

Raising awareness of severe ME - Lismore artist and writer Corina Duyn participates in online exhibition

By Jo Bell

Corina Duyn - an artist and writer who lived for many years in Lismore - recently exhibited her work in an online exhibition aimed at raising awareness of Severe ME (Myalgic Encephalomyelitis).

ME AND SEVERE ME

Myalgic Encephalomyelitis (ME) is a complex, multi-system disease that causes profound physical and cognitive impairment.

Severe Myalgic Encephalomyelitis is marked by intense, unrelenting symptoms including extreme pain, profound cognitive dysfunction, paralysis, difficulty swallowing, multiple hypersensitivities - especially to light, sound, smell and movement, and a profound intolerance and critical response to even the slightest exertion including the most minor voluntary or involuntary response to stimulus.

Many individuals are unable to communicate, move independently, or tolerate basic sensory input. Some individuals with Severe ME cannot eat without assistance. For others, even the quiet presence of another person in the same room is

unbearable. Those with the most severe forms of ME endure a devastating level of disability - confined to bed for months, years, or even decades. In its most extreme form, ME inflicts unimaginable suffering and total incapacitation. Patients endure relentless pain, severe dehydration, and near-total cognitive shutdown. Some require tube feeding. Severe ME forces patients into a state of extreme isolation - often invisible, overlooked, and misunderstood by both society and healthcare systems.

THE EXHIBITION

The exhibition was organised by Moira Dillon advocate and co-founder with ME Advocates Ireland (MEAI), who lives with ME, herself. The exhibition explores themes of grief, loss, isolation, and disconnection, as well as the often-hidden nature of ME and its profoundly challenging symptoms. It also reflects on self-awareness in the context of disability, the confrontation of adversity, and the vital role of empathy and understanding. The 31 artists involved explored both the

challenges and moments of hope in living with Severe ME, providing a multifaceted view of the condition.

"I hoped to raise awareness of Severe ME, particularly highlighting the experiences of those who are most affected, and to remember those who we have lost," Moira explained. "I wanted to create a platform where artists in the ME community could express the realities of living with this disease and share it with a wider audience in accessible, online formats."

"The online art exhibition offers a poignant insight into the lived experience of Severe ME - a glimpse into that hidden world. The artworks presented reflect not only the suffering associated with this disease, but also the courage, resilience, and humanity of those affected. Each piece of art, whether created by those with Severe ME or their caregivers or supporters, reflects the inner lives of people too often unseen and unheard."

CORINA DUYN

Corina Duyn spent her early years in the Netherlands, and trained and worked as a care-nurse and social care worker. She became a full time artist after she moved to Lismore in 1989. At the age of 36, Corina's health declined. She said: "The sudden start and rapid decline in health due to the debilitating neurological illness ME at the age of 36 changed my creative ability, intensity and output. My previous work - a reflection on Irish folklore - quickly changed to exploring the internal landscape of illness. This resulted in a visual and written diary of life with illness out of necessity to find a way forward within my utterly changed life."

In April 2021, Corina took the difficult decision to move into full time nursing home care. "I needed to do this to keep hold on the narrative of my life," she said.

Moira chose to include Corina, who is also a member of MEAI, as one of 31 artists in the exhibition, due to her ability to portray the reality of living with Severe ME through her creations. "Corina's creative work is profoundly evocative and deeply insightful," she said. "Her art and writing reflects both the vulnerability and resilience of people living with severe ME, expressing emotions that are often beyond words. It felt only natural to include her pieces in the exhibition, as their depth