



TRANSPARENT TROUBLES

Unseen But Not Unfelt



A collection of surveys of people with invisible illnesses and how their day to day lives are affected

FOR MY SENIOR CAPSTONE

I wanted to do a project on how invisible illnesses affect people. I wanted to show the many different ways they can affect a persons life and how they can handle it. Using AR and 3D modeling techniques, as well as surveys from people within our community, I have created an exhibit that at first is not visible to the naked eye until you use a phone or tablet to see the Models, which you can click on to see their illnesses and how most of the people have no outward appearance of having an illness.

They / He / She
Age 24
White

VIC L



INVISIBLE ILLNESSES

Ehlers-Danlos Syndrome (EDS)
Postural Orthostatic Tachycardia Syndrome (POTS)
Greigs cephalopolysyndactyly Syndrome (GCPS)
Attention-Deficit/Hyperactivity Disorder (ADHD)
Complex Post Traumatic Stress Disorder (cPTSD)
Rejection Sensitive Dysphoria
Seasonal Affective Disorder
Depression
Anxiety

VISIBLE ILLNESSES

Scarring from surgeries
Using my cane on my flare up days

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I face many issues in my day to day life due to the illnesses I have and how late in my life many of them were diagnosed. The late diagnoses have caused me to develop imposter syndrome and believe that I was not actually in pain which causes me to not listen when my body is telling me I need to rest.

I am constantly having to explain to people what illnesses I have and how they affect me, which often causes people to try and tell me 'no that can't be true, you're not actually sick, you are too young to be sick'. This leads to me feeling like I must prove that I am sick and injured.

While my illnesses have not yet become regularly debilitating they do still make life more difficult than it needs to be. While medication would help many of my symptoms, most medications don't work as they are supposed to and just make me nauseous. Medication creates more problems than it helps, so I end up going without it most days.

Due to my EDS and POTS, **I often have issues standing in one place,** walking a long distance or walking on uneven ground, so I tend to lean when standing or park in a handicap stall so I don't have to walk as far. This often causes people to give me strange looks or try

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

My visible illnesses often cause people to ask prying questions about the scarring, especially the large scar I have on my shoulder from a surgery. People tend to look at that and ask what happened then I'll have to explain it. I do not mind explaining my disorders to people, I enjoy educating them on the different disorders. However, those that pity me or try to give me unsolicited medical advice are very annoying, since usually the responses are either things I have tried, like medications, or the advice goes against what medical professionals have told me to do.

I have had 12 surgeries and will have to have countless more, so I expect to have more surgery scars and more explaining to do.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

I have countless doctor's appointments which affect my job and other aspects within my life. With the amount of Appointments and medications they want me to try, those bills start to pile up and become very expensive. **I constantly have to turn down offers to go do things because I am unable to do them due to the pain I am in.**

With Rejection Sensitive Dysphoria I constantly believe anytime someone appears to be mad or even just indifferent towards me that I have done something

to confront me for "stealing the spot of someone who actually needs it". If it weren't for my handicap permit, I would not be able to go many places due to not being able to walk far. Often after I have been confronted my anxiety will get the best of me and I will not listen to my body and overexert myself, which tends to lead to me having a flare up lasting multiple days because of it. **Flare ups tend to be painful due to my muscles spasming from overuse trying to keep my joints in the correct places.** Most flare up days include a horrible headache due to the muscles in my neck cramping so much.

With cPTSD and anxiety I am constantly looking over my shoulder expecting to see people from my past who should not know where I am, and have no business being in the area.

Along with my depression, I have what is called seasonal affective disorder which causes me to go into deeper depressions during the winter months due to lack of sunlight and vitamin D. This means I often will end up wanting to hang out less which causes the depression to deepen. Luckily my friends are able to notice when the spiral begins and can help pull me out of it.

