

AVASCULAR NECROSIS OSTEONECROSIS

A Detailed Guide to Diagnosis: By Patients, for Patients



www.facebook.com/groups/DeadBoneDiseaseAVN

Written by Deborah L. Andio



To the family members of the patients:

We want you to know we love you, and we understand you can't possibly comprehend the pain we feel. We don't want anyone's pity.

We would like you to be supportive; learn about Osteonecrosis. There will be days when we feel pretty good and other days terrible and seem cranky, but we're not upset at you, it's the pain.

Those are the days when we need you the most; a kind word, a phone call, or maybe simply make or pick up dinner.



This information booklet is provided by the FB Support Group Avascular Necrosis/Osteonecrosis Support Int'l

www.facebook.com/groups/DeadBoneDiseaseAVN/



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SO YOU HAVE BEEN DIAGNOSED WITH OSTEONECROSIS: NOW WHAT?

Here is important information you will need to know, put together by patients that know what you're going through.

Osteonecrosis is a rare disease caused by the reduced blood flow to bones in the joints. With too little blood, the bone starts to die and may break down.

OSTEONECROSIS IS ALSO KNOWN AS:

• Avascular necrosis • Aseptic necrosis • Ischemic necrosis • Idiopathic necrosis

Osteonecrosis is most often found in the hips, knees, shoulders, and ankles, but can attack any bone or joint including the jaw. You may have osteonecrosis in one or more bones, so if diagnosed you should always get checked bilaterally (both sides).

In people with healthy bones, new bone is always replacing old bone. This process keeps bones strong and also happens when children grow or if a bone is injured. In osteonecrosis, bone breaks down faster than the body can make enough strong, new bone. If you do not get treatment, the disease worsens and the bones in the joints break down. You may not be able to bend or move the affected joint very well, and you may have moderate to extreme pain in the joint.

WHO GETS OSTEONECROSIS?

Osteonecrosis can occur in people of any age.

WHAT CAUSES OSTEONECROSIS?

Osteonecrosis is caused when the blood flow to the bone decreases, but why this happens is not always clear. Some known causes of osteonecrosis are steroid medications, alcohol use, injury/trauma or increased pressure inside the bone.

RISK FACTORS FOR OSTEONECROSIS ARE:

Radiation treatment • Chemotherapy • Kidney and other organ transplants.

OSTEONECROSIS IS MORE COMMON IN PEOPLE WITH ILLNESSES SUCH AS:

Cancer • Caisson Disease • Gaucher's Disease • Gout • HIV • Lupus • Vasculitis • Osteoarthritis • Osteoporosis • Blood disorders such as Factor V Leiden, MTHFR and Sickle Cell Disease.



OSTEONECROSIS CAN ALSO AFFECT PEOPLE FOR NO KNOWN REASON, EVEN IF THEY HAVE NO OTHER HEALTH PROBLEMS.

WHAT ARE THE SYMPTOMS OF OSTEONECROSIS?

When osteonecrosis first begins, you may not have any symptoms. You may start to feel pain when you put weight on the joint with osteonecrosis. As the disease gets worse, you may have more pain and the joint may hurt even when you rest. Pain may be mild to severe.

If the bone and joint start to break down, you may have severe pain and not be able to use the joint. The time from the start of symptoms to losing use of the joint can range from months to more than a year.

HOW IS OSTEONECROSIS DIAGNOSED?

To diagnose osteonecrosis, your doctor will take your medical history and do a physical exam. Your doctor may then order one or more tests to see which bones are affected: X ray (not detectable in early stage) • Magnetic resonance imaging (MRI) • Computed tomography (CT) scan • Bone scan • Bone biopsy • Measure of the pressure inside the bone.

Treatment helps more if the disease is diagnosed early.

HOW IS OSTEONECROSIS TREATED?

Treatment depends on your age, stage of the disease and where and how much bone has osteonecrosis

THE GOALS IN TREATING OSTEONECROSIS ARE.

To improve use of the joint • To stop further damage • To protect bones and joints. For early stage disease, doctors may first order nonsurgical treatments. If they do not help, surgery may be needed.

