

VISUAL VIRTUAL VIRAL

Maggie
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Communicating Disease and Disability Experience Through Art in the Digital Age

More and more people living with chronic illness and/or disability are turning to art as a form of therapy and creative expression. As a result, the digital landscape is changing, and the way we communicate our personal experiences is changing along with it. Modern technology has not only expanded our ability to connect on a large scale; it has produced entirely new media with which to create – from diagnostic imaging tools to digital illustration software. This study examines the role of art in communicating personal disease narratives in the digital age and the impact of these works on our collective understanding of chronic illness and disability. Click on each image to learn more.

1 Painted Hackberry Eating Spoon

Evan Hebenstreit, woodcarving

Evan Hebenstreit is the founder of Bear River Woodcraft and Spoons for Spoonies, an international community of spoon carvers bringing awareness to chronic illness and disability with beautifully hand-carved wooden spoons.

2 Gilded Mask

Christina Baltais, kintsugi

Inspired by the traditional Japanese art of repairing broken pottery with gold, Christina Baltais – who struggles with myalgic encephalomyelitis (ME) – created this “broken” mask, representing identity and the painful experience of chronic illness.

3 Pills

Laura Marcuet, pen/ink

French illustrator and graphic designer Laura Marcuet created *Pills*, a series of illustrations challenging the absurd notion that anything can be cured with a pill. Each pill depicts a positive or negative emotion.

4 Head Above Water

Avril Lavigne, song

This song, which was released in 2018, was written in response to Avril Lavigne’s personal battle with Lyme disease. She also sings about her experience with Lyme in her song “Warrior.”



1

5 Ehlers Danlos Syndrome

Emma Jones, photography

Emma Jones shares intimate windows into the lives of those with chronic illness through The Nightstand Collective. This image shows the nightstand of a person with Ehlers Danlos Syndrome, including books, a glass of water and several toys.

6 AI

Trina Merry, body painting

Body painter Trina Merry tells the stories of people living with chronic pain in bold, visceral detail.

7 This is Endometriosis

Georgie Wileman, photography

Photographer Georgie Wileman captures the reality of life with endometriosis in her collection featuring vivid images of patients and their scars. Her work highlights the all-too-common problem of misdiagnosis and mistreatment within the healthcare system.

8 CripplePunk 53

Michaela Oteri, digital illustration

Digital artist Michaela Oteri portrays diverse people with disabilities in her CripplePunk Portrait series, which includes dozens of commissioned pieces.

9 Mad Math

Emily Bracale, mixed media

Her book, *In the Lyme-Light: Portraits of Illness and Healing*, includes art and writing that describe Emily Bracale’s experience living with Lyme disease. This piece illustrates the effects of Lyme on the brain with various textural (and textual) elements.



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10 Transient Aphasia

Abi Stevens, digital illustration

The Chronic Project, by UK-based artist Abi Stevens, features bold self-portraits depicting various symptoms of chronic migraine disease, from pain and photosensitivity to transient aphasia.

11 Mind on Fire

Elizabeth Jameson, MRI art

As Elizabeth Jameson’s multiple sclerosis (MS) progressed, she began creating art from her MRI scans, as a way of “reclaiming agency of her own medical data.” Her colorful reimaginings spark conversation about what it means to live with a chronic illness or disability.

12 Joanne

Lady Gaga, song

This song was inspired by Lady Gaga’s late aunt who died of complications from lupus when she was only 19. Joanne, who was an artist herself, has inspired much of her niece’s work.



