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'Can You See What I See?': An Art Project Promoting Living Well with Dementia

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Abstract

Caroline Hyland, an illustrator and former occupational therapist based in Dublin, Ireland, provided the cover art for the Winter 2023 edition of *The Open Journal of Occupational Therapy* (OJOT). "Can You See What I See?" is an acrylic painting on black textured paper. The piece was inspired by Caroline's grandmother Kathleen Duhig, her love of flowers, and the song "The Dutchman." Kathleen and three of her sisters lived with dementia. This painting, and several others, are featured in a book Caroline wrote to support living well with dementia. By combining her artistic talents and training as an occupational therapist, Caroline advocates for a society that sees people first, not the disease, dementia.

Keywords

occupation, occupational therapy, art, illustration, dementia, health literacy, Caroline Hyland, advocacy

Credentials Display

Jennifer Fortuna, PhD., OTR/L

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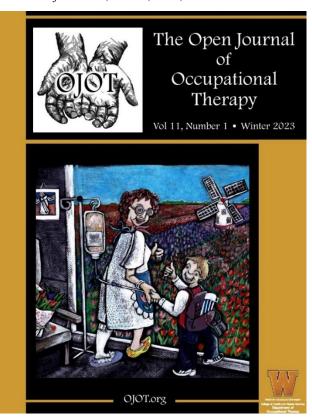
Dementia is a disabling condition that causes loss of memory, language, and problem-solving skills (Alzheimer's Association, 2023). In 2022, the World Health Organization (WHO) estimated there are more than 55 million people living with dementia worldwide. Because of the rapidly aging population, the number of cases is expected to rise to 78 million by 2030. Dementia has a negative impact on the quality of life for individuals, families, and communities. A lack of understanding of dementia often creates stigma and barriers to care (Who, 2023). Illustrator Caroline Hyland uses art to advocate for people with dementia. Her paintings are inspired by extensive family experience with the disease. "My granny and her three sisters had dementia," she said. Their lived experiences led Caroline on a journey to find out what people with dementia want us to know. "I learned people want to be seen first," she said. "We need to listen with all our senses. Listen with our hearts." Caroline's book, "Can You See What I See?" advocates for a society that empowers people with dementia to live well and remain engaged with the community. Her bespoke illustrations and person-centered approach serve as reminders that every person, no matter their diagnosis or disability, deserves to be seen as a person first.

Caroline Hyland, an illustrator and former occupational therapist based in Dublin, Ireland, provided the cover art for the Winter 2023 edition of *The Open Journal of Occupational Therapy* (OJOT) (Figure 1). "Can You See What I See?" is an acrylic painting on black textured paper. The piece was inspired by Caroline's grandmother Kathleen Duhig, her love of flowers, and the song "The Dutchman," often sung by her father. Like the main character in the song, Kathleen and three of her sisters lived with dementia. This painting, and several others, are featured in a book Caroline wrote to support living well with dementia. By combining her artistic talents and training as an occupational therapist, Caroline advocates for a society that sees people with dementia first, not their disease.

Caroline was born and raised in Dublin, Ireland. Her father worked for an ice cream company. During her childhood, Caroline's father frequently Figure 1 brought home a big box of ice cream to share with the neighborhood children. Her mother worked at the local bank until Caroline was born. "At the time, women were not allowed to keep their jobs after having children," she said. Caroline was named after President John F. Kennedy's daughter. Her younger sister, Lisa Marie, was named after Elvis Presley's daughter. "Mom loved them both," said Caroline.

Caroline has always been interested in art, but as a teenager, she was unsure about pursuing art as a career. Caroline also loved sports. After high school, she applied for a sports science program. She was accepted but soon had a change of heart. Caroline enrolled at Technological University Dublin to study visual communications. She took courses photography, graphic design, and illustration. "I really enjoyed these courses, particularly illustration," she said. Caroline's favorite medium is a dry brush painting technique combining acrylic paint and black textured paper. The method is slow and uses very little

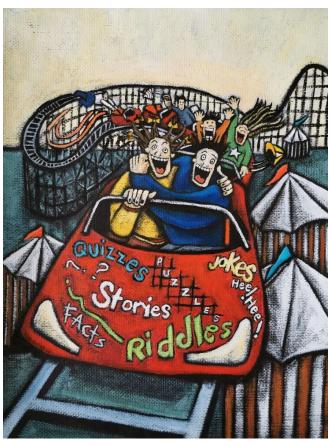
Cover Art for OJOT, Vol 11, No 1, Winter 2023.



water to ensure the thin layers of paint will build gradually on the paper grain. The result is a soft, pastel appearance. After graduation, Caroline gained employment as an illustrator. Her work has been featured in books, magazines, and newspapers. Figure 2 is a painting Caroline created for the cover of a children's quiz book.