Nonsurgical treatments: May relieve pain in the short term, but they do not cure the disease. One or more of these treatments may be used at the same time. PRP, Stem Cell and Prolotherapy are promising.

Medications: Nonsteroidal anti-inflammatory drugs (NSAIDs) are used to reduce pain and swelling. For people with blood clotting problems, blood thinners may be used to prevent clots that block the blood supply to the bone. If you take steroid medications, cholesterol-lowering drugs may be used to reduce fat in the blood.

Limit weight bearing: Taking weight off the joint. Your doctor may suggest that you limit your activity or use crutches This may slow bone damage and allow some healing. If combined with NSAIDs, it may help you avoid or delay surgery.

Range-of-motion exercises: Exercise of the joints with osteonecrosis may help increase their range of motion. Electrical stimulation research has shown that this can prompt bone growth. Stem Cell injections or PRP may help in the early stage.



SURGERY

In time, people with osteonecrosis may require surgery. There are four types of surgery used for osteonecrosis. Your doctor and you will decide if you need surgery and what type is best for you.

- 1. Core decompression surgery: Lowers pressure inside the bone to increase blood flow to the bone.
- 2. Osteotomy: Reshapes the bone to reduce stress on the damaged joint.
- 3. Bone graft. Takes healthy bone from one part of the body and uses it to replace diseased bone.
- 4. Total joint replacement. Replaces the joint with a manmade one.

IF YOU NEED SURGERY: A TOTAL JOINT REPLACEMENT

Remember, this is not a simple surgery. If you smoke, stop! It's not good for your bones and circulation. Take comfy, baggy clothes like jogging pants and loose fitting shirts etc. to the hospital with you.

Total Knee Replacement: The knee joint is the largest joint in the body. It is the "hinge" joint of the leg. It's the joint that allows the leg to bend and straighten. The knee joint is located at the meeting point of the thigh bone (femur) and the shin bone (tibia). The knee cap (patella) covers the area where the two bones meet.

During total knee replacement surgery, the damaged part of your knee is removed and replaced with an implant. Implants are made of various materials: stainless steel, titanium, chrome, cobalt, or polyethylene. Bone cement may also be used in the repair.

Total Hip Replacement Surgery: The hip joint helps us keep our balance and supports our weight in all of its movements. The upper end of the leg bone (femur) has a rounded head (femoral head) that fits into a socket (acetabulum) in the pelvis to form the hip joint. During total hip replacement surgery, the damaged part of the hip is removed and replaced with implants, called components. Your surgeon selects the components that are best for you based on your age, activity level, and body type.

Circulation Exercises: Although swelling is a normal response after surgery, circulation exercises help control swelling and prevent more serious complications, such as blood clots. Talk to you Doctor and learn the circulation exercises before surgery to make them easier to perform after your surgery.

Diet and Nutrition: Healthy eating and proper nutrition before your surgery aids the healing process. Eat light meals, especially a day or two before surgery.



Listed below are suggestions for preparing your home for a safe recovery.

Traffic Pattern

Move obstacles such as throw rugs, extension cords, and footstools out of your walkway. Create a wide, clear path from your bedroom to your bathroom and kitchen so you can easily move about with a walker or crutches.

Bathroom

Ask an occupational therapist how to adapt your bathroom to meet your needs during recovery. You will likely need an elevated toilet seat or commode and a shower chair.

Sitting

Sit in chairs that keep your knees lower than your hips. Choose a firm, straight-back chair to avoid reaching or bending. Keep frequently used items within easy reach, especially in the kitchen, bathroom, and bedroom, for example, food, medications, phone. It's a good idea to carry a cell phone or portable phone with you at all times during your recovery.

Stair Climbing

Talk to your doctor to see if it's okay to climb stairs without assistance, if you are able. However, you may need help with climbing stairs when you first get home. Consider installing handrails or make sure existing handrails are secure.

Laundry and cleaning

Get help with cleaning and laundry. Have a few weeks of clean clothes available.

Mail and Newspaper

Arrange for somebody to collect mail or place delivery on hold.

Meals

Arrange for help with your meals and perishable foods or buy good, healthy frozen meals.