Due to a few of the surgeries, I have very little cartilage left in my feet. This means when I walk I have no natural cushioning, so I sometimes will use a cane to help alleviate the amount of weight put on my feet. I also use it when standing, so I can stand for longer periods of time with less pain. While I have a cane, I do try not to use it too often since it can cause a lot of shoulder and elbow pain. Unless the foot pain is very bad, I will not use my cane. I also often get people looking at my cane when I use it and asking why I need to use a cane and why someone so young would have one and I must be faking it.

horrible and they hate me. RSD mixed with Anxiety and Depression have caused me to become a people pleaser and do things outside my limits to please them. **I will try to help out with things that are above my ability at the time so I do not feel like I've made anyone upset.** I have been able to get better at this due to therapy and friends stopping me when they notice. I still have days I will push too hard which then makes me unable to do things later on.

SORCHA H.

She / Her
Age 22
White

INVISIBLE ILLNESSES

Ehlers-Danlos Syndrome (EDS)
Mast Cell Activation Syndrome
Dysautonomia
Sarcoma Cancer

VISIBLE ILLNESSES

My Ehlers-Danlos Syndrome can be visible if I use mobility assistance such as my cane or walker



HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Almost every single aspect of my daily life is impacted by my illnesses. Living with a whole host of symptoms, including severe chronic pain and chronic fatigue, I can experience debilitating conditions that make it difficult to function day to day. With my EDS, my joints will subluxate and dislocate at random times impacting whatever I am doing.

With my dysautonomia, environmental factors, such as temperature, can lead to symptoms affecting the autonomic nervous system. Then my Mast Cell Activation Syndrome greatly reduces products I can use, when and what I can eat, and I deal with random allergic reactions from hives to full anaphylaxis. I also experience symptoms resulting from my medications to treat these conditions, such as my chemotherapy.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

While my symptoms remain the same no matter if I use mobility assistance, the way people treat me differs if my illnesses are visible. There is much more assistance and acceptance about my disabilities when they can be seen but there is also more judgment and discrimination

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Almost every day. The way people treat me almost always changes when people hear about my conditions. While there are many people who treat me with understanding and respect regardless, typically I am viewed as weaker. When people know about my conditions, they often start to pity me or treat me as fragile (with kid gloves). They treat me like I am somehow a major inspiration for even existing day to day and often tokenize me.

She / Her
Age 24
Black / White

KIRA H.

INVISIBLE ILLNESSES

Meniere's disease
Attention-Deficit/Hyperactivity
Disorder (ADHD)
Obsessive Compulsive Disorder (OCD)

VISIBLE ILLNESSES

Meniere's disease
(on attack days)



HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I have issues with focusing, intrusive thoughts and rituals, vertigo, dizziness, balance issues, and hearing loss.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I suffer from vertigo, dizziness, balance issues, hearing loss on days when I get an Meniere's attack.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

People get so weird around me when I'm in my wheelchair and I find that some think the whole thing is bullshit unless I'm in my chair actively having an attack

LIAM HAY

Any / All
Age 24
White



INVISIBLE ILLNESSES

Major Depression Disorder (MDD)
Generalized Anxiety Disorder (GAD)
Attention-Deficit/Hyperactivity
Disorder (ADHD)
Asthma
Possible Autism
Possible Ehlers-Danlos
Syndrome (EDS)

VISIBLE ILLNESSES

I need glasses, more than most
people who need glasses

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I have to limit physical activity that might flare up my asthma or EDS symptoms. The mental things are hard to state specifically because they affect everything.

