

Girl in the Dark by Anna Lyndsey

Review

Lyndsey's book is about living with extreme light sensitivity which for ten years forced her to live in the twilight and sometimes complete darkness. The story is written with grace and wit and is an inspiration to all who live with any life-altering illness, especially the various environmental sensitivities. It is also a story of the difficulty of having an illness that is little understood and thus controversial.

Keywords: light sensitivity, photo sensitivity, environmental illness, screen dermatitis, controversy, contested illness, unexplained illness, hostile press, Anna Lyndsey

Anna Lyndsey is 33 years old with a college degree in history and works as a line manager at a government ministry in downtown London, England. She lives by herself in a London flat and likes her freedom, though she has been dating a nice guy named Pete for two years. She is very light skinned and has always protected her face with wide-brimmed hats.

In the spring of 2005 it is a busy time at the ministry. Anna is working on a briefing paper for an incoming official when she notices her face is burning whenever she sits in front of the computer. She copes by installing a fan that blows air directly onto her face. Some days later she notices that fluorescent lights make her face burn as well, though there is no redness or other visible change. She describes it as "an invisible fire."

The situation rapidly becomes unmanageable and she goes on medical leave. She hopes it'll just go away again, but a few weeks later her face begins to burn in moderate sunlight while she visits a nature preserve where she is far from any computer or fluorescent lights.

Her doctor has little to offer and she is put on a waiting list to see a dermatologist who specializes in light sensitivity.

She realizes she needs help coping and asks her boyfriend if she can move into his house outside London. He agrees and it turns out very well between the two, despite the many restrictions Anna's illness places on him. He eventually proposes marriage.

Anna's light sensitivity continues to get worse. It is finally time for her appointment with a specialist doctor. She travels to London by train while wearing a veil to protect her face, which alarms a fellow passenger.

At the light sensitivity clinic they conduct several tests and rule out the common causes, such as lupus and porphyria. None of the test show anything abnormal. The doctor says he has seen a few people as severe as her and with no known cause. He admits that medical science doesn't know enough and has little help to offer.

Anna gets in contact with other people with various little-understood illnesses who:

wander in the twilight zone where doctors diagnose but cannot cure, and the faint miasma of societal suspicion, never attached to those with cancer, or with heart disease, hangs about them, that somehow it must all be psychosomatic, or that at a deep level they actually want to be ill.

One of her new friends lives in France and has bi-polar disease (also called manic-depressive). This woman says that when she tells people about her mental illness:

the reactions range from horrified withdrawal to the advocacy of New Age therapies, instructions to pull herself together, because everyone has mood swings, or a recommendation to submit herself to the Roman Catholic Church.

Anna realizes her career in the civil service is over and wonders what she can do instead, without leaving home, with no computer and with limited light. She manages to become a certified piano teacher, but she continues to become worse and becomes confined to a completely darkened room instead of the perpetual twilight she lived in for the first year.

In complete darkness the options for entertainment are quite limited. She listens to audio books, talks a lot on the phone and does complex word games in her head. She has the company of her fiancé and some family also visits, but she feels much alone. Old friends simply disappear, unable to deal with such an alien situation.

It is no longer just her face that “burns like a blowtorch,” when she is exposed to light, but now her entire body. Her realization and acceptance of the new normal is vividly described, though only people who have faced such a situation themselves will really understand what it truly means:

With casual brutality, illness reminds us of the limits of human will. At each stage of my decline, getting the first inklings of the next phase of horror, I would say to myself, repeatedly, “I will not let this happen.” And it happened, nonetheless. In my body, something was afoot; there had been treachery within the citadel. Quietly an alien force crept in, overwhelming the loyal defenders, taking and holding the positions of strength. My will is left to roam impotently in one small tower, surveying its occupied domain.

She becomes unable to travel to the light sensitivity clinic in London and begs the physician to come to her house. She even offers extra money, but he refuses. No other physician is willing to come either, but a few are willing to do phone consultations and send someone to draw blood for lab tests. She is surprised that there is no interest in actually studying the problem scientifically, nobody ever did a skin biopsy.

She then ventures into various forms of alternative health treatments. The practitioners are usually willing to come to her home, but:

like so many people who are chronically ill, I am released into the wild healthcare borderland, a trackless and confusing country, where what signposts there are point in multiple directions, sat navs fall silent, and strange beasts roam.

None of the alternative treatments are really helpful. Anna gets upset when one of the healers suggest that her illness is what keeps her relationship with Pete going or that she hides in the dark out of fear that people may look at her. People with as-yet poorly understood illnesses are commonly subjected to such pop psychology.

Her experiences with conventional health care makes her realize they will not, or cannot, accommodate her needs if she needs to go to a hospital or even a dentist's office.

She contemplates suicide, like many people in such a situation, but where to get the necessary tools when cut off from the world? Once she figures out a suitable method it gives her peace just knowing there is an exit if needed.

She has periods where the sensitivities wane somewhat so she can go outside and jog at dusk. She just has to avoid street lights, car's headlights and the occasional motion-detector light booby trap. With this wiggle room the couple shows great inventiveness with light meters, a shielded cage in the back of the car and other measures. The kind keepers of a public rose garden even allows the couple access after-hours.

Anna becomes an activist against the ban on incandescent light bulbs and the LED lamps the town wants to erect on all streets. The bluish-white LED light is much more troublesome than the older yellow street lights.

This issue has first recently received some mainstream notice, such as in the October 2016 issue of *IEEE Spectrum* magazine.

This is a delightful book. It could so easily have been a sob story, an angry story or one of artificial cheerfulness, but it is none of those. The story is told with grace, humor and intelligence with interesting details that never become boring.

This reviewer knows about other people in similar situations. They all have other environmental sensitivities, especially MCS and electrical sensitivities. Anna Lyndsey never mentions any of those, though a journalist who later interviewed her was puzzled that she required him to not bring any electronics with him and not wear any fragrances. Perhaps Lyndsey decided one “weird” diagnosis was enough for one book.

Media commentary

The *New York Times* reviewer didn’t have much to say beyond incessantly complaining that the whole book was written in the present tense.

The *Guardian* liked the book better, but found the story “impossible to take . . . at face value.” It seemed too unusual to be anything other than psychosomatic, in the eyes of the reviewer.

The *New Yorker* went much further. Their journalist tracked down Anna Lyndsey and actually visited her. The journalist was clearly on a mission to “expose” her as mentally ill. He interpreted everything through this lens and allowed Anna no benefit of doubt. Unfortunately, such hack jobs are common in media coverage of contested illnesses.

Other reviews

Other books and movies about environmental illnesses are reviewed on www.eiwellspring.org/booksandreviews.html.