Driving

Arrange for someone to drive you to your after-surgery appointments. Do not drive until your surgeon tells you it's okay to do so. Absolutely do not drive while taking narcotic medications.

Personal Items to Make Life a Bit Easier at Home

Walker (with 5 inch wheels, not a Rollators or walker with seat), cane, reacher (or grabber), crutches, sock aid, long-handled shoehorn, elastic shoe laces, sturdy slide-on shoes with enclosed heel.



Bathroom

Elevated commode seat, toilet seat riser, shower chair, grab bar for shower / tub, hand-held shower head, long-handled bath sponge.

Before Your Surgery Checklists:

- I have spoke to the doctor and have no further questions.
- I have not shaved my legs 3 days before my surgery.
- I have arranged for someone to drive me home when I'm discharged from the hospital.
- I have arranged for someone to drive me to my follow-up appointments.
- I have attended the total joint replacement education class.
- I quit smoking to improve healing and reduce the risk of infection after surgery.
- I had a dental check-up to make sure all my dental needs are taken care of before surgery.
- I have someone to help me for at least a couple weeks.

What to Bring to the Hospital:

A current list of medications and supplements, noting which ones have been stopped, loose pajamas or nightgown to knee length, under garments, eyeglasses, slippers with backs and rubberized sole or walking sneakers/shoes, cell phone and charger.

DO NOT BRING VALUABLES. NO JEWELRY CREDIT CARDS, CHECKBOOKS, OR CASH!

Total Joint Precautions

While recovering from surgery, you will follow specific precautions provided to you by your therapists. These precautions allow you to heal properly and help prevent potential complications. Make sure to ask your surgeon when it is safe to stop following these precautions.

Knee

- Do not pivot or twist your operated leg.
- Do not kneel or squat.

Hip

Precautions may vary, depending on the surgical approach. Your surgeon and therapist will discuss your specific precautions. General precautions are as follows:

- Do not bend your operated leg beyond a 90 degree angle.
- Do not pivot or twist your operated leg.
- Do not cross your operated leg or ankle.



YOUR HOSPITAL DISCHARGE

Most patients are ready to be discharged from the hospital one to three days after surgery; however, specific criteria must be met. You will be discharged from the hospital when:

Your medical condition is stable • You are able to eat and urinate • Your pain is controlled with oral pain medication • Your home is prepared for your safety • You successfully met physical and occupational therapy goals.

*If you have not met the criteria to be discharged home, you will be discharged to a skilled nursing facility. The hospital staff will contact the facility to arrange all that but make sure ahead of time

In general, you will do well but give it time you just had a traumatic surgery, and you will experience pain. However, it's important that you contact the surgeon's office if any of the following occur:

You have increasing pain in the operative site • There is new or increased redness or warmth since discharge • There is new or increased drainage from your incision • The operative site is increasingly swollen • Your calf becomes swollen, tender, warm, or reddened • You have a temperature above 101 for more than 24 hours

For total knee replacement, your ability to flex (bend your knee) has decreased or remains the same as when you were discharged from the hospital or rehab facility. No matter how much you prepared for your homecoming, it will be an adjustment. You will likely experience anxiety and question whether you were discharged too early. This is a normal feeling, so relax and focus on your recovery.

COMPLICATIONS

Blood Clots

Blood clots are potential complications following hip or knee joint replacement surgery. A blood clot from your leg can travel to your lungs and cause serious health complications.

The symptoms of a blood clot include: Pain and / or redness in your calf and leg unrelated to your incision. Increased swelling of your thigh, calf, ankle, or foot. Increased skin temperature at the site of the incision, shortness of breath and chest pain or pain when breathing. If you experience these contact your doctor or ER ASAP.

Surgical Site Infection

A surgical site infection is an infection that occurs after surgery in the part of the body where the surgery took place. Most patients who have surgery do not develop an infection. Some common symptoms of surgical site infection are: Increased redness and pain around the area where you had surgery. Any drainage, in particular cloudy fluid from your surgical wound. Fever: If any of these symptoms occur contact your surgeon's office immediately.