It's difficult to accomplish basic tasks, which makes other people think you're lazy when you are exerting as much effort as you can at all times. I can't get myself to do things that I love and think make life worth living. I experience regular suicidal thoughts, even when I'm not in a bad mood. I have to take significant time out of my day once a week for in-patient treatment, after which I am not allowed to drive for the rest of the day, on top of other appointments with therapists and psychiatric professionals. People find intrinsic parts of my personality (that are likely autism symptoms, according professionals) are annoying or weird.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I have to fumble around when I'm not sure where they are.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

My anxiety is largely social, so I have incredible difficulty talking to new people, communicating on the phone, talking to people in service roles, and countless other little things. Additionally, **autism is characterized by difficulty with social cues**. My understanding of reading people's emotions is all things I had to teach myself

I lose everything, all the time. **Systems are built around the assumption that brains work a certain way that mine doesn't.**

According to a genetic test, I actually don't absorb dopamine the way other people do, such that accomplishing tasks does not make me feel better or satisfied, so I have no desire to do them.

In order to be treated for mental disorders, or to get accommodations, **you have to take many steps that involve interacting with people and navigating complex systems**. Those are the things that depression, anxiety, ADHD, and autism make difficult. To get help doing the things I have difficulty with, I have to first do the things I have difficulty with.

that other people do naturally. Many of my genuine emotional responses to things are things that I actively had to practice until they became second nature, because people could never tell what I was feeling when I was younger.

TYLER Z.

He/ Him
Age 25
White



INVISIBLE ILLNESSES

Attention-Deficit/Hyperactivity Disorder (ADHD)
Asperger's Syndrome Features

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Can't work without meds. With meds I have side effects such as obsessive picking, but can focus on work. Lack inherent understanding of social cues, leads to so called social deficiency. Would feel sadness from alienation but have good community so not really anymore.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

I am certain there have been nigh uncountable social opportunities that I have squandered or demolished unknowingly thanks to my lack of social intuition, and I can be frustrating to speak with sometimes because my brain has difficulty keeping a single track of thought.

KYLIE RUNG

She / Her
Age 22
White



INVISIBLE ILLNESSES

Narcolepsy
Post Traumatic Stress Disorder (PTSD)

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I would say these illnesses have dramatically affected my day to day like in so many ways that I don't even notice them all. The most obvious example I can give is that I am exhausted most of the day, I will always take a nap if I am able. As you can imagine, being tired all the time creates challenges in maintaining a positive attitude. I'm sure you can think of many times you've acted or said something you didn't mean because you were tired.

Narcolepsy has SO many different symptoms that vary day to day for me. Thankfully I am able to take medication that helps me stay awake, but it can only do so much.

As far as PTSD goes, that had changed my life upside down. (Full disclaimer, it's very mild now) For me, it stemmed from a toxic relationship. **I was unable to be in social situations without being in fight or flight, I was in fight or flight for years.** I would shake uncontrollably if something triggered me. I would look at normal things like a building and get intense flashbacks/unwanted memories, I could look at a persons face and my brain could convince me it was someone it wasn't. I didn't sleep for more than 90 minutes at a time. I had debilitating nightmares, night sweats, sleep paralysis, and night cravings. I was unable to cry for almost a year. I somehow managed to avoid any and all interactions with men, except for people like my professors or bosses. Because my experience with PTSD was so bad, I did EMDR therapy which essentially mimics REM sleep while you are awake to process memories in your brain. That brought up TONS of suppressed memories and flashbacks. My experience with PTSD was so extreme, it manifested into physical illness as well. I developed high blood pressure... (still to sure where that comes from but for now I associate it with the PTSD), was sick consistently for about 2 years, developed temporary allergies and had numerous reactions to random things like the sun and ibuprofen. This made it incredibly difficult to survive physically and mentally.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Absolutely. For me, being narcoleptic is always something that becomes someone else's burden, although it has been manageable this far. I would say PTSD had affected other the most. I lost almost all of my friends, most intentional, some unintentional, because I couldn't keep being around people who were in association with the person who caused the PTSD. **Even after all this time, it is still a burden to share things like this with someone new.**

KELSEY FAWL

She / They
Age 33
White



INVISIBLE ILLNESSES

Hyperadrenergic Postural Orthostatic
Tachycardia Syndrome (POTS)
hypermobile Ehlers-Danlos
Syndrome (hEDS)
Mastocytosis
Fructose intolerance