In 1999, Caroline returned to school to pursue a higher diploma in Art, Craft, and Design Education. After completing the program, Caroline took a year off to backpack in Australia, New Zealand, and Thailand. Upon her return to Ireland, she began working as a resource teacher in a secondary school. Here she taught Eoin, a student with quadriplegic cerebral palsy. Caroline found creative ways to motivate and engage Eoin based on his interests. She often incorporated art, music, and novel activities into lessons to retain his attention. They had a lot of fun learning together and remain good friends today. Meeting Eoin greatly influenced Caroline's career path. "Flying Pancakes" (see Figure 3) is a painting made with acrylic on textured paper. This painting illustrates a cooking activity Caroline planned for Eoin. "Our first time making pancakes together was not exactly successful!" she said. During the summer, Caroline worked as an Art Facilitator at the National Rehabilitation Centre. She led creative projects with groups of children and adults recovering from traumatic injuries. At the

Figure 2
Cover of a Children's Quiz Book by Caroline Hyland.



hospital, Caroline met other staff, including a few occupational therapists. "I would not have known what OT was if I had not learned about it at the hospital," she said. These experiences led Caroline to pursue a career in occupational therapy.

In 2005, Caroline enrolled in the Occupational Therapy program at the University of Limerick. At the age of 28, this step represented a significant change in her career. Moving to Limerick provided Caroline opportunities to visit with her granny, who by this time had been diagnosed with dementia. "Granny Kathleen died during my first year of college," she said. After graduation, Caroline's practice was primarily focused on individuals with intellectual disabilities. When her son Tomás was born, Caroline decided to leave the occupational therapy profession and return to art. She is a big believer in community art programs. "Art is for everybody," she said. "Creativity is in all of us." For Caroline, art is a social experience that provides the opportunity to belong. In 2012, Caroline began working as a freelance mentor and facilitator at a supportive art studio. "I found myself working with clients I had previously treated as an OT," she said. Caroline also discovered the Living Well with Dementia program and started volunteering with the dance and art classes. In 2019, she was invited to take over the art facilitation. Caroline says her training as an occupational therapist has come in handy as an art facilitator. "The therapeutic relationship is also important in art," she said. "I have that OT bit of knowledge and use it in

a different way." For Caroline, art is a social experience that provides opportunities for everyone to belong and express creativity in a safe and welcoming environment.

In 2021, Caroline self-published her book, "Can You See What I See?" Writing a book was not something she ever intended to do, but it seemed like a natural way to reach a greater audience. "A oneoff painting I did for the hospital started the entire project," she said. The original painting (see Figure 1) was created in 2017 for a solo art exhibition at Tallaght University Hospital. "Something inside of me made me want to do these paintings," said Caroline. "I had spent a few years creating doodles in a sketch book," she said. These drawings guided Caroline's creative process. Fear was an initial factor influencing the reasoning behind the project. Caroline was fearful of her family

Figure 3 "Flying Pancakes" by Caroline Hyland.



history of dementia and wanted to learn more. "This project helped me to recognize and face my fears," she said. Throughout the project, Caroline was very conscious and respectful to people who live with dementia and those who support them. The project title, "Can You See What I See?" is Caroline posing a question to the viewer. Her eyes were opened through her research. Caroline wanted to share this learning

with others. "Love" (see Figure 4) is an acrylic painting on black textured paper. The painting features a husband and wife as they are learning to cope. "I named the child Tomás, after my own son, to recognize my own fears and to highlight that dementia is not just for old people," she said. It affects younger people and families too." Caroline hopes her book will help other families overcome their fears and encourage supportive communities to protect these family units.