MEGAN'S STORY

I was diagnosed with avascular necrosis of the leg/hip when I was 9 years old, then a month later I found out got it in my right hip. I spent 6 hours in A&E to finally get diagnosed. My journey was like a rollercoaster, I had struggles. I have had 3 main operations and was in hospital for 5 weeks when I was 10.

The pain was so bad all I did was cry. I had sleepless nights, constantly in pain; it was unreal, I couldn't handle it. I am now 18 years old, I am 16 weeks from a right hip replacement. I am pain free from my right hip. The hip replacement was hard for the first 3 weeks but I finally got there.

I felt like giving up when I was younger but as I got older I realised there's no point in giving up. I am glad I never did, as I couldn't be who I am today!

Megan ~ UK

NATIE'S STORY

My journey with Avascular Necrosis began three years ago. I was working full time and began feeling symptoms, which consisted of numbing of the feet, pins and needles pain and in addition, my balance was off. I was sent to a Neurologist because all signs at the time pointed to peripheral neuropathy. The pain in my hips arrived quite suddenly and I found that I was unable to stand for long periods of time without severe pain and stiffness. Eventually, the scariest event occurred.

I woke up and couldn't move. After numerous tests, I continued to receive different diagnoses, which was quite frustrating. I quit my job because I simply couldn't drive any longer and lost my health insurance. I was devastated because I had no idea what the issue was and I no longer had income. I was lucky to have parents that offered to help me. After seeing the Neurologist once again, he decided that I needed an MRI, which was ironically the best thing I could've done.

My answers were clear. I have Avascular Necrosis in both hips. This was devastating, yet a relief at the same time. This process has been life changing and I had to hire an attorney to help me build a case for disability. It was clear that I couldn't work. My hips were collapsing and the pain that I was in was indescribable. After nearly two years, my case was heard and I was approved.



My first hip replacement was in October after seeing two orthopedic surgeons and I already feel that my quality of life is returning. I finally have a range of motion and my joint is no longer popping out of place.

I have one hip replacement remaining in December, but I am optimistic. I have knowledgeable friends in a social media support group that told me their stories. It felt good to finally have people that have experienced this and also, people that have heard of the disease! I finally feel like I have my life back and as an added bonus, I gained genuine friends that support me.

Natie ~ Georgia

DEBBIE'S STORY

I remember this day so clearly. It was the day my life would change, and I didn't even know it. On January 22nd 2014 I started having excruciating pain in my left shoulder. Pain like I had never felt. The best way I can describe it is that it felt like someone was stabbing me with an ice pick with any movement. I went to an Orthopedic doctor who said it was tendinitis and to take Aleve and come back in a month. I didn't know what was wrong but I knew it wasn't tendinitis.

I scheduled a second opinion appointment. I had an MRI. They called me with the results and said I had Avascular Necrosis. I had no clue what that was. I told a friend who is a nurse and her response was "Oh God". I would soon come to understand this response. On March 26th 2014 I had Core Decompression on that shoulder. In about a week and a half I really had no pain at all! I thought that was it and my life could continue as it had prior to this diagnosis. I was so wrong.

Within the next year and 4 months I was diagnosed with AVN in both shoulders, both hips, both elbows, both knees and left ribs. I had two failed Core Decompression surgeries on my right shoulder. As I was diagnosed with this disease in all these joints in a relatively short period of time, they seem to be progressing at a similar rate. AVN is a horrible disease that takes so much from the person who has it. Let alone the excruciating pain it causes.

I have not been able to go back to work. I have worked my whole life. I have a hard time walking. I have crutches and a walker. However, I do my best to not let this disease rob me of my sense of humor, my relationships with friends and family and my own sanity. I belong to a group on Facebook where I can vent if I need to and learn valuable information. But more importantly it let's me know that I am never alone when dealing with this disease.

Debbie ~ Massachusetts USA



TG'S STORY

My journey with Talus (Ankle) AVN, started with pain, around 2003. At that time, I was doing sports, such as Karate, diving, sailing, etc. I lived a very active life. First my AVN was treated as just a simple ligament sprain, and I was NWB (non weight bearing) for about 1 month.

