and some people swear by them, but there is really no good evidence that they are helpful</p> <ul style="list-style-type: none"> - Betahistine - Endolymphatic sac surgery (there is some new data regarding a variant of this procedure that is discussed below)
Treatments that work, but do so by ablating (destroying) inner ear function	<p>This category covers several very effective treatments. However, they all work by damaging the inner ear. The concept is that by damaging the ear, the ear will become too "weak" to generate attacks of vertigo. However, they come at a cost, which is that any remaining hearing function of the ear can be lost.</p> <ul style="list-style-type: none"> - Gentamicin - Labyrinthectomy - Vestibular Nerve Section
Rehabilitation	<p>This category covers treatments that help compensate for the damage done to the inner ear by Meniere's disease</p> <ul style="list-style-type: none"> - Hearing aids - Cochlear Implants - Vestibular Rehabilitation
Symptomatic Treatments	<p>These treatments aren't thought to change the disease. Instead, they just treat symptoms caused by the attacks of vertigo, including dizziness, and nausea</p> <ul style="list-style-type: none"> - Meclizine

	<ul style="list-style-type: none"> - Phenergan - Benzodiazepines - Zofran
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Ok, now that we have gone over the broad details, let's go through each treatment in detail.

Category	Treatment	Details
Treatments that aren't harmful (most of the time), and seem to be helpful for some people	Low Salt Diet	<p>Low salt diet is very commonly used as the first line treatment for Meniere's disease. It's thought to lower the pressure in the inner ear. While there is little evidence that it is helpful, there are certainly some patients who notice a difference. Finally, a low salt diet (like 1500 mg of sodium daily) is recommended by the American Heart Association for overall health anyway. Here is a link to some information regarding a low salt diet: https://www.ucsfhealth.org/education/guidelines_for_a_low_sodium_diet/.</p>
	Diuretic/Water Pill	<p>A diuretic (like triamterene/hydrochlorothiazide, or acetazolamide) is also very commonly used a first line therapy. The concept is similar to the low salt diet: attempting to lower the pressure in the ear. Reviews of the best available evidence show inconclusive findings, but low quality evidence seems to indicate that diuretics may be helpful, at least for some patients³ ⁴. To date, there have been two clinical trials performed with a placebo group, and patients randomized to treatment.⁵ ⁶ They both concluded that diuretics are helpful with preventing attacks of vertigo, but both study designs have been criticized. It's recommended that you keep an eye on your blood pressure and electrolytes (such as potassium) while on a diuretic, and this is done through your primary care doctor.</p>
	Steroid Injections	There have been several studies that

	(Intratympanic Steroids)	<p>show benefit of intratympanic steroid injections. This is a procedure that involved numbing an area of the eardrum, and then injecting a steroid solution through the eardrum directly into the ear. The procedure takes about a minute, and can cause brief discomfort. Most patients tolerate the procedure fine. Afterwards, you lie down with the injected ear facing upwards for 20-30 minutes. Then you may return to your normal daily activities. For a few weeks after the injection, it's recommended to avoid getting water in the ear. The risks of the procedure are really low. There is about a 1% risk of a perforated eardrum. A small trial in 2005 in Mexico showed benefits of steroid over placebo.⁷ Two other larger trials compared steroid injections to gentamicin injections (discussed below), and found conflicting results.^{8 9} Casani et al. found that gentamicin provided much better control of vertigo, whereas Patel et al. found that gentamicin and steroid injections provided similar control of vertigo. Given all this, we think that there is good evidence to support the use of steroid injections in Meniere's disease, given that the risks are low, and the potential benefits are high. They clearly do not work in everyone, but it is most reasonable to try this treatment prior to any destructive treatments.</p>
	Betahistine	<p>Betahistine is a medication that is taken by mouth for Meniere's disease. It is very commonly used in Europe, Canada, and other parts of the world, and much less commonly used in the United States. It's not clear how it works, some think that it improves blood flow to the cochlea. In a large multicenter randomized clinical trial (BEMED trial), patients did equally well on placebo, low-dose betahistine, or high-dose betahistine.¹⁰ That means that</p>