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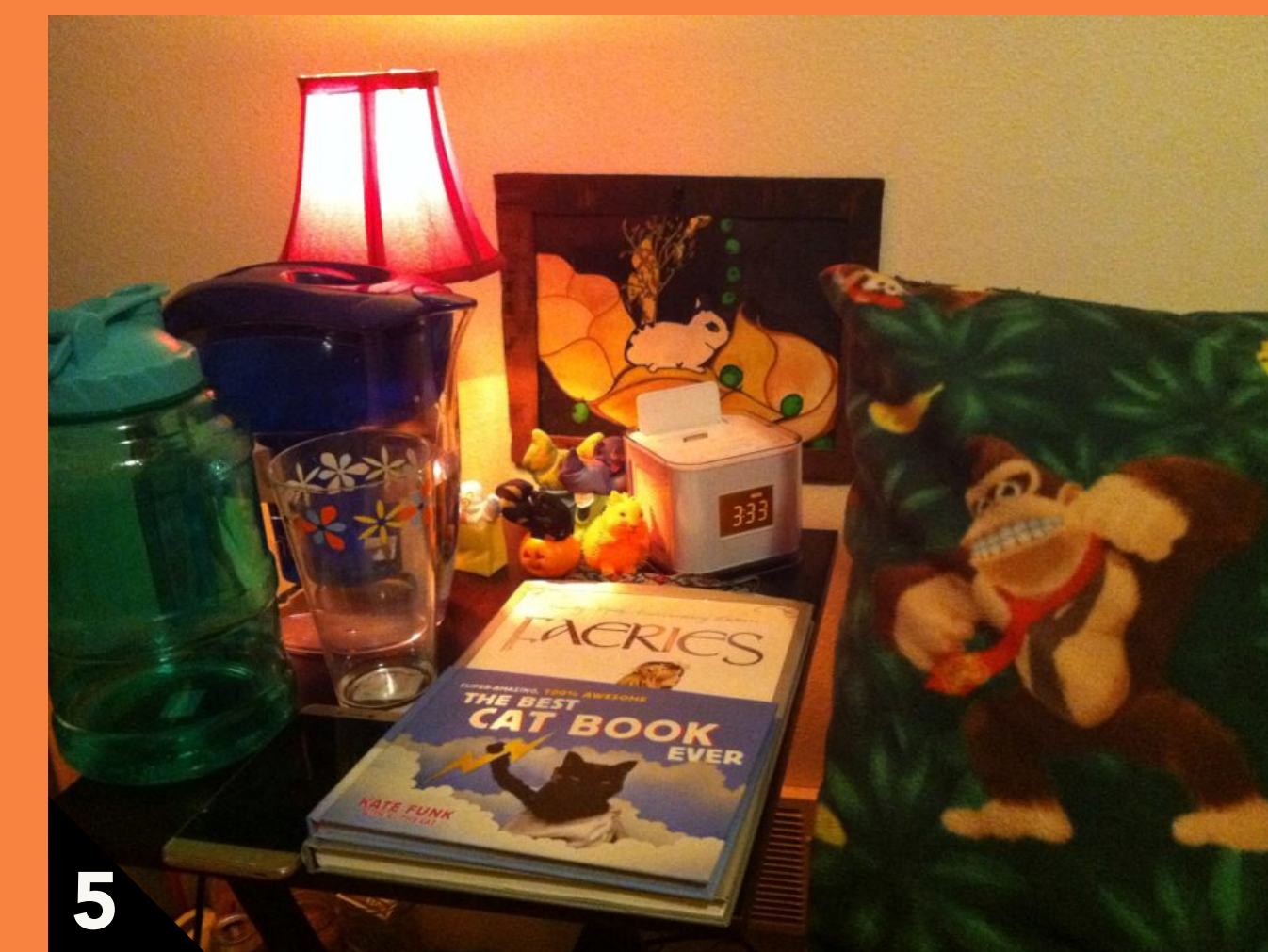


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13 Breakout My Pelvic Sorcery

