

A woman with long brown hair tied in a ponytail is sitting on a sandy beach. She is wearing a light-colored sweater and blue jeans. She is holding a silver laptop in her lap and looking off to the side with a thoughtful expression. The background is a soft, out-of-focus view of the ocean and sky.

7 Things You Need To Know When You're Diagnosed With MS

A guide created by,

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Having a new diagnosis can be scary.

Even after it's not so new anymore.

When I was diagnosed with multiple sclerosis in 2000, I was in my early 20's and half way through my masters program. I didn't have a clue what to do so I just started taking frantic action. In short - I freaked out. Sure I had support and plenty of people to tell me it would be ok. But I didn't have anyone tell me how it would all fit together.

Sometimes it's hard to take that leap towards "everything will be ok" without first knowing how that will be true.

There's a lot of information coming your way after a diagnosis. Some supportive, some scary, some down right insulting. I want to help guide you through this. But I'm not going to tell you it will be ok and that it will all work out just fine if you want it badly enough.

Instead I'm going to tell you *how you can make it ok*.

Right now you may feel powerless, confused, scared, and a maybe a bit hopeful. I get it. I'm still on this journey with you and I've learned some things that have truly changed my life - and my health. And I want to share them with you.

Inside this guide are 7 things I wish someone had told me when I was diagnosed. This guide is not exhaustive by any means. But it's one hell of a good start and gives you an insider's take on where to look (and where to not bother).

Read through it, digest it, and feel free to email me any questions you have. I'm here for you as a resource (Andrea@AndreaHansonCoaching.com).

Right now you may feel like you have anything *but* control over your situation. But you have more control than you may know. And I'll show you how to start using it.

Take care-

A handwritten signature in black ink that reads "Andrea". The signature is written in a cursive, flowing style with a long horizontal line underneath the name.

1. You Can Wear Your PJ's To Your MRI

It's a cramped little tube that's super loud and gives you news that will make or break your day. On top of that, you can't move- even a little bit - or it will last a really long time.

MRI's are not so fun.

Even if you're like me and practically fall asleep during the scan, it's still something I would rather not do. Here are a few things that make it a little more comfy.

Wear your own clothes. Yes - this is possible IF AND ONLY IF you make extra special care that NOTHING is metal. No underwire bras, no lettering or anything reflective on your clothes (a hidden source of metallic no-no's), no zippers, or brads around drawstrings. Pick an outfit that you know has NO metal at all, and keep it as your MRI gear. For me it's worth it to not change into a gown.

Bring your own tunes. You will probably have to burn a CD, but it's so worth it. Think relaxing music - nothing that makes you want to move. Favorites for me are India Arie, or trans/spa/ yoga music. Have a radio station you like as well because they may not be able to play a CD for you. I suggest something musical as you may not be able to hear words that clearly. It's a bit loud in there and you will have earplugs, but having that backdrop of calming music can really help.

Have a small towel to put over your eyes. The techs may have one there for you. Just like at the spa, having a towel across your eyes will help you keep them closed. This both helps you to get relaxed (there's nothing soothing about your eyes darting around the little tube) and it helps the MRI because moving your eyes a lot may effect the image and result in a scan do-over.

Ask the tech to countdown your time (or not). For me, it helps to know how much longer there is (are we there yet?). For others, it doesn't help at all. Play around with this to see which option works for you. Then make sure you tell the tech what you prefer.

Your objectives for MRI's are most likely 1. Get out as quickly as possible 2. Be as comfy as possible.

The techs want the same thing for you (let them worry about getting a good scan).

Do yourself a favor and optimize your MRI's. Learn what makes your MRI most comfortable and let the techs know. You will have many of these, and getting a system that works will make your MRI go much smoother.

2. The Key To Getting All Your Questions Answered

You are diagnosed and Bam! - you now have 1,000 points of data to keep track of. Ok - it may just seem that way. But there is a lot.

If you take one thing away from this guide, let it be this:

You are your biggest and best advocate. Everywhere, all the time.
Not your doctor or even your Mother - you.

One way to make this job as easy as possible is to plan ahead. You don't have to create a spreadsheet or anything (unless that's your thing) but start thinking about questions ahead of time to avoid rushing and missing information when it's important.