		<p>we have some reasonable evidence that betahistine doesn't really work. Therefore, we do not usually suggest it as a treatment option. On the other hand, it does not seem to cause significant side effects, and it is very safe. Therefore, if a patient wants to give it a try, based on their own research, we don't see much harm in that, and we are happy to provide a prescription. In the US, the drug has to be compounded (made for you by a special pharmacy), or ordered from Canada, and therefore it can be a little expensive. It takes more effort to get this medication than other medications that are approved by the FDA.</p>
	<p>Meniett Device</p>	<p>The Meniett device uses pulses of pressure to treat Meniere's disease. Since the eardrum prevents pressure transmission to the ear, an ear tube must be placed prior to using the device. Ear tubes are placed in the office, and it takes about 2 minutes for placement. There is always a small risk (1-2%) of having a persistent hole in the eardrum after placing an ear tube. There have been several placebo controlled randomized trials looking at whether or not the Meniett device works. Ultimately, there does not seem to be a beneficial effect from the device.¹¹ A recent, large, multicenter trial did not find any advantage of the device over a placebo.¹² Given the available evidence to date, we do not routinely recommend the Meniett device. However, we do believe it to be low risk, so if someone really wants to try it, based on their own research, we can help facilitate that.</p>
	<p>Endolymphatic Sac Surgery</p>	<p>The endolymphatic sac is a part of the inner ear. While no one is really sure of its exact function, there are theories that it's involved with absorption of endolymph, or that it has an immune related function. In 1927, Portman</p>

described shunting of the endolymphatic sac as a treatment for Meniere's disease, and it has been hotly debated ever since. The surgery involves a relatively safe procedure that takes about 3 hours, with patients able to go home the same day. However, all surgeries do carry some element of risk, related to general anesthesia, the incision (infection, numbness, bleeding, scarring, pain) and the vulnerable structures near the area of surgery (hearing and balance mechanism, nerve that moves the muscles of the face, eardrum, ear canal, and brain). To date, there have been 2 clinical trials that examined this surgery,¹³ both by the same group of authors. They found that patients improved after endolymphatic sac surgery, but that patients also improved after a "placebo" surgery. Therefore, they concluded that endolymphatic sac surgery is not effective. Other authors have argued that their analysis of the data was incorrect.¹⁴ Also, some would argue that if ~2/3rd of patients get better with surgery, perhaps it is worth doing even if there is a "placebo effect". Therefore, our approach is to say that we are certainly willing (and able) to perform endolymphatic sac surgery, but that we cannot strongly recommend it based on current evidence.

More recently, a group in Montreal led by Professor Issam Saliba have published results on a variation of the endolymphatic sac procedure.¹⁵ Instead of trying to decompress or "shunt" the sac, they separate the sac from the rest of the inner ear. That is accomplished with placing titanium surgical clips along the endolymphatic duct, which connects the sac to the inner ear. Dr. Saliba has done this procedure in over 200 patients, and reports that the results are quite good,

		<p>with 95% of patients getting permanent relief from vertigo, and ~20% getting improvement in hearing. However, these results are early, and have not been corroborated with other centers. Furthermore, there is a long history of proposed “miracle cures” for Meniere’s disease, and in general we advise suspicion until there are well conducted studies that prove that a new treatment is efficacious. While we don’t have much personal experience with this procedure, based on the published results and the relatively low risk of side effects we are happy to discuss the procedure to patients who are not getting any benefit with other treatments in person.</p>
<p>Treatments that work, but do so by ablating (destroying) inner ear function</p>	<p>Gentamicin Injection</p>	<p>Gentamicin is an antibiotic within a class of antibiotics called aminoglycosides. Long ago, aminoglycosides were noted to have the side effect of causing hearing and balance impairments. This has been studied further, and it turns out that gentamicin is toxic to inner ear hair cells, which are critical to the sensory function of the ear. Interestingly, gentamicin is much more toxic to vestibular hair cells (ones responsible for balance, and also responsible for the symptoms of Meniere’s disease), than to cochlear hair cells (the ones responsible for hearing). The basic idea behind gentamicin is to further weaken/damage the inner ear, so that it can no longer cause episodes of vertigo. In cases where Meniere’s has already damaged the ear, it is sometimes advantageous to just “finish the job”, and further poison the ear so that the Meniere’s “burns out”, or is no longer capable of causing symptoms. This procedure is done in the office, and is similar to a steroid injection in the ear. The risk of creating a hole in the eardrum is low, about 1%. There is a risk hearing loss (about 17% risk of a small change in</p>