Eugenie Lee, experiential art

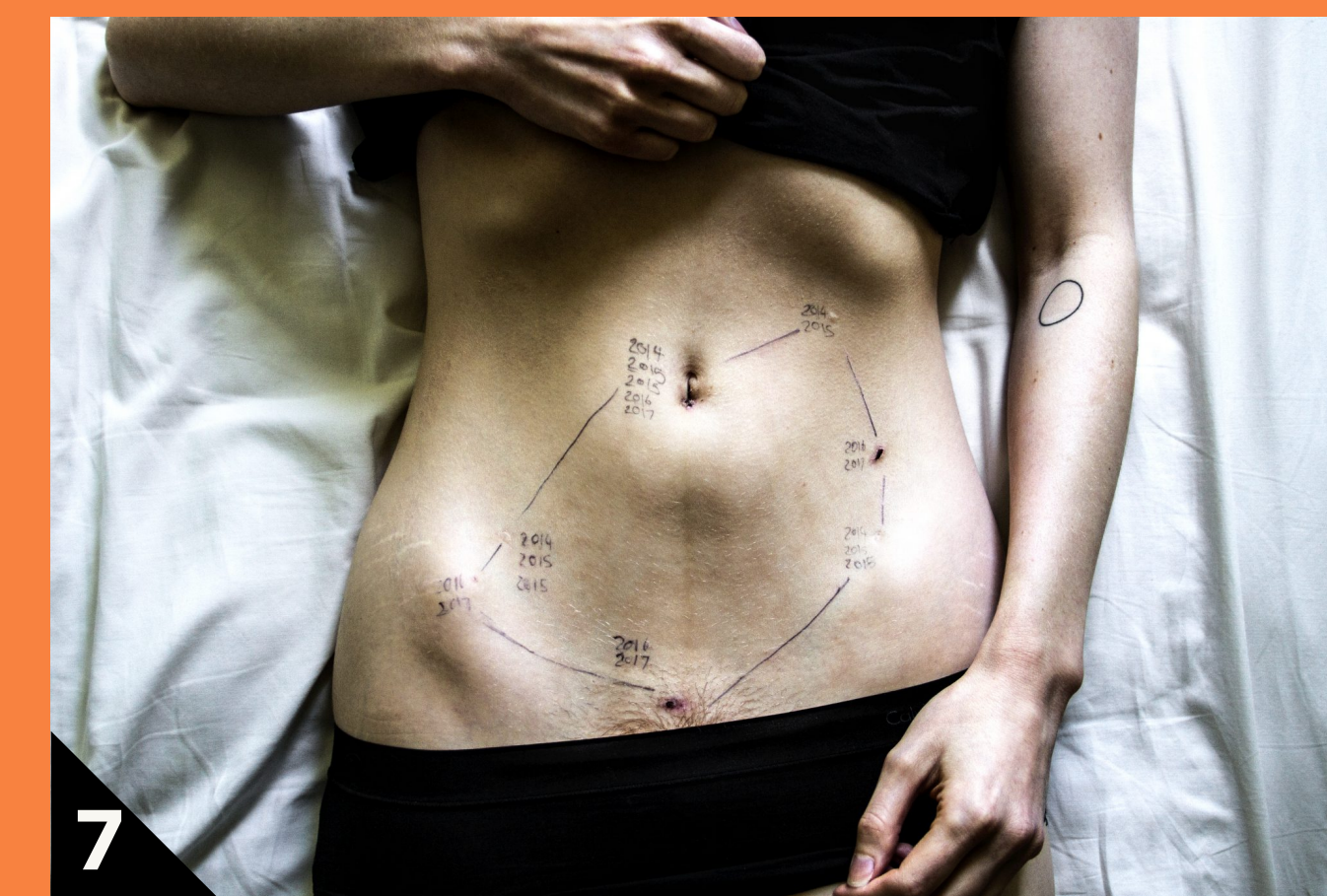
In this collaborative project, participants experience pelvic pain-like sensations through a custom-built haptic belt, while attempting to play a simple game. The experiential aspect of this project aims to challenge the stigma and common misconceptions surrounding chronic pain and illness.



