

# Without Words: The Visibility of the “Invisible” in Eliza Dee’s Universes

By Rebecca Finch Vitsmun

This document contains a list of the ways in which Eliza’s Autism Spectrum Disorder (ASD), her physical conditions hypermobile Ehlers-Danlos Syndrome (hEDS), Postural Orthostatic Tachycardia Syndrome (POTS), Mast Cell Activation Syndrome (MCAS), and night-blindness, and her experience of hyperphantasia are depicted in Eliza Dee’s Universes.

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## Note from the Author

Please use this document to develop a better understanding of all of these conditions.

You could help your neighbor, student, friend, family or community member, or even yourself in discovering these conditions. One of the first 10 people who ever read Eliza Dee's Universes realized she was represented in the book and pursued finding support for her hypermobility.

For the purposes of this document, I will be citing statistics related to gender, but it should be noted these traits are not exclusive along gender lines.

I am not a doctor. This is not medical advice. Anyone who might have any of these conditions needs to be working with professionals to manage their symptoms. Spreading awareness can help those who need specialized care receive the resources and services they need.

There is movement to change the phrase "invisible disabilities" to "hidden disabilities." For the purposes of Eliza Dee's Universes, I believed I could do more to benefit our community by using the language that has not yet been changed and explaining it here.

Thank you,

Rebecca Finch Vitsmun

# Definitions

The following are simple definitions for Eliza's conditions. Please visit the links in the bookmarked endnotes for detailed education.

## **What is ASD?**

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder that affects social interactions, communication, learning, and behavior.<sup>1</sup> The American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5) is the current criteria used to diagnose ASD.<sup>2</sup> The presentation of ASD has been noted to have distinct differences between males and females<sup>3</sup>, though males can present with the "female" phenotype and females can present with the "male" phenotype.<sup>4</sup>

## **What is hEDS?**

Hypermobile Ehlers-Danlos Syndrome (hEDS) is a multi-systemic connective tissue disorder that causes generalized joint hypermobility, joint instability, and chronic pain along with an array of other symptoms and comorbid conditions that affect the body.<sup>5</sup>

## **What is POTS?**

Postural Orthostatic Tachycardia Syndrome (POTS) is a blood circulation disorder that results in a significant increase in heart rate while standing. People with this condition will not be able to stand in one place for long without symptoms.<sup>6</sup>

## **What is MCAS?**

Mast Cell Activation Syndrome (MCAS) is a condition in which a person experiences repeated episodes of major allergic reactions, such as hives, swelling, low blood pressure, difficulty breathing, and severe diarrhea (symptoms of anaphylaxis).<sup>7</sup>

## **What is night-blindness?**

Night-blindness is the inability to see in dark or dim light. It can be caused by a number of different factors, such as vitamin A deficiency and various genetic mutations.<sup>89</sup>

## **What is hyperphantasia?**

Hyperphantasia is the condition of having extremely vivid mental imagery that is said to be "as vivid as seeing"<sup>10</sup> and "photo-like."<sup>11</sup> People who experience hyperphantasia have extremely detailed memory<sup>12</sup> as well the ability to mentally construct projections of future events<sup>13</sup> (theories, hypotheses, fictions, etc...).<sup>1415</sup>

# The Relationship Between Eliza's Conditions

## **EDS, POTS, and MCAS**

Known as the “trifecta,” EDS, POTS, and MCAS are frequently co-occurring conditions.<sup>16</sup> In a study of 48 participants, POTS, Orthostatic Hypotension, or some form of orthostatic intolerance was found in 78% of joint hypermobility syndrome patients compared with 10% of the control group.<sup>17</sup> In another study of 35 patients with Joint Hypermobility Syndrome/hypermobile Ehlers-Danlos Syndrome, POTS was found in 48.6% of participants, and Orthostatic Intolerance was found in 31.4%.<sup>18</sup> And in a study of 195 participants, the rate of MCAS among those diagnosed with POTS and EDS was 31% versus 2% among the control group.<sup>19</sup>

## **EDS and ASD**

Researchers in 2020 proposed that hereditary connective tissue disorders (such as EDS) represent a subtype of autism and suggest connective tissue impairment may influence brain development. More research is needed to determine the exact relationship between these conditions.<sup>20</sup>

## **EDS and Night-blindness**

Because the eye is made of 80% connective tissue, various mutations that result in EDS show up in various types of eye issues. Dr. Jefferson Doyle postulates EDS can manifest in night-blindness<sup>21</sup>, but further research would need to be conducted to determine if Eliza's pathogenic variant mutation at the SLC24A1 that results in her night-blindness (Congenital Stationary Night Blindness) additionally causes her EDS and comorbid conditions.

## **ASD and Hyperphantasia**

While there have not been many studies into hyperphantasia, researchers are finding the presence of a vivid imagination in autistic girls.<sup>22232425</sup> Autistic girls have additionally been associated with hyper-empathy<sup>26</sup>, which is in alignment with emotional hyper-imagination as is seen in hyperphantasia.<sup>27</sup> More research is needed into the experience of hyperphantasia in autistic women and girls.