Create a list of questions for your doctor. I have a notes section on my phone where I write my questions as they come up even months ahead of time. Then I just enter the answers below as I ask them. This way you're not searching for a question while you're on the spot.

Check them off as you ask - and make sure they're all answered. During your visit, there will be tangents, and new things to think about, and...Squirrel! Keep going back to that list and make sure it's all answered to your satisfaction. Go back over questions if you think you don't fully understand the answer. If you don't know it well enough to explain it to someone else, ask for more clarity.

An Advisory Committee member can really work for you here. I'll talk more about this in the next video. If you have someone you trust, bring them with you. Having another set of ears can really help. I didn't have this when I was first diagnosed, and was afraid to ask someone. I wish I had. Now, the Hubs comes with me and it's really interesting to hear his take on the visit versus mine. (His is a lot less dramatic.) If you don't feel comfortable bringing someone, use a voice memo to record what your doctor says (be polite- ask first).

Super bonus organizing points - create a file with all your correspondence. Your questions, answers, dates, emails, MRI results. This will become a long-term account that will be really helpful to you in the future.

3. You Need An Advisory Committee

Think support system on steroids. We have well meaning people in our lives who are ready to support us when we need it. So put them on the clock. We can have a blind spot when the subject matter is close to our hearts (our health and wellbeing is definitely on that list).

The purpose of your advisory committee is to help cover all angles that you may not see. Each person has a different role; Someone for medical support, someone for social support, someone for love. Someone to tell you if they notice a change with you (better or worse). Someone to talk you off the ledge (I may have used this person a few times). These are all very important roles.

My committee right now has my MS Specialist and physician's assistant for medical support. My parents, sister and husband for reality checks and to tell me if something seems different about me. My friends for humor and distraction. I also have a life coach, psychologist and other healers that give me valuable perspective. Everyone on my committee is signed up for support and love.

Your committee may change over time. When I was diagnosed, I wasn't married and didn't have a boyfriend. And unfortunately a few of my friends weren't very supportive when the subject turned from partying to "crap you never thought would happen to you". That's ok. You may find some people aren't as supportive as you thought they would be. Don't try to change them, just take them off the committee. Over time your relationships will change and your committee will get stronger.

Who's on your Advisory Committee? Ideally, start with this basic structure:

Medical Support (I strongly suggest an MS Specialist, nurses, social workers.)

Social Support (Family and friends you know are compassionate and loyal.)

Love (This does not have to be romantic love. Just a deep connection with family or a friend.)

Observation Duty (This doesn't have to be creepy. Just someone you trust to not drop the ball and tell you, lovingly, that they see a change.)

Reality Check Duty (MS or not, Reality Checks are always necessary.)

The people in these roles may change. Notice who's helpful and who isn't and tweak your committee as necessary. This is for you - so optimize it.

The most important thing to remember- tell participants they're on the committee. Don't assume they know. Make sure they understand their role and are ok with it. All of these spots should be filled with willing participants who are informed and that you love and trust.

4. You Can Live A “Normal” Life And Have MS

You feel like the game of life just delivered a surprise left hook. You may feel like everyone is looking at you differently and they just *know*.

You just want to be “normal” again.

I have good news. You can be normal and have MS.

The two are not mutually exclusive. Nor do you need to have zero symptoms for that to be true.

I have clients with visible disabilities that have a completely normal life. I have clients with no visible symptoms (or even no symptoms) who come to me feeling like they aren't normal and everyone knows.

Your symptoms - or lack thereof - don't decide if you have a normal life.

You do.

One of the biggest moments in my life happened when I realized that none of the situations in our lives get to decide how we feel. What we *think* about situations determines how we feel.

If a stranger walks up to you and gives you \$500 in cash- what would you think?

How would you feel?

What if that same stranger hands \$500 to an 80 year old woman? What do you think she would think and feel?

What if that same stranger hands \$500 to a 5 year old girl? What would she think and feel?

The 80 year old may think it's really strange and feel suspicious.

You may think it's a fabulous and feel loved.

The 5 year old may think it's stranger-danger and feel afraid.

If the stranger with the \$500 was what caused you to feel something, everyone here would feel the same way. But they don't.