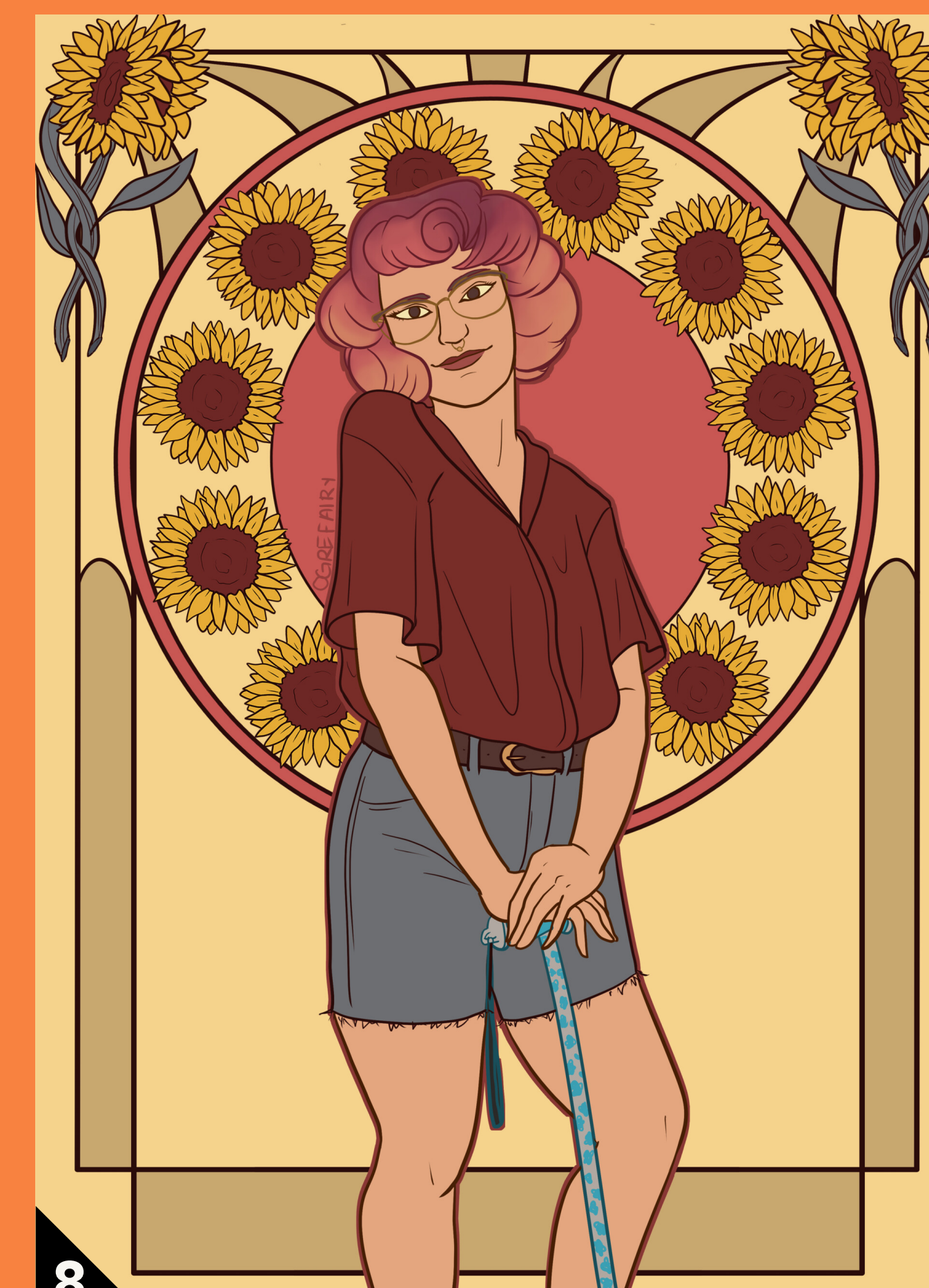
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