VISIBLE ILLNESSES

Compression Tights for
hyperadrenergic POTS
Cane and Body Braid for hEDS

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Due to my connective tissue disorder I have joint subluxations dozens of times a day. I have had chronic pain daily for at least 9 years (even with pain management). I have had to give up some of my favorite hobbies/passions, unicycling, rolla bolla, and performing for local circus events. I had to quit several jobs to find less physically demanding work due to my inability to do the minimum requirements of each position because of my increasing physical limitations & fatigue. I am now on disability.

I am rarely able to eat something without it causing some form of abdominal discomfort. Even when I drink sugar-free items the sugar substitute still causes my throat to mildly burn. This is because of my fructose intolerance, which also requires me to avoid fructans which are things like onions and garlic. Occasionally I will break out in what looks like bug bites with a tiny blister that itch & burn when scratched. We recently discovered that this is more that likely mastocytosis and that my episodes are triggered by stress.

A few of the things I struggle with due to my hyperPOTS include having pre-syncope (pre-fainting) symptoms, syncope (fainting) on rare occasions, temperature intolerance for both hot and cold, and an elevated HR upon sitting and standing. I am required to take a beta blocker to regulate my HR, though recently I have been experiencing lowered and fluctuating BPs. **I have to wear compression tights daily, and must add an abdominal binder when my BP is lower than normal.**

I struggling opening doors and carrying things. I wear orthotics daily which drastically limits the kind of shoes

I can wear. I also have AFOs and a multitude of braces that I wear as needed. I have used a cane for 6 years now. I was prescribed an electric wheelchair several years ago, but ended up selling it because I had no way to transport it. Eventually I will purchase a light weight powerchair, even though 40-60 lbs is still too heavy for me to lift myself. I almost always use the electric carts in stores when they are available.

My symptoms have grown more significant over the years and has required me to adapt frequently. There are periods of time where my health is well managed, and although I logically know my conditions will progress it still is disheartening whenever that time comes... Regardless of how much I have prepared myself. There is a grieving process when it comes to loss of function that a majority of folks are unable to fully comprehend unless they have experienced it themselves. Especially when it is regarding a decline that happens in several segments.

Fortunately at this point in my life I am not bothered by folks asking me about my cane. I tend to see it as an opportunity to briefly educate others about how disability can happen to anyone at any age, and that it isn't always noticeable. Though it baffles me how some people phrase their questions. The one that throws me off the most is What's wrong with you? I also use those situations to inform whoever is asking that although I may not mind answering their questions that it can be very intrusive and painful to others depending on how their disability occurred, how new it is to them, or a whole host of other reasons.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I take meds 3 times a day, I use mobility aids, compression garments, braces, & ring splints. I have to rest way more frequently and use ice or heat depending on my levels of pain and injury. I am much more likely to have repetitive stress injury symptoms from seemingly simple tasks. I am also more likely to postpone, cancel, or to not commit to an event/plans/goals based on how symptomatic I have been.

It is very frustrating, but it some ways it has forced my to prioritize my health and well-being, but as an extrovert it has taken a huge toll on my social needs. It has also made it a big struggle to commit to getting my business off the ground. There is a intense back

and forth of desire to accomplish my goals & defeat of feeling as if I won't be able to maintain whatever it is that I accomplish... if I'm even able to accomplish them. As you can imagine the emotional tug-o-war can cause an upswing in anxiety and depression. Given that I already have an overactive adrenaline response from my HyperPOTS, anxiety medication only does so much in these situations. Fortunately I have made a huge effort in building and maintaining my support system. Therapy is also super beneficial on the days I'm struggling the most and need to untangle some of my internalized ableism or just to process how my conditions effects me.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Absolutely. Certain people will avoid striking up a conversation because of how I present, whereas others will go out of their way to talk with me because they see my cane.