hearing), and deafness (~3% risk).¹⁶ Many patients we see are under the impression that gentamicin always causes deafness, but this is certainly not the case, it's just a known potential side effect. The other side effect is that gentamicin can reduce the normal functioning of the balance system beyond the injected ear. This is most notable with a reflex called the vestibulo-ocular reflex, which keeps things that we are looking at (visual targets) steady as we walk or move our heads. With damage to that reflex, one can experience dizziness or blurred vision with rapid head turns. What is really occurring is that the eyes now need a fraction of a second to catch up with the head. Luckily, vestibular physical therapy is pretty effective in rehabilitating that reflex (like all rehab, it can never restore perfect function, but it does restore good enough function). About 50% of patients get relief with one injection of gentamicin, and the other 50% need more than one injection. We prefer to slowly titrate the injections, meaning that we give one, and then see how you do and repeat as needed. The reasons we space out injections are to minimize risk to hearing, and also to maintain any residual balance function. The decision to proceed with gentamicin is a tough one to make, given all the information above. However, there is really good evidence from multiple trials that it's highly effective.¹⁷ It is the one treatment that almost always works, which is pretty remarkable considering it's a procedure done in the office. For patients who have tried the non-destructive treatments, have not gotten better, and feel that their disease is significantly changing their lives, we do recommend gentamicin. The decision is much easier to make if the Meniere's

	<p>disease has already damaged the hearing, as you have less to potentially lose. Finally, there are some cases (about 5%) of bilateral Meniere's, where the disease affects both ears. In those cases, we do employ extra caution when considering gentamicin, because we don't want you to lose balance function in both ears. That can result in severe imbalance and unsteadiness. Luckily, bilateral Meniere's disease is relatively rare.</p>
Labyrinthectomy	<p>Labyrinthectomy refers to surgical destruction of the inner ear ("the labyrinth"). The procedure is done under general anesthesia, and usually takes about 3 hours. All residual hearing and balance function is lost with the procedure. Unlike gentamicin, which can produce a partial ablation, labyrinthectomy always produces a complete loss of function. The rationale for this procedure is similar to gentamicin: since the ear has been damaged by Meniere's disease, by "finishing the job", or completing the damage, the ear will no longer be able to generate attacks of vertigo. The success rate is very high, provided that the diagnosis of Meniere's disease was correct. However, like with gentamicin, there are certain "costs" associated with destroying the ear. This includes loss of all residual hearing ("deaf ear"), and also loss of any remaining balance function. This can cause dizziness with head movements, and also unsteadiness. Vestibular physical therapy is used to help with compensation afterwards. You usually stay in the hospital for 1-3 days after the surgery. Additionally, there are risks related to any ear surgery, including infection, numbness, bleeding, scarring, and pain, damage to the nerve that moves the muscles of the face, to the taste nerve, to the ear canal or eardrum, and leakage</p>

