

## **Living in the twilight – my life with severe light sensitivity**



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I live in twilight all day. I can't go outside in the sunlight, and indoors I have to keep the lights low.

If I expose my face to direct sunlight for a minute or two, it will start to burn about twenty minutes later. It does not get red, it just feels like a lightly irritated sensation as a normal person may feel after a full day in the sun.

With another minute or two of direct sun-exposure, I may get little red splotches and bumps on my face.

I also get some weird neurological sensation in my legs, even though they are only exposed through clothing.

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I haven't tried too many "experiments" as I've had some overexposures that permanently made me more light sensitive.

My normal skin color is "Nordic white." After I moved to the desert, I got a nice year-round tan. Now my face looks "sun kissed" all the time, despite the near-total lack of sun. I wonder if it would go away if I had to live in total darkness (I don't want to find out).

I had to block the windows and modify the lights inside. It is all indirect lighting. I use low-wattage task lights that shine directly down on what I am working on.

They are not much brighter than night lights. Even the reflections from white paper can be too much after some hours of reading.

### **Going outside**

I love to go outside after sunset and before sunrise. I live in a rural area where there are no street lights so I can hike around the area. It is best to hike in the twilight, or when the moon provides enough light, but I also hike in the dark with a flashlight. Best is when there is a full moon – that really works.



*The full moon is lovely for hiking. The free-range cows seem to like it too.*

In the summer I have to be careful with the rattlesnakes. When it cools down in the evening, they seek out the warmth of my driveway and the road. They hear me before I see them. If I get too close, they give me a warning with their rattles. That makes me jump every time, as they are then about ten feet (3 meters) away.

I sometimes have to go outside in the daytime, but briefly, and I can stay in the deep shade. Then I have to bundle up like a bedouin, with a big hat, a face shield and a scarf, all specifically made for people with light sensitivity.

About once a month I need to do some chores outside where I have to be in direct sunlight. Then I need to be outside three times, with two of the trips taking about ten minutes. I actually enjoy that. It is exhilarating to feel the warmth of the sun, and as the symptoms come later I often quietly wonder whether “this time may be different.” Maybe I tolerate the sun more this time?

Alas, nine out of ten times this brief excursion is too much. My protective gear is not perfect. If you hold the fabric up against the sun, you can see the sun through it. But the main problem is the areas of my face where the sunglasses meet the face shield and scarf. Sunlight sneaks through and irritates small strips of skin. Sometimes it gets through on the neck too.

Overcast days are only a little better. I once had to do some emergency repairs outside. A snowstorm was approaching and the repair could not wait until after dark. The sky was heavily overcast, so I thought I would be fine. I was outside for 45 minutes, wearing my “bedouin” outfit, but it took a couple days for me to recover. Overcast days seem so enticing, but they are not dark enough.

## **Visitors**

I live alone, but have frequent visitors. One friend comes every week, others come less often. It takes several minutes for their eyes to adjust from the desert sun outside to my indoor twilight. I’ve had visitors who came after sunset, so we could be outside. Without the help of my friends, this would be a lot more difficult.

## **Gradually worse**

I moved to rural Arizona to get away from mold, pollen, cell towers, and air pollution. I felt so much better here, it was such a relief.

But the sunlight is strong out here. After a couple of years my eyes needed extra-dark sunglasses, otherwise they really hurt. Once I found such a pair, everything was fine again for a few years.

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Then my skin got irritated by the sunlight. A friend had the same problem and showed me special lightweight sunprotection clothes. With a hat with oversized brim and a flap to protect the back of the neck, things were fine again for a dozen years.

If I needed to be out in direct sunlight for hours, I just had to wear two layers of this fabric, and a face shield made of the same fabric.

I didn't tolerate sun screens. Eventually I figured out how to make my own without any chemical additives, but they are not as effective as the protective clothes.

If you smear it on a piece of glass, you can see how much light still gets through. It is made of titanium, which makes my face completely white. That disturbs some people.

The problem was under control for a dozen years. There were just a few times when I got too much sun on me and I had to stay inside in the dark house for a day to recover.

Then I began to have more episodes where I tolerated the sun less. That included a month where I had to drive to town before sunrise. Then it got back to almost "normal" again, but not quite. A few months later I had to deal with a situation that required me to be outside every other day for a couple of hours for a period of seven weeks. At the end, my sun sensitivity had gotten worse. Whenever I went to town, I had to stay inside the next day to recover.

I went to a outdoor party at a friend's house. I stayed on the shady porch for the three hours, and wore a face shield the whole time, but it was still too much. I had to stay inside my house for two days afterwards, and from then on any daytrip required two days inside to recover.

For years I could only watch a movie for about 45 minutes. Now I could only tolerate the screen-light for fifteen minutes. Soon I had to give it up entirely. I'd had to give up using computers long ago (someone else typed this).

I had to go shopping before sunrise, but drive home in daylight. That too became a problem.