BREANN MATLOCK

She / Her
Age 22
Caucasian



INVISIBLE ILLNESSES

Depression
Anxiety
Attention-Deficit/Hyperactivity Disorder
(ADHD)
Autism

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I struggle with motivation and executive function so even the smallest tasks are difficult and sometimes impossible. Social interactions can be helpful for my mental health but are frequently overwhelming. I crave structure and organization, and I love making plans for myself. However, I can rarely follow-through or keep it up for longer than a week. **I am constantly trying out different ideas on how to make certain tasks easier and I have found a few that work but most don't.** Hygiene is a struggle because routines are so hard to keep, and some activities - like showering - are extremely overstimulating. I am always fighting between being overstimulated and understimulated, there aren't very many instances where I just feel at peace.

It is hard to find self-care activities because my needs are always changing. I am medicated for my ADHD which helps some but also comes with side effects and doesn't fix anything, just makes it a little easier to handle. Medications for mental illnesses are usually really intense and have a lot of side effects. I tried anti-depressants but the side effects were unbearable. It is hard for me to balance work, school, and life and I am constantly burnt-out.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

I get confused sometimes when talking to people and feel out of the loop a lot, misunderstandings are a very common occurrence. I can't always give the important people in my life the support and attention they need and deserve, so sometimes that causes distance. I am sometimes seen as lazy and unfocused by people around me.



She / Her
Age 22
Caucasian

AVA SCHICKE

INVISIBLE ILLNESSES

Anxiety

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Depending on the day, my anxiety can be worse. My anxiety can prevent me from completing work, school, going to social gatherings, and getting closer to people. It causes me to doubt myself over the silliest things and can also sometimes lead to anxiety attacks where it's hard to breathe.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes - my anxiety has prevented me from opening up or public speaking.

SHAYDAN BAYLESS

She / Her
Age 22
White



INVISIBLE ILLNESSES

Anxiety/Depression
Premenstrual Dysphoric Disorder (PMDD)
Celiac Disease
Hypothyroidism
Endometriosis

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Anxiety makes it hard for me to want to be around people and go places, especially busy places. So, it has definitely affected my relationships with my friends and forming friendships in general. I struggle with falling asleep at night because I have so many anxious thoughts and I am anticipating the next day. I am constantly worrying, overthinking, and stressing myself out. I live my life in a constant state of panic where I feel overwhelmed. Physically, I am an anxious skin picker and I bite my nails. I also sometimes experience vasovagal syncope when I am greatly emotionally distressed.

My depression makes it super difficult to be motivated. I often find myself struggling to make it out of bed. Taking care of myself (eating, showering, cleaning) can feel impossible like an impossible task at times. **Tasks that may seem small or routine to many, can feel very unachievable to people like me who struggle with depression.** Additionally, I've quit or stopped doing things I love because of my depression. The negative thoughts are what have gotten to me the most. Depression makes everyday more difficult when you have that negative voice constantly in your head. I think depression makes you feel stuck like there is nothing to do to fix it. To me, that is one of the worst parts, but the good news is there are ways to come with it. I have struggled with both anxiety and depression since I was 11 years old. But I am finding new ways of coping as I get older.

Celiac Disease is an illness caused by an immune reaction to eating gluten. It damages your small intestines lining and prevents it from absorbing nutrients, a condition called malabsorption. This means I have a strict diet where I avoid eating any wheat, barley, or rye. If I eat gluten by accident, I experience sharp stomach pains, muscle cramps, and extreme fatigue. Having celiac disease can be frustrating for many reasons. Oftentimes people aren't aware of how damaging the disease can be. Also, I've noticed that people tend to minimize the seriousness of celiac disease due to their unfamiliarity with it. This can also make dining a nightmare as it can be a struggle trying to find restaurants that will suit my dietary needs.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Both depression and anxiety have affected the way I interact with others. My anxiety and depression makes me not want to be social with people and I rather stay at home most of the time. You can only decline an invitation so many times before people stopped inviting you. Also, I've never been a person with a ton of friends because my anxiety makes it more difficult to form relationships.