		<p>of spinal fluid. Since the advent of gentamicin, we are doing labyrinthectomies much less frequently. This is because we can usually achieve the same result, but with an outpatient procedure, rather than an invasive surgery. Furthermore, since gentamicin produces a partial loss of function, and labyrinthectomy produces a complete loss of function, rehabilitation is usually better and easier after gentamicin. Therefore, we are usually doing labyrinthectomies in only a few situations: if someone had gentamicin, but didn't get any benefit, or if we want to do another surgical procedure at the same time (like a cochlear implant to restore hearing).</p>
	Vestibular nerve section	<p>A vestibular nerve section is a surgical procedure where the vestibular (balance) nerve is divided. This procedure is done under anesthesia, and involves a "craniotomy", which means creating an opening in the skull to access the brain cavity. The nerve is then cut near the opening of the internal auditory canal, which is a bony tunnel through which the hearing and balance and facial nerves travel on their way from the brain to the ear. Because of this, the procedure carries all the risks of a labyrinthectomy, but also leakage of spinal fluid, and damage to the brain (seizure/stroke/death). With that said, risks are actually pretty low, and it's considered a safe procedure. The usual hospital stay is 2-4 days. The procedure is often done with both an ear surgeon and a neurosurgeon. The distinct advantage of this procedure over a labyrinthectomy is that hearing is preserved, because only the balance nerves are cut, not the hearing nerve. Hearing loss is always a risk of the procedure, but that risk is low (~5%).</p>

		<p>However, similar to a labyrinthectomy, this produces a complete loss of balance function. Since gentamicin is much lower risk, and it only produces a partial loss of balance function, and the risk to hearing is relatively low, we generally think that gentamicin injections are preferable to a vestibular nerve section.</p>
Rehabilitation	Regular Hearing Aid	<p>Hearing aids are very useful for restoring hearing that has been lost due to Meniere's disease. Every year hearing aid options and function improve, as technology advances. Today's current models employ a variety of technologies designed to improve sound clarity, including directional microphones, background noise reduction, and digital processing of the sound information. Additionally, it is increasingly easy to connect a hearing aid to other devices, such as a cellphone, or a TV. For Meniere's disease, we recommend seeing an audiologist to properly fit the hearing aid rather than ordering a listening device online. That is because there are some nuances with hearing aids and Meniere's disease. For example, the hearing can deteriorate over time, and therefore you usually want to get a more powerful hearing aid than you need, just in case that occurs. Hearing aids are tailored (programmed) to your specific pattern of hearing loss based on your hearing test. It's worth paying particular attention to one variable on the hearing test: the word recognition score (WRS). This score is a measure of how clearly words are perceived, provided that they are loud enough. This is important, because beyond a certain level of hearing loss, it doesn't really matter how loud you can make the sound with a hearing aid, speech will just sound like noise without clarity. As a rule of thumb, if the WRS is above 50% correct, then a hearing aid is</p>

	<p>helpful in restoring sound for communication. If the value is below 50%, then a hearing aid is more likely to just amplify noise, and not provide clear sound, and is therefore not as helpful. In those cases, a CROS hearing aid, a bone anchored hearing aid, or a cochlear implant can be helpful (see below). Hearing aids are also the single best treatment for tinnitus, or ringing in the ears.</p>
CROS Hearing Aid	<p>A CROS (contralateral routing of sound) hearing aid is a specialized type of hearing aid that takes sounds from the side of the bad ear, and sends them over to the good ear. This requires wearing two devices, a microphone on the bad ear, and a receiver (aka speaker) in the good ear. Patients with single sided deafness usually experience 4 problems:</p> <ul style="list-style-type: none">- Trouble hearing sounds that are directed towards the bad ear. For example, if I have right sided hearing loss, and I am driving a car, I will have trouble hearing the passenger.- Difficulty telling where sounds are coming from.- Increased difficulty with listening in noisy environments.- Listening takes more energy, so you are more tired at the end of the day. <p>CROS hearing aids are good for the first problem (hearing sounds on bad side), they don't help with the second problem (sound localization), and there are mild benefits with the third and fourth problems (background noise and listening fatigue). However, they are non-invasive, and there is a trial period for all hearing aids allowing you to return them within 45 days if you do not find them helpful. There are no downsides, other than lost time/money. Therefore, it's</p>