The difference here is what they *think* about the stranger with \$500. Each person thinks something different. That's what causes the suspicion, the love and the fear.

MS is no different. MS doesn't make you feel worried or scared or grateful.

You do because of what you think about your MS.

When I learned this, I felt like I struck gold. I'm the one who decides if I feel normal. Not the MS. Not the symptoms. Me.

5. It's Ok To Cry

You're mad, upset, scared, worried, don't even know what- but it sucks. It's ok to be all of these. Negative emotions are not only normal, they're essential - especially when you've been handed this news. You're grieving the loss of your life before the diagnosis.

There's a lot of talk right now about staying positive.

Have a positive attitude. A positive mindset. Just be happy.
And it's true. I teach the power of a positive mindset to everyone I work with.

But I also teach the power of feeling your emotions - all of them. And that negative emotions are here for a reason. Suppressing them in the name of 'staying positive' is a nasty cycle to get into. One that leaves you white-knuckling your happiness.

Don't fight the negative emotions, welcome them. Feel them move through your body because that's what they do. Allow yourself to shout or cry or throw a temper tantrum. That's the only way to get them to go away. (Pushing them away or distracting yourself won't banish them for long.) The first time I was alone in the hospital after I heard the diagnosis I took a shower and had an epic cry. And it hurt. And I felt every moment of it. And then I moved on. At the time I thought it was strange how I was gut wrenchingly sad and terrified for a few minutes and then the tears stopped. I could breathe and stand ready for what was next. I thought the crying should have kept going for hours. Days even. But I just had an honest, fully allowed, ugly cry. And when you completely feel it, it's not meant to last for days.

One of my favorite stories is Jill Bolte Taylor's. She had a stroke and temporarily lost the entire left hemisphere of her brain. After a long journey, she has recovered and is writing about her experience (I highly recommend anything by her). She teaches that when you truly allow an emotion, it runs through you in about 90 seconds. When you resist your emotions that they stick around and seem to never leave. Think about when you're laughing. Generally, we don't resist a good belly laugh. How long does it last, really? A few minutes? The laugh will die out, because the emotion is allowed to move through you without resistance.

Think about that next time you feel a negative emotion. That feeling isn't wrong, or something to push away, or going to ruin your happy disposition. It's just meant to tell you something and to be felt. And then move on.

The next time you feel an emotion - positive or negative - pay close attention to it. Where do you feel it in your body? (In your stomach, shoulders or throat for example). Can you breath into it and sit with it, without trying to make it go away?

6. The Internet Can Be Scary

There is great social support and information on the internet. Any tiny question has an answer. But it's helpful to know the internet's limits.

It's very easy to go down the rabbit hole of "This super bad thing that I didn't even know existed has an 80% chance of happening to me". I've been in that hole. There's nothing valuable there.

There are a few reasons why it exists.

Many news and research articles may end by telling you how devastating MS is. I've coached and spoken with hundreds of people with MS. Very few of them would agree that MS is devastating. These articles are often put out by news organizations who rely on the "click bait" of negative, shocking news. Don't fall for it.

Many of the studies that are quoted are old and there are new drugs on the market each year. Articles on the internet can often be either over generalized, or very specific to people that don't have much in common with you.

Ever hear of the placebo effect? That's where someone believes they're taking a super powerful drug and is healed - even though the "drug" is actually a sugar pill with no medicine at all.

Why is this important? If we expect something will happen, there's a good chance it will. If we expect something not to happen, chances are it won't. If we expect a symptom of MS to pop up because we just read that there's an 80% chance of it happening - there's a possibility it will pop up in some form. Even if it's just enough to drive you crazy.

I'm not saying to bury your head in the sand. Just be cautious of what you read. If it's a news article - is someone knowledgeable writing it? If it's a study - notice when it was done, how many people there were and what the circumstances were. If it's an op-ed piece- what's the angle? Is it click bait? If it's someone you're supporting in an online group - know that what happens to them may never happen to you.

We should approach everything we read online cautiously anyway. But when it comes to MS, we need to be extra cautious because it can plant seeds that don't need planting.

Yes, the internet can be helpful, but be wise about it. We need our time and attention for more important things than worrying about something that may never happen.