I tried to give it a rest by not going anywhere for a month. Then I drove to town and just ignored the symptoms. That was a big mistake. The next day even the ceiling lights in my house were a problem. That had not happened before.



*Ah sunset! Now I can go outside.*

I didn't know the ceiling lights could cause trouble, so it took a couple of days to figure that out. The burning sensations don't just stop once I get out of the light, and they don't start right away, so it takes some experimentation to be sure.

This happened nearly two years ago. I never recovered.

## **Shopping**

I do not go shopping any more. In the winter I could make it there and back in the dark evenings, but the lights inside the stores and their parking lots are now too strong. Driving there is a problem too, most people drive big pickup trucks on our rural roads, and many do not turn down their high beams.

I had to hire a shopper. He goes to town for me every two weeks. He washes his clothes at a laundromat, so they often reek of fabric softener from the shared dryers. That stuff makes me very sick, so I can't let him in the house. Instead, I meet him outside on my shady porch.

I am bundled up and that works well. It doesn't take long and I can stay in the shade the whole time.

### **Visit to the dentist**

I didn't go to the dentist for two years because of the COVID pandemic. Then I couldn't go because of my light sensitivity. I have good teeth, but one tooth started aching.

I waited until the short days of December. Then I called the dentist and explained my situation. I've gone there for well over a decade, and they serve a lot of people with various environmental illnesses. They know how to accommodate people with multiple chemical sensitivity (MCS) or electrical hypersensitivity (EHS), so they are used to "strange" requests.

Sunset was at 5pm, and the dentist cheerfully kept her clinic open until 6:30 for one evening, so I could get there and didn't need any windows covered.

They turned off all their bright LED ceiling lights and used just the lights they really needed. I was relieved they did not have to use flashlights, other than the headlight she always use.

I was inside for an hour, as it was difficult to find out what the problem was with that tooth. I was getting worried she'd write me off as imagining things – doctors tend to jump to that one if you have a controversial disease. Then she said there was only one possibility left, and that was the problem. She took care of it, and the tooth has been fine since.

I had expected to have to sit in a completely dark room for a couple of days afterwards, but I had no symptoms the next morning and could do my regular low-light lifestyle. I wonder how many other dentists would be this kind.

### **It can get worse**

I do test my limits – perhaps more than I should, but it is hard not to. I know it can get worse yet, where people have to live in total darkness and are not able to do anything productive. I have visited two houses where people live that way.

I have for years exchanged letters with a woman in Australia whose husband sat in an adjacent room with a light, while his wife sat in complete darkness. She dictated her letters through the wall, and he read for her that way. After eight years she got better enough to do her own writing.

I have met another person whose eyes are so sensitive to light that she has to cover them with a dense scarf wrapped around her head. She can only remove it at night as she can't darken her house enough in the daytime. Even at night she can't really have any lights on.

Her skin is not particularly sensitive to light. With the thick scarf around her head, she can walk outside in bright sunlight, but she is effectively blind and must use a cane to feel her way.

There is a book, *Girl in the Dark*, about a British woman with a similar story as mine.

Light sensitivity is common among people who have electrical hypersensitivity, which I also have, but it is almost always much milder, like I had it for a dozen years. The severe cases are rare.

### **What causes it?**

There are many known causes of light sensitivity, including chemical sun screens, lupus, porphyria, Sjogren's, and several prescription drugs.

Porphyria appears to be particularly common among people with multiple chemical sensitivities (MCS) and electrical hypersensitivity (EHS). I also fit the symptom profile for porphyria, but a blood test came back negative.

Since few of the known causes are curable, finding it is mostly academic. Though it would be useful to have a proper diagnosis if I ever had to go to a hospital, so my requests to turn off the lights would be respected.

### **It is not anxiety**

A well-meaning doctor suggested I might have some sort of anxiety. To find out, I read the book *Anxiety for Dummies*, but I did not see myself described there at all. I do not have the symptoms listed in the book as typical for anxiety.

I do not feel a sense of dread when I do need to go outside in the sun. In fact, I always enjoy it, as the symptoms come later. Occasionally I do not get the burnings later on – if they were caused by anxieties, wouldn't I get them every time, as I expect?

When I go outside, or need to use more light inside, I look at it as similar to crossing a busy road. I do it with respect, I do it efficiently, but it is not such a big deal, as long as I don't overdo it.

The book also says that avoidance does not work for anxieties. It has worked many times for my light sensitivity, it still helps, but not enough any more.

There have been times where I got caught up in what I was doing, and forgot the time. Then I got reminded when the symptoms started. I don't think anxiety works that way.

I don't want to live in twilight or darkness. Sometimes I overexpose myself and have to turn off all the lights for a few hours (occasionally days). When doctors don't know, they tend to blame the victim. When they didn't understand what migraines, eczema, and asthma was, they said those were anxieties too.

### **More information**

The book *Girl in the Dark* by Anna Lyndsey tells a similar story.

Descriptions of environmental illnesses on [www.eiwellspring.org/intromenu.html](http://www.eiwellspring.org/intromenu.html).