		always reasonable to try a CROS hearing aid.
	Bone Anchored Hearing Aid (BAHA)	<p>Similar to a CROS hearing aid, a BAHA is used to treat single sided deafness. However, this is a surgical procedure. The concept is that by vibrating the skull on the bad side, the sounds can be sent through the skull to the good side (meaning we don't "feel" those vibrations, we "hear" them, and they sound just like regular sounds). There are two BAHA variants: one where a screw is placed into the skull, and comes out through the skin, and a sound processor is snapped onto that. In the second variation, a magnet is screwed to the skull, then it is coupled to an external magnet, which is attached to the sound processor. In this second type, there is no screw coming out through the skin as a magnet holds the processor in place. The sound quality is slightly better with the screw coming through the skin (because no sound energy is lost in transmission of vibrations across skin), but on the other hand, some people don't want to have a screw coming out through their skin. Interested patients are encouraged to visit the company websites (www.cochlear.com , www.oticonmedical.com and www.sophono.com). In general, the sound quality is very good with a BAHA, and you only have to wear one device (as opposed to two with a CROS aid). However, it does involve a surgical procedure, with risks of infection, wound problems, healing problems, bleeding, scarring, pain, and failure of the device to properly heal into the bone.</p>
	Cochlear Implant	<p>Cochlear implants are used to restore hearing for single sided deafness. Unlike the CROS and the BAHA, they actually restore hearing to the damaged ear, rather than sending sounds over to the good ear. A surgical procedure is needed</p>

		<p>to place the implant, which takes 2-3 hours. The procedure is done as an outpatient, and you go home the same day. It's important to know that this is a fundamentally new and different way of hearing, and therefore it takes quite a bit of time for the brain to adapt and "relearn" how to hear. It also takes effort, and wearing the device as often as possible is necessary to maximize benefit. It's also important to know that at the time of writing, the FDA has not yet approved the devices for use with single sided deafness, instead they require both ears be deaf prior to implantation. This means we are using the devices in an "off label" fashion, and also that we may have a fight with your insurance company to get the device approved. Interested patients are encouraged to learn more through the company websites: www.cochlear.com, www.advancedbionics.com, and www.medel.com. Interestingly, cochlear implants seem to be really helpful for tinnitus associated with single sided hearing loss.</p> <p>-----</p> <p>Vestibular rehabilitation therapy (VRT)</p> <p>-----</p> <p>Some physical therapists (PTs) are specifically trained in evaluation and rehabilitation of vestibular weaknesses. These PTs can meet with you to assess your balance abilities and then teach you a series of exercises to help your balance system compensate for the damage done by Meniere's disease or due to treatments for the disease. VRT typically requires a series of 3-5 visits with a PT, with exercises done by patients at home in between.</p>
Symptomatic Treatments	Meclizine	Meclizine is an antihistamine that is used to treat dizziness. The most common misconception is that it can prevent

	<p>dizziness. This is not the case, instead meclizine is used to make you feel better if you have dizziness (meaning to reduce the intensity of the dizziness that you are feeling). Sedation is common, and dry mouth can occur. It is usually taken by mouth, as needed for dizziness, and 25 mg is the typical dose. It should be used very cautiously in the elderly, if at all.</p>
<p>Benzodiazepines (like Clonazepam/ Klonopin or Valium/Diazepam)</p>	<p>Benzodiazepines are also used to symptomatically treat dizziness. That means that they will lessen the intensity of the dizziness that you experience, but they do not prevent future attacks of dizziness. They are stronger than meclizine, and therefore should be tried if meclizine is not found to be effective. A common dosage is 0.25 or 0.5 mg of clonazepam, taken as needed for dizziness. One serious concern with benzodiazepines is their addictive potential. Therefore, great caution is needed, and they should only be used a couple times per month. We believe that more frequent usage can be dangerous to you, addicting, and counterproductive to your balance system. Side effects include sedation, mood changes, and dizziness (ironically all medications that treat dizziness carry this possible side effect).</p>
<p>Zofran</p>	<p>Zofran is a strong anti-nausea medication. It is fast acting, and effective. The usual dose is 4 mg, and there is a formulation that dissolves under the tongue. Possible side effects include headache, heart rhythm changes, and liver and GI problems. However, most of the time it is well tolerated, and it seems to be very effective.</p>
<p>Phenergan</p>	<p>Phenergan is another anti-nausea medication. The usual dosage is 25 mg; it can be given orally or as a suppository. It is usually well tolerated, but possible side effects can include heart problems, skin problems, allergic reactions, dry mouth,</p>

	dizziness, sedation, and other rare but serious side effects. We usually find that Zofran is more effective, but Phenergan is a good option to try in patients who don't get good nausea relief with Zofran.
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Which treatment should I choose?