When the pain didn't subside, my doctor ordered my first MRI. As I look back, now it doesn't surprise me,why I started collecting so many different diagnoses, the radiologist reading my MRI's probably hadn't seen a case of talus AVN before. So, in 2004, a debridement, and CD (core decompression) was done.

Debridement is the medical removal of dead, damaged, or infected tissue to improve the healing potential of the remaining healthy tissue. And once again I was NWB for about 6 weeks then started physical therapy. However, I couldn't weight bear without intense pain.

So ,for a period of 5 years, my husband and I went to see several foot and ankle specialists around the country. It wasn't until we got to Mayo Clinic, where the No 1 Foot and Ankle Facility was at that time, that the diagnosis of AVN came. Finally a correct diagnosis however it didn't change the pain or outcome.

I tried several different braces, and had no relief not one specialist offered to do a total ankle replacement, (TAR) as it wasn't a posibility if I had AVN. The most difficult part, has been the emotional one, as I lost my career which I loved, the constant search for the correct diagnosis over an extended period of time from a ligament sprain to cancerous tumor inside the bone, and the final correct diagnosis of avascular necrosis in talus, plus being on crutches and in a wheelchair, limited my life as well as my family's.

There has been some progress for those with early stage avn. I see the latest options science has developed and we have wonderful new alternatives, such as Total Talus Replacement, and even newer, a TAR designed for patients with AVN. Ankle fusion for advanced talar avn.

There are 3D joints and parts that can be custom made for the patient, stem cell injections and so many other new things on the horizon. Still we need more research and development of new treatments for those suffering. I am thankful to be able to talk to people going through the same journey as I am.

TG ~ Texas USA



DEBORAH'S STORY

Hi Im Deborah from Ohio. I have Osteonecrosis in my knee I was diagnosed in November 2014 I am not sure exactly how I got Osteonecrosis or really how long I had it the Doctors are not exactly sure either. They are assuming it came from when I was exercising and got a pretty bad meniscal tear and injured my patellar.

I went to my family doctor after doing some exercise and experienced a lightening bolt pain hit my knee, that did not go away, he did some tests, and wanted to send me for MRI to confirm the meniscus tear which it did ,but to my surprise I also that day was diagnosed with Osteonecrosis.

I was told my knee looked like butter. Dr felt TKR (Total knee Replacement) was not an option at this time, as he said TKR may last 10 yrs, so we should wait, the only problem with waiting is it can lead to the bone collapsing, so I was told to limit my weight bearing.

Noone wanted to even repair my torn meniscus as they said it can lead to even more complications. Words cannot really discribe the pain I had most days, it can be unbearable, draining, simple things are now so very hard like walking up stairs or down stairs.

When I was first diagnosted there were days I'd force myself to move and cry later in the day from pain and frustration. Most days it feels like there is a tourniquet above and below my knee, the pressure is intense and pain is always there ,plus its very cold to the touch while inside it feels like its on fire.

I had a few opinions and basically was told the same thing. The feeling of frustration set in,the more help I tried to find the more I found out many dont know about this rare disease nor the cause,or really how to treat it.

In todays age of regenerative medicine and saving your joints why is it so hard to find doctors that are experts in this area? You see today we have Stem cell therapy, Prolotherapy, PRP(Platelet Rich Plasma) to help the joints from futher damage, however finding someone to do it in NE Ohio is a chore all its own, and in my research not many treat it in the USA, they are few and very far between.



Plus its rarely if ever covered by any insurance and can range from 5000.00 to 10.000 usd depending on what you have done. So my quest began, if i was feeling this frustrated what were others feeling, as when you have ON/AVN you have constant pain, It is second only in pain to bone cancer, the death of the bones/joints are the same.

Treatments for it are mostly surgically interventive, with no way to predict or guarantee outcomes or results.ON/AVN does not respect age, gender, or ethnic background; it can strike anyone at any time.Of the 20,000 joint replacements in the USA every year, at least 20 percent of them are due to ON/AVN.

ON/AVN is still considered a rare condition with not all orthopedic doctors being equally experienced in diagnosing and/or treating it.