# Representation of Conditions in Eliza Dee's Universes

In this section, individual instances of physical and symbolic representation are listed in bold followed by an explanation of their depiction and important notes.

## Physical Conditions

**The zebra is the mascot of EDS.** In med school doctors are taught, "if you hear hoofbeats behind you, don't expect to see a zebra." EDS is a multi-systemic connective tissue disorder that results in many body differences in patients. In the same way you wouldn't use a horse doctor to properly treat a zebra, EDS patients need specialized care. Because doctors are not educated properly on the existence of EDS, many patients have been significantly denied proper care on the way to their diagnosis.<sup>28</sup>

**EDS/POTS patients can find it difficult to sit with their legs outstretched.** Due to an impairment in the connective tissue that would normally send the blood back up to the brain, blood can pool in the legs. Common sitting positions for EDS/POTS patients can be concave-sitting (54.15%) or w-sitting (39.21%)<sup>29</sup>, and they can also be seen sitting knees to chest<sup>30</sup>, reverse-w-sitting, sitting on top of their feet, with severely twisted legs, or other positions that compress or elevate the legs. While other children may sit like this occasionally, children experiencing symptoms of these conditions will be seen in these positions most of the time when seated. If you require children to, "sit correctly," you could be limiting the blood supply to a child's brain.

**hEDS is related to an impairment in proprioception.**<sup>31</sup> Eliza has an impairment of her sense of where her body is in space.

**"Bending your body for entertainment purposes, such as "party tricks" that move joints beyond a normal range of motion, can lead to long-term complications."** Part of the natural history of hEDS patients includes performing "party tricks" using their joint laxity as children and adolescents, entering into pain in their second decade, and finally entering into stiffness in their fifties and beyond.<sup>32</sup> Repeated over-stretching can lead to dislocations and subluxations.<sup>33</sup> This text was developed in conjunction with the Norris Lab, leading hEDS researchers, via email in 2022 for the back matter of Eliza Dee's Universes. These "party tricks" in youth can lead to significant issues later in life.

**MCAS patients are commonly allergic to pollen.**<sup>34</sup> One of the reasons Eliza dreams of the universe of flowers is because she loves the look of flowers, but she could have an allergic reaction that lasts for days if she comes into contact with them.

**All star depictions are specifically incorrect.** People with night-blindness, unless they develop it later in life, cannot understand what stars look like to people who can see them. Eliza

uses her special interests in art and astronomy to imagine what's in the nighttime sky. Her birth constellation, Pisces, is always present.

**Night-blind people risk tripping and falling in the dark without aid.**<sup>35</sup> Eliza is depicted being carried to the observatory, because she could easily trip and fall while walking in the dark. Lighting that would normally be sufficient to assist others is not enough light for her eyes.

## Neurodivergence

**Autistic girls are significantly associated with creative special interests.**<sup>36</sup> Eliza's interest in art is common for autistic girls.

**Autistic girls are associated with having special interests in animals.**<sup>37</sup> Eliza's interest in zebras is in alignment with typical interests in autistic girls.

**Autistic special interests in females are associated with camouflaging.**<sup>38</sup> With viewing stars being a ubiquitous way that human beings share experience, Eliza's development of a special interest in astronomy developed out of camouflaging her night-blindness while “pretending to be normal.”<sup>39</sup>

**Astronomy is a common special interest for autistic people.**<sup>40</sup> Many famous astronomers in history are believed to have been autistic,<sup>41</sup> including Sir Isaac Newton.<sup>42</sup>

**13% of autistic children become obsessed with a television show.**<sup>43</sup> For Eliza, it is a show with an astronaut zebra named Cutie.

**Eliza's drawing at her desk is of her favorite show.** As an artistic autistic child who is obsessed with a show, Eliza's drawing is of a planet from her Cutie poster.

**Eliza's first new universe depicts outer space from her favorite show.** As Eliza is flying through the new universe she creates, the planet from her drawing is present, as well as the look of the “space” from the posters on her wall next to her desk.

**Eliza is presumably picturing herself sitting on the planet Cutie lives on in her favorite show in the final illustration.** With the planet in the sky, and what seems to be nighttime on a planet, Cutie is seen without the space helmet depicted on the poster in her room, and it can be assumed this is his home world from her favorite show. Because Eliza has seen this show so frequently, she can picture every detail of the experience of being with him in a scene of the show where Cutie is looking into his world's nighttime sky.