With PMDD I tend to either withdraw myself from those around me or become upset easily which has affected my relationships and interactions with others. **Similarly with conditions like PMDD and endometriosis women are often told that they are fine or experiencing normal symptoms when in fact they are not.** People sometimes have to fight for a diagnosis of an invisible illness.

PMDD is a hormone-related disorder that occurs one to two weeks before a menstrual cycle. I always can tell when I am experiencing it because I turn into another, more miserable version of myself. I notice I am quick to anger and I am extremely irritable. My existing anxiety and depression worsens. I feel extremely sad, hopeless, and even suicidal at times. I really become emotionally uncontrollable. I experience episodes of crying due to my poor self-image that becomes distorted while experiencing symptoms. **Since PMDD affects the way I view myself, my perception of how others view me also becomes distorted.** Additionally, it affects those close to me because I tend to push them out or become upset with them while experiencing PMDD symptoms. It makes life at home and school even more challenging when I don't feel like myself. Sometimes my symptoms can be so engulfing that it scares me. I think the way PMDD impacts the brain is something people can't comprehend, but I wish more people knew about how debilitating it is.

Brain fog, fatigue, dry skin, hair thinning, weight gain, and sensitive to cold are some symptoms I've experienced with hypothyroidism. **Hypothyroidism, or underachieve thyroid, happens when the thyroid gland doesn't make enough thyroid hormone.** Brain fog has been a huge symptom for me. I find it making it difficult to concentrate, I lose my train of thought, and I sometimes have trouble remembering things. This can make school difficult for me and it takes me extra time to complete assignments while experiencing brain fog. I feel exhausted and I am constantly trying to keep myself warm with extra layers of clothing and blankets.

Endometriosis is a disease in which tissue similar to the lining of the uterus grows outside the uterus. It is a chronic disease associated with severe, life-impacting pain during periods, sexual intercourse, bowel movements and/or urination, chronic pelvic pain, abdominal bloating, nausea, fatigue, and sometimes depression, anxiety, and infertility. What I wish people knew about endometriosis is that it can make period pain severely worse. At times, the pain is unbearable to me. It makes me have horrible back pain and cramps that are absolutely debilitating.

DANAE CONTINO

She / Her
Age 39
White



INVISIBLE ILLNESSES

Hemiplegic Migraines
Depression

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Depending on the day, I deal with a broad range of neurological interference. From lighter symptoms like tingles down my arms and legs to more intense symptoms like visual disturbance, nausea, and drilling head pain.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes. Symptoms like slow or jumble speech or irritability affect social interactions.

NICOLE GEIB

She / Her
Age 22
White

INVISIBLE ILLNESSES

Eating disorders
Anxiety
Depression



HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I struggle to eat comfortably every day for the past 10 years of my life.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes, personal relationships are affected, but i haven't had that issue in about 2 years.

INVISIBLE ILLNESSES

Severe allergies
Asthma
Hashimotos
Celiac

VISIBLE ILLNESSES

Hives

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Allergies and asthma make it difficult to be outside the bulk of the year, and almost never without a mask, and are definitely my most difficult chronic illnesses to deal with. Having to go gluten free feels less and less like an issue the more widespread it becomes, though early days made me feel like I had to defend myself when asking for gluten free.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

If it's a flare up, life stopped the first few times, after that though I just had to keep going. What else are you supposed to do? I'm on a really nice biologic and get injections once a month that keeps hives at bay 99% of the time!

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes, but it feels superficial to say that. I can't eat at an outdoor table so I don't go out because I don't want to feel like I'm forcing people to not be able to enjoy a patio table. I guess we also had to hire lawn care people because I just can't do that anymore, but they don't weed and do some of the other stuff, so I always feel like my neighbors aren't happy with me. I know so many that have much more debilitating illnesses, it's hard to take mine as seriously.