Bonus: Becoming Your #1 Priority

This is where my clients often ask “What about my family?”, “What about my job?”. We feel like we’ll have to abandon everything we hold dear if we put ourselves first. These are big concerns because of a few myths we’re told when growing up.

Myth #1 - Putting ourselves first is selfish. And being selfish is bad.

Putting yourself first simply means your primary concern is your own wellbeing. Personally, as a human who wants to live a long, happy life, I like this idea. It’s also the opposite of selfish because modeling this self-care will be inspiring and help others to heal themselves.

Myth #2 - Putting ourselves first means neglecting everything and everyone else.

This can seem true because chances are you’re doing the exact opposite right now. Putting other people, your job, your appearances, all ahead of yourself and your own wellbeing. We all do this on some level. But I assure you, you don’t have to neglect everything and everybody else in your life. When you put yourself first, you are able to give so much more to others because you’re not depleted from stretching yourself thin.

If there’s one message your body is giving you when you get a diagnosis, it’s “pay attention to me”. Focus on your health - emotionally, physically and spiritually. Focus on learning what energizes you, what rejuvenates you and what depletes you.

You won’t find the answer by pushing yourself to work 80 hours a week while your body is telling you to slow down. But the answer *will* be clear if you give yourself your full attention.

Have a discussion with yourself. One that’s honest and ongoing. Start by literally asking yourself, “What do I need?”

What I’ve learned by making myself my #1 priority - I can be an introvert and taking time by myself rejuvenates me. That I’m way more focused when I’ve had time to meditate. I’ve learned the subtle cues my body uses to communicate - and I can respond early and keep a little problem from becoming big.

The biggest thing I’ve realized when I decided to put myself first is that no one noticed. They didn’t get mad or feel neglected. Actually, that’s not true- they did notice because I was so much happier and no longer an unfocused shell of myself when I was with them.

Where’s one place in your life you can put yourself first? Spending five minutes alone to ask yourself what you need? Taking something off your calendar that irritates you? It may not be seamless and you will have to make a conscious effort to put yourself first if you’re not used to it.

But you’re worth it.

Thoughts to leave you with

(Excerpt from *The Inside Guide to MS*)

You are in charge.

Always.

Not your Doctors. Not your parents.

Not your partner, or your kids, or your ex-whatever.

And certainly not your MS.

You *are*.

Without question.

How do you want to feel right now?

How do you want to feel about your MS?

Whatever your answer, it's possible.

You can make this journey mean whatever you want.

Good or bad.

Success or failure.

Living free or living in a cage.

Only you can do it.

In fact, only you must do it.

And yes - you are strong enough.

I won't lie to you - this can be tough.

But so are you.

There will be bumps. But you can ride them all.

There will be fears. But you can be afraid and move forward anyway.

Hold onto your control.

Hold onto your love and support for yourself.

Hold onto what's working and what you can make even better in the future.

Most importantly, hold onto you.

Because even through the tears, the mistakes,
through your best sit-down-and-sulk protests,
you are enough.

You're the strongest ally you will have.

You.

A force to be reckoned with.

I'm Andrea Hanson, author of *The Inside Guide to MS*. I work with women who are newly diagnosed with Multiple Sclerosis. They're dealing with a serious new factor in their life and are overwhelmed with the often scary information coming their way. It can seem like MS is their new identity and life as they knew it is gone for good.

I help them regain control, power and clarity in their journey with MS and, ultimately, their life. They can focus on their relationships, jobs, and school without letting their fears pull them away.

I help people live their life...not their diagnosis.

I'm passionate about this work because I was diagnosed with MS in January, 2000. I spent the first ten years of my diagnosis suffering and feeling like I was getting blown around. I was constantly reacting to issues in my life instead of controlling them.

When I discovered the concepts and techniques I use through coaching, my life completely changed. I was able to gain control of my life (actually for the first time ever) and realize that I decide how I want to feel and what my life looks like. Knowing that has been life changing for me and my MS.

And now I'm teaching what I learned to my clients.

Want to know more?

Come to www.AndreaHansonCoaching.com to find out about working with me.

If you have questions or comments on this guide send me a note at andrea@andreahansoncoaching.com. I love hearing from you and am I'm happy to help.

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