While there isn't a right or wrong answer to this question, here is my advice:

- Everyone should eat a low salt diet. It's not harmful, and the American Heart Association recommends keeping salt under 1500 mg anyway for cardiovascular health. Plus, it may be beneficial for Meniere's.
- Everyone should try a diuretic at some point. While the evidence isn't great, this treatment is considered "standard of care", and the benefits seem to outweigh the risks. We don't advocate for being on a diuretic forever if you don't feel like it is helping. We do feel that a 3-month trial is very reasonable in everyone with Meniere's disease, to see if it's helpful to you.
- If you are still getting vertigo attacks, despite eating a low salt diet, and taking a diuretic, then you should try steroid injections. There is good evidence that they are helpful for many patients. In fact, I recommend trying a steroid shot at least 3 times. The harm (risk of a small hole in the eardrum) is relatively low (1%), and the procedure is usually well tolerated (meaning while it certainly isn't fun, most patients don't think it's particularly painful).
- If you are still getting vertigo attacks, and low salt diet, diuretic, and steroid injections aren't helping, you should think about endolymphatic sac surgery. See above for an in-depth discussion.
- If you are still getting vertigo attacks, and low salt diet, diuretic, and steroid injections aren't helping, you should think about a gentamicin injection. We see many patients whom I think would benefit from gentamicin, but who choose not to try it for fear of side effects. While there are certainly side effects to gentamicin injection, it's very effective at preventing attacks of vertigo. Therefore, you have to weigh which is worse- the side effects, or the attacks of vertigo. The side effects include a possibility (17%) of worsened hearing, 3% risk of deafness, and likelihood of oscillopsia (inability of the eyes to keep up with the head with

- quick head movement, resulting in blurring of the visual world with quick head movements)¹⁶. However, hearing loss can be treated with a hearing aid or cochlear implant, and oscillopsia can be treated with vestibular physical therapy.
- You should definitely do your own research, and talk to other Meniere's patients through online chat rooms and support groups.
 - If hearing loss bothers you, you should consider a hearing aid, or a cochlear implant. The device can be a traditional hearing aid if there is still some hearing in the ear, or a CROS or bone anchored hearing aid if there isn't adequate hearing in the affected ear.
 - If you have imbalance, or oscillopsia (blurring of the visual world with quick head movements), then you should do vestibular physical therapy.
 - You should have a plan for any attacks of vertigo, with medications to help you feel better during attacks. This usually includes a medication to treat nausea (like Zofran, which comes in a form that dissolves under the tongue), and also a medication for dizziness (like Clonazepam or Meclizine).
 - Anyone who develops anxiety or depression because of Meniere's disease should see a mental health professional.
 - If you have a history of migraine, then you should try migraine treatments before doing any ablative treatments for Meniere's disease. The two disorders are closely related, and we find that patients will often get better with migraine treatments.

Migraine

More than half of patients with a clear diagnosis of Meniere's disease have a history of migraine, which is way higher than would be expected by chance.¹⁸ There is a strong connection between these two diseases, which we don't really understand. It's possible that migraines predispose people to the development of Meniere's disease. Furthermore, migraine is the most common cause of dizziness in the United States, far more common than Meniere's disease. Sometimes patients with Meniere's disease, and a history of migraine, have "migrainous" features during attacks of vertigo, including light sensitivity, sound sensitivity, or headache/head pressure. Therefore, if there is a history of migraine, or migrainous features during attacks of vertigo, the migraine aspect of the disease should be treated.

It's beyond the scope of this review to discuss migraine treatments, but please consider reading this excellent review of migraine associated dizziness:

http://www.hopkinsmedicine.org/otolaryngology/_docs/Migraine%20patient%20handout.pdf.

In short, migraine treatment involves avoidance of migraine triggers (such as stress, poor sleep, pain, certain foods, hormonal changes, and sensory trigger like bright lights or strong smells), use of vitamins/dietary supplements (magnesium, riboflavin, and others), and prescription medications.