She / Her
Age 46
White

**SANDRA
IRVIN-DINGER**

**HAYLEY
MANZER**

She / Her
Age 22
Caucasian

INVISIBLE ILLNESSES

Severe hearing loss
Hypothyroidism
Hashimoto's

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

During Covid, things were super difficult because I couldn't hear people around me even with hearing aids and I wasn't able to read lips, so my everyday life was altered in a dramatic way trying to come up with a new way to compensate for my loss. As far as my thyroid stuff and things I have a weakened immune system so staying home and staying safe was obviously very important. **Beyond that I've learned to live with everything.** Sometimes I pretend to hear what others say so I don't have to say what a million times and get made fun of. Usually I make a lot of eye contact and read lips so I can be apart of the conversation. I also make sure to maintain my medicine for the thyroid so I don't see too many side-effects but if I get off track or its the wrong dosage then I become forgetful, mood swings, hair loss, weight loss/gain, depression, tired/can't sleep, and so on.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes, I would say I pass up opportunities and interactions because of my hearing loss I have a lot of social anxiety and avoid doing things because of it.

INVISIBLE ILLNESSES

Bipolar Type 1

They / Them
Age 21
White

LIV BROWN

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Depressive episodes have made struggles with daily functions, routines, and motivation and willingness to pursue long term goals. Manic episodes have caused hallucinations, which led to unwillingly dropping out of college, at risk for things such as dangerous driving, cooking or cutting food for meals, over spending money, and choosing life altering decisions without much prior thought. The decline from a manic episode brings a lot of guilt and shame and has made me retreat from people, groups, and activities out of embarrassment, which made it hard to sustain friendships. There is fear and anxiety about approaching manic episodes, and it can be embarrassing having to explain my situation to people. **It is scary to share when you feel as though you may lose the trust or respect of someone.**

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Keeping friends can be difficult mostly due to withdrawal from them due to my own embarrassment over erratic and intense manic episode behavior, as well as finding it emotionally and mentally taxing to reach out to people when in a depressive episode. While professors/teachers have always been accommodating and kind to me in school about it, **I do still put off reaching out to them for help because I'm worried about being seen as less capable of my future career or unable to control myself**, so it has affected interactions due to my lack of wanting to reach out and inform people. Bipolar disorder has different daily effects due to whether it is during a manic episode or depressive episode.

LOGAN S.

He / Him
Age 25
Caucasian

INVISIBLE ILLNESSES

Back pain
Lower-joint pain
Allergies
Foot Pain from a hit & Run

VISIBLE ILLNESSES

The caustic-burn scars have exacerbated the limp by preventing full extension of the limb due to taunt skin/scars, other visible illness do not generally affect my day to day life.

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

It has led to reduction in activity so as to not stress the affected areas and the damage to my foot has led to a limp. Furthermore, allergies cause me to practically shut down during the spring.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

The caustic-burn scars have exacerbated the limp by preventing full extension of the limb due to taunt skin/scars, other visible illness do not generally affect my day to day life.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

I am limited in my day to day interactions because of them, yes.

He / Him
Age 24
White

CAMERON

INVISIBLE ILLNESSES

Possible Autism

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Resulting Social Anxiety and Hyper Self-Awareness significantly reduce the number of interactions I have with new people / people I don't frequently associate with

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

I have stopped talking with many old friends simply because too much time has passed

ANONYMOUS

She / Her
Age 24
Caucasian

INVISIBLE ILLNESSES

Potential Anxiety
Potential Attention-Deficit/
Hyperactivity Disorder (ADHD)

VISIBLE ILLNESSES

Auto-immune issue
causing a rash

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I am easily distracted, and can easily become overwhelmed.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I am asked constant questions about the rash, and then am told about many unrequested remedies.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

The more stressed I get due to questions the worse the rash looks.