Valuable time is lost in trying to treat the patient, sometimes leading to a collapsed or otherwise destroyed joint. Very little research is on-going for Osteonecrosis and this has to change. Since 2014 I have been on my own mission, to raise awareness, I started a support group on FB called Avascular Necrosis/Osteonecrosis Support Int'l.

I have compiled a list for people looking for Doctors with experience in treating this rare disease. Now I am working on a list worldwide.

Osteonecrosis aka Avascular Necrosis its also known as aseptic necrosis, and ischemic necrosis, and in young children its known as Legg—Calvé—Perthes disease (LCPD).

It's been 3 years since my Osteonecrosis diagnosis, and I had a Prp injection. Once that initial swelling and pain went away I will say it has helped some. I still have some bad days where pain becomes somewhat intolerable. Especially in the winter.

But changing to mostly plant based has helped my pain so much. I love eating healthy clean real food. Overall, I eat a mostly vegan but I am a flexitarian . I just enjoy how a plant-based diet makes me feel. Day to day, my diet consists of mostly vegetables, some fruits, nuts and seeds, some grains like oats, quinoa and some beans and lentils. I will never go back to my old way of eating. And hopefully I will drop a few pounds too.

I also try to walk 15-20 minutes 3-4 times a week or ride recumbent bike a few days a week if body and weather allow.

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I love cooking healthy meals at home, full of every color in the rainbow. I enjoy experimenting in the kitchen making new recipes and tweaking old recipes and trying new foods. We owe it to ourselves to eat as healthy as we can. And if you smoke stop. It's not as hard as you think I quit after smoking 40 years trust me your body will love you for it.

As for drinks, I am working on drinking more water but I do enjoy herbal teas and decaf coffee and a healthy smoothie a couple times a week. And for a treat I do splurge on a mocha frappe I just hold the whip and drizzle.

I am in the process of writing a book. Stay tuned.
I will announce it on my blog: ChronicallyGratefulDebla.com. Lastly,

Quick Tips & Recipes:

When it comes to sweeteners, I typically use dates and maple syrup or stevia or coconut sugar to sweeten recipes. I also have a Stevia Plant and I make my own liquid stevia.

Use dry stevia leaves to make a syrup for sweetening beverages, sauces or other syrups. Add one cup of warm water to one-quarter cup of fresh, finely crushed stevia leaves. Put the mixture in an airtight container and allow it to set for 24 hours before straining the leaves from the mixture. Store in air-tight containter; lasts 6 weeks in refrigerator.

No Bake Energy Bites Vegan and Gluten-free

No Bake Cranberry Coconut Energy Bites: an easy, 7 ingredient recipe for delicious protein-packed energy bites made from simple ingredients. Vegan, Dairy Free, Gluten Free.

INGREDIENTS:

Dry Ingredients

- 1/2 cup dried cranberries chopped (you can use dried cherries or blueberries in place of cranberries)
- 1/3 cup walnuts, finely chopped
- 3/4 cup gluten-free rolled oats
- 1 cup unsweetened coconut shreds or flakes
- 1/4 cup ground flaxseed

Wet Ingredients

- 1 cup natural, unsalted almond butter*
- 1/3 cup pure maple syrup

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INSTRUCTIONS:

- 1. In a large bowl, mix together all of the dry ingredients: cranberries, walnuts, oats, coconut and flax.
- 2. Add almond butter and maple syrup. Using a sturdy spatula, stir and fold together until well incorporated.
- 3. Scoop mixture into your hands (mine are 2 tablespoons each). Roll and press into bites. If the mixture is too dry, add in a bit more almond butter or maple syrup. If the mixture is too wet, add in a bit more coconut or oats. You want a slightly sticky dough texture.
- 4. Enjoy!

Homemade Pain Rubs Recipe

INGREDIENTS:

- 1/2 cup organic Coconut Oil
- 2 teaspoons Beeswax pellets
- 6 drops Camphor oil
- 5 drops Peppermint oil
- 6 drops Eucalyptus oil

DIRECTIONS:

Melt the coconut oil and beeswax together. You can do this in the microwave, in a double boiler, or what I did was set a small saucepan on the stove for a minute or two and then turned the burner off and added the coconut oil and beeswax. Stir until melted.