Caroline's book serves several purposes. Most importantly, it is a brilliant educational resource. Before she started illustrating or writing, Caroline researched



Figure 4 "Love" by Caroline Hyland.

what people with dementia want. She sought information from people diagnosed with the condition, their families and caregivers, and medical professionals. The layout of the book is akin to an art exhibition. Each painting is accompanied by text presented in two colors. The blue text tells the story in the painting and identifies difficulties often experienced by an individual with dementia. The orange text provides

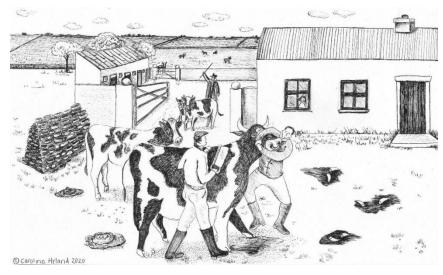
strategies for addressing the difficulties and offering support. Caroline hopes sharing this information will increase awareness of the little things we can all do to help people with dementia feel included in society. Caroline's book also serves as a fundraiser. All proceeds go to the Living Well with Dementia program located in Dublin (Health Service Executive, 2019). This community-based program is focused on providing person-centered care and resources for individuals with dementia and their families. Caroline has met several people who have benefitted from the money raised by her book. "It is just so lovely to be invited to meet people benefitting from the program," she said.

Caroline's goal is to make health information more accessible. "People seeking health care services are scared. They can't think," she said. "Health information needs to be clear, accessible, and inclusive. If you have to work to access the information, it's a challenge." Using. pictures to relay information is an effective strategy for improving health literacy and patient-provider communication (Institute for Healthcare Improvement, 2023). "An illustration allows time for the viewer to explore, interact with, and emotionally respond to the image," said Caroline." It also allows space for conversations to evolve. Caroline believes illustration can be a powerful tool with potential to influence minds, hearts, and actions. Recently, a local hospital asked Caroline to get involved in a project that uses animation to support understanding of health information. "This could be powerful. There is potential here," she said. "The illustrations don't have to be pretty. They just need to be functional and compliment the information you are trying to share." Caroline believes we all learn and interpret information in very different ways. Having a visual can fuel conversations and reinforce understanding. "The more channels of learning you provide, the more people will take away from it," she said.

Of late, Caroline has started illustrating special life stories for the public. In 2021, she founded Caroline Hyland Illustrations. During a recent collaboration, Caroline created personalized illustrations

for Mary, a client writing a memoir. Because of a lockdown in Ireland, Caroline and Mary met over Zoom. Mary shared several family stories from her childhood growing up on a farm. Caroline doodled as listened. During one memorable tale, Mary described how men working on the farm would cut the horns off the cattle. The scene took place in the front yard of the family home. "As a little girl, Mary watched from her bedroom window," said Caroline. "This was traumatic very experience." Caroline's illustration,

Figure 5 "The Sculling of the Cattle" by Caroline Hyland.



"The Sculling of the Cattle" (Figure 5) is a pen and ink drawing on watercolor paper. This drawing was the result of Caroline's conversations with Mary. When the book was finished, Mary gave each of her siblings a copy. "It was Mary's way to share her life with family members," she said. Moving forward, Caroline hopes to continue growing her business by using illustration to celebrate people's life stories, support their voices, and make information more accessible.

Caroline Hyland is a strong advocate for a society that sees people with dementia as individuals, not a diagnosis. Her training as an illustrator, educator, and occupational therapist led to an art project that started as a single painting. The piece evolved into a full traveling exhibition, speaking engagements, workshops, presentations, and her book. These wonderful resources promote a more supportive society for people with dementia and their families. Through her art, Caroline reminds us there are little things we can all do to help.

View more of Caroline Hyland's art in the OJOT gallery:

https://scholarworks.wmich.edu/ojot_occupationandartist/41/

Visit Caroline's Website:

Caroline Hyland Illustrations https://carolinehyland.com/

Read a Case Study Based on Caroline's Art Project:

http://www.artsandhealth.ie/case-studies/can-you-see-what-i-see/

Follow Caroline on Instagram:

@carolinehylandillustrations

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