MICHELLE SHAVLIK

She / Her
Age 33
Caucasian

INVISIBLE ILLNESSES

Ankylosing Spondylitis
Asthma

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I'm in constant pain. Walking is difficult. Standing is difficult. Even sitting for too long hurts.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

My AS causes me to need mobility aids at some points. I have noticed children and the elderly staring, and people are just awkward about it in general if they don't know me personally. I also have a coworker who has told me that if I ask him to cover a shift because I can barely move it feels like I'm guilt tripping him, but it's OK because he doesn't care that I'm in pain.

INVISIBLE ILLNESSES

Generalized anxiety disorder

VISIBLE ILLNESSES

Vision impairment - Glasses

They / Them
Age 26
White

ANONYMOUS

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Social anxiety when interacting with others, especially those in a position of authority. Overthinking simple tasks. Frequent stomach aches and loss of appetite. Difficulty relaxing.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Glasses are inconvenient. Rain/water droplets, smudges, fogging all impair vision.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes. Social anxiety, overthinking, and heightened baseline anxiety have impacted most interactions with other people.

ANONYMOUS

She / Her
Age 42
Caucasian

INVISIBLE ILLNESSES

Low Thyroid
High blood pressure
Low nocturnal oxygen

VISIBLE ILLNESSES

Obese

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

It is hard to get up some days. I have to go to multiple medical appointments.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

It affects job relationships.

INVISIBLE ILLNESSES

Stage 4 Metastatic Prostate Cancer
with spinal cord compression

VISIBLE ILLNESSES

Walk with a cane
Fatigue and weakness

He / Him
Age 60
White

ANONYMOUS

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I am unable to work or drive.

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I end up mostly staying at home but I am doing well.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

Yes, a friend got tested for prostate cancer and he had it and they caught it early.

INVISIBLE ILLNESSES

Chronic Childhood Trauma (CCT)

She / Her
Age 32
Hispanic

ANONYMOUS

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I am easily triggered by stimuli in my environment that do not seem to connect to my experience. I can see the make of a vehicle, hear an expression, or catch a scent and be launched into a trauma spiral. This can manifest as invasive thoughts that become insomnia, crippling anxiety, panic attacks, mistrust and impulsive actions, and isolation and hyper-independence. Some days, I have no symptoms. Some days, I cannot function in the current societal systems as run currently.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

I have had, and continue to have, interactions I wish I could take back that are direct impacts of experiencing my illness. Some of this is due to responding in a survival state to well-meaning or simultaneously triggered individuals. Some of this is due to general misunderstanding and discrimination against humans experiencing the impacts of trauma.

ANONYMOUS

She / They
Age 71
Caucasian

INVISIBLE ILLNESSES

Diabetes
Cancer
Hardened arteries
Neuropathy

VISIBLE ILLNESSES

Double mastectomy
Prosthetic causing lymphedema
if worn a lot.

HOW DO THE INVISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

Stumbling on uneven surfaces, falling, problems typing, tiring easily

HOW DO THE VISIBLE ILLNESSES AFFECT YOU ON A DAILY BASIS?

I can't do as much as I want. I can't walk in my neighborhood without an assist. People get mad when I wear a mask even if I explain that it's for my health and why.

HAVE PAST INTERACTIONS WITH OTHER PEOPLE BEEN AFFECTED BY YOUR ILLNESS?

People get uncomfortable when they can't figure out whether I'm male or female. They are especially upset if they have guessed incorrectly.

HOPEFULLY,

reading the surveys I have collected have opened your eyes to the unseen world of invisible illnesses. While many of the surveys have had different interactions with others, a lot of the interactions could have had very different results, if more people were made aware of the existence of invisible illnesses and how they affect people.

If you want to see more of my work check it out at sixcreations.info

Thank you for taking time to look at my work. I hope you have a great day!