**Having one or more special interests may be related to communication impairment.**<sup>44</sup> While Eliza is not depicted speaking and the book is inclusive of nonverbal autistic people, if she did speak, her ability to communicate would be caged by her intense special interests. She may

find difficulties relating to the interests of others or putting time into topics outside of her interests. She could sound like she speaks “nearly constantly,” but her speaking abilities would be limited in topic and she could struggle to understand what things are or are not important.<sup>45</sup>

**Autistic children struggle with emotional regulation<sup>46</sup> and can find crumpling paper soothing.** Her crumpled papers in her trash depict a child that struggles with emotional regulation as some autistic children may crumple papers after perceiving “mistakes.”<sup>47</sup> Eliza may use this action for self-soothing.<sup>4849</sup>

**Autistic girls are associated with pixies.** Despite the association of the Manic Pixie Dream Girl trope with autistic girls, it’s important to remember, Eliza is a child who is sitting on some grass who has a very dense filter and needs significant support she does not have the ability to communicate effectively about.<sup>50</sup> Seeing a girl that gives the “little pixie wrapped up in her thoughts” vibe can be a symptom at least worth looking into, with attention paid to the difference in presentation of ASD in women and girls.

**Jumping is a common autistic stim.<sup>5152</sup>** Eliza’s love of puddle jumping and jumping in her fantasies are related to her sensory-seeking.

**Autistic children can have mixed feelings about water.<sup>5354</sup>** Eliza likes puddle jumping, but not being rained on. Her adult caregiver is understanding of her seemingly unaligned feelings and protects her from the rain while she jumps in a puddle.

**Autistic children can fear weather.<sup>55</sup>** Eliza’s ability to see the sunshine through the rain can give some readers a different way of thinking about weather. This was confirmed in the feedback of one of the first 10 people to ever read Eliza Dee’s Universes.

**Dancing is therapeutic for autistic children<sup>56</sup>, but caution is needed with hypermobility.** Eliza’s enjoyment of dance is related to receiving therapy in alignment with the advice of physicians, though Eliza would have needed specialized dance classes designed for children with hypermobility to receive safe therapeutic benefits.<sup>5758</sup>

**Autistic females are associated with attempting to socialize through their special interests.<sup>59</sup>** In the final line of the book, Eliza wonders how fun it would be to share her newly-found special interest of creating new universes with others and what kind of amazing things those others would say or create.

**They say about autistic children, “they’re in their own little world.”** Autistic women and girls are known for creating entire worlds in their heads and escaping into those worlds.<sup>60</sup> The use of “little” in this context is considered ableism.<sup>61</sup> Eliza can explore her own expansive universes.

**63.2% of autistic girls create imaginary companions.** Eliza’s creation of imaginary companions, such as personifying her Cutie stuffie, may enable her to be significantly more



likely to be interested in making friends and spending time with them than children who do not do this.<sup>62</sup>

**Hyperphantasia is associated with exceptional autobiographical memory recall.**<sup>63</sup> As Eliza sits on the grass during the sunset, her mind takes off thinking about her special interests with photo-like memories of herself that come in flash-memories that she has connected together in her mind.

**Autistic people are associated with patterned thinking.**<sup>64</sup> Eliza's hyperphantasia starts with a human rhythmic pattern of looking into the sky and considering the sun, the moon, and the stars. She can run this thought pattern in her mind repeatedly to see what her brain comes up with next as it continues to push further into what it is capable of dreaming.

## Elements of the Book

**Many neurodivergent people self-identify overusing punctuation.**<sup>65</sup> The book overuses ellipses for inclusion of this writing style.

**People with these conditions can have any background.** The answer for "what is the beam of light," is left up to the interpretation of the reader to keep the story inclusive of all backgrounds. Whatever every individual believes gives them the ability to create, to live, to breathe, that is the answer to "what is the beam of light?"

**"Where science ends, imagination begins."** Einstein, who was believed to be autistic,<sup>6667</sup> said, "imagination is more important than knowledge," and it "embraces the entire world."<sup>68</sup>

Hypotheses are a part of science that allows itself to tap into imagination, as was the intent of Einstein's quote,<sup>69</sup> to find what more can be shown to be observable and not merely imagined. So for the purposes of this sentence, science, in relation to any specific subset of thoughts, is presumed to "end" at the rejected hypothesis.

For Eliza, there is a distinct difference between what she experiences, learns, and observes, and what she dreams. Past the seriousness of reality, as female autistic people are known for being honest<sup>70</sup>, logical, straight-forward, and principled<sup>71</sup>, she is free to explore her imagination and play.

## Advice

Dialectical Behavioral Therapy may be beneficial for autistic people with emotional or sensory difficulties.<sup>72</sup>

EDS, POTS, and MCAS are 3 common comorbid conditions, but depending on the location of the mutation, EDS patients experience a vast array of other comorbid conditions. The most thorough book I have seen on this topic is *Disjointed: Navigating the Diagnosis and Management of hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders*.<sup>73</sup>

## Disclaimer

I am not a doctor or medical professional. I'm an autistic children's book writer trying to communicate about my children's picture book, Eliza Dee's Universes.

For any proposed alterations to this document, email [rebecca@rebeccavitsmun.com](mailto:rebecca@rebeccavitsmun.com).

Leaning toward APA for the citations; weigh in if you think another would be more appropriate.

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