Many people underestimate migraine, and how much it can be contributing to balance and ear symptoms.

When should I get vestibular testing done?

Vestibular testing, at this point in time, is not needed to diagnose Meniere's disease. In the late stages of the disease, many patients do end up with abnormalities on vestibular testing. These are not specific to Meniere's disease, but are a marker of the damage it does. This includes unilateral weakness on caloric testing, and changes to the VEMP (vestibular evoked myogenic potentials) responses. Interestingly, vHIT (video head impulse test) testing is usually normal (except during attacks). It seems clear that testing should be done before any ablative treatment, like gentamicin or surgery.

What about other treatments that I heard about, or found through research on the Internet?

Meniere's disease is life changing, and while there are numerous treatments available, there isn't currently an ideal "cure". In that vacuum, there is a never-ending supply of unproven treatments. All of them are supported by anecdotal evidence (meaning that some people tried them, and found them to be effective). We cannot endorse any treatment that has not been evaluated in a scientific study. This is because we know that no matter what we do, some patients will get better (just because the disease tends to get better over time). Unless a new treatment is evaluated by a scientific study, where it is compared to a placebo, we really don't know if it is effective. Furthermore, as with all medical treatments, there is always a potential for harm. So, feel free to do your own research, but please maintain a good degree of suspicion.

If these therapies really worked, then why wouldn't their inventors want to study them scientifically, and prove it?

Are there any good resources on the Internet for Meniere's disease?

Yes- there are. See below. In particular, I think there is a lot of really good information on Dr. Timothy Hain's website, which is the first link.

Dr. Tim Hain Website, section on Meniere's disease (highly recommended)

<http://www.dizziness-and-balance.com/disorders/menieres/menieres.html>

National Institute of Health (NIH) website

<https://www.nidcd.nih.gov/health/menieres-disease>

Vestibular Disorders Association

<http://vestibular.org/menieres-disease>

Wikipedia

https://en.wikipedia.org/wiki/M%C3%A9ni%C3%A8re%27s_disease

Final thoughts:

Meniere's disease can be horrible to experience. It is a life changing illness that causes sudden and violent episodes of dizziness, tinnitus, and ear pressure, all the while slowly destroying the inner ear, causing permanent hearing damage. The episodes occur suddenly and without warning, and are very intense, so it is common to experience anxiety, stress, sadness, and a sense of hopelessness. These are all important things that have to be addressed as well. Sometimes patients do well with their own coping strategies, like family/friend support, meditation, mindfulness, exercise, yoga, tai chi, and things like that. Other times, they require help, like from a psychiatrist, to help treat any anxiety and depression that can occur.

With treatment of Meniere's, the goal is to reduce and prevent the episodes of dizziness. We are usually able to achieve that goal, because we have the option of chemically or surgically damaging the inner ear intentionally so that it can no longer cause episodes of vertigo or dizziness. Currently, we don't seem to be able to prevent the hearing loss that occurs over time, but we are able to offer treatments for that hearing loss (like hearing aids, or cochlear implants when hearing aids are no longer successful). Many scientists around the world studying Meniere's disease, and we continue to hope that we can figure out the causes of Meniere's disease, and how to cure it.

Meniere's disease worksheet

(Please indicate what prior treatments you have had.) The purpose of the worksheet is to help you figure out what you have already tried, what works for you, and what you have not yet tried that perhaps would be reasonable.

Treatment	Tried It?	Did it Help?	Details
Low Salt Diet			
Diuretic (water pills- like HCTZ/Triamterene, or Diamox)			
Oral Steroids (Steroids, like prednisone, taken by mouth)			
Intratympanic Steroids (steroid injections into the ear)			
Betahistine			
Meniett Device			
Endolymphatic Sac Surgery			
Intratympanic Gentamicin (Injection of antibiotic into the ear, with the goal of poisoning the inner ear balance system)			
Vestibular nerve			

section (surgical cutting of the balance nerve)			
Labyrinthectomy (Surgical destruction of the inner ear)			

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