Allow the mixture to cool for a few minutes, then add oils. Put in a container with a good sealed lid to cover later, and allow to cool completely lid off. When it is completely cooled it will be a solid rather than liquid cover, store in a cool dark place. but The minute it hits your warm skin...it will liquify again. That's what coconut oil does, which makes it perfect for massaging onto sore muscles and joints.

These homemade joint muscle rub penetrates deep into my muscles and helps my joints by bringing a soothing and relaxing sensation.

As you've undoubtedly noticed, essential oils have taken the natural health world by storm. As someone who uses essential oils for my own wellness. They have so many benefits. And I make my own pain rubs.

I made it a point to do a patch test first. Before direct application on the skin. I did a skin patch test to check its effects on my skin.

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Rub the diluted oil onto the inside of the forearm. If I don't experience any irritation or discomfort within 24 hours, the oil should be safe for you to use.

To blend your essential oils into a synergy, You only need to use a few drops of essential oil, the standard is to add 2-3 drops of essential oil to every tablespoon of your carrier oil.

Be sure to only use the purest grade of carrier oils since they have therapeutic properties of their own and enhance the action of the essential oils. So don't cheap out on cost of essential oils or carrier oils.

Never ingest essential oils in my personal opinion.

Essential oils are so highly concentrated. It takes approximately 40 roses to make a few drops of rose essential oil. Would you eat that many roses? Use common sense. Also do your homework on it.

I only use oils for external and aromatherapy never internally.

Pain Rub Recipe 2

INGREDIENTS:

- 20 drops pure frankincense essential oil
- 10 drops pure ginger essential oil
- 20 drops myrrh essential oil
- 4 ounces unrefined coconut oil
- 3 teaspoons beeswax pellets

DIRECTIONS:

Melt the coconut oil and beeswax together. You can do this in the microwave, in a double boiler, or what I did was set a small saucepan on the stove for a minute or two and then turned the burner off and added the coconut oil and beeswax. Stir until melted.

Allow the mixture to cool for a few minutes, then add oils.

Put in a container with a good sealed lid to cover later, and allow to cool completely lid off. When it is completely cooled it will be a solid rather than liquid cover, store in a cool dark place.

- *Never use pain rubs on broken skin
- *Never ingest pain rubs or essential oils.
- *Always consult your doctor before using any pain rubs ,doing any dietary changes or starting to exercise.



TO DOCTORS What Patients want their Doctors to know

Dear Doctor,

Are you looking through our charts, our lengthy and complicated charts, wondering what the heck you got yourself into? Yeah, we know. We know we aren't the type of patient most doctors like to take on.

We can't be easily fixed and we know that can be concerning and frustrating for you. We also get nervous and frustrated, but we want to work together so we can have the best options for our health and care.

Here's what we want you to know about being our doctor

We appreciate you, but it's very possible we know more about our illnesses than you do, especially since it's rare and we live with it every day. We know you are human and we promise not to hold that against you. But remember, we are also human, so please don't dismiss our questions and concerns.

Listening

We need your undivided attention for 5 minutes.

Clear explanations

Partnership: patients want to be involved in treatment options and decision making for their health.

Appointments

We want to be seen in a reasonable amount of time.

Equipment

Better chairs in your office wait area, Ones easy to get out of after surgery.

Patient Understanding

Use plain, non-medical language.

Pain

Please take our pain seriously.

Regenerative Medicine

We want options like Prp, Stem cell, prolotherapy.

Blood Tests

Please check us for underlying disorders like Factor V Leiden MTHFR, eNOS.



Quotes to Live By

"True compassion means not to just feel another individuals pain but also be moved by it and wanting to help relieve it."

"Fate whispers to the warrior: 'You cannot withstand the storm', and the warrior whispers back; 'I am the storm.""

"You never know how strong you are until being strong is the only choice you have."

"The mind is an amazing thing. Talk to your body; tell it that the pain signals it is sending are no longer necessary. Ask your body to come into balance. Live a grateful life even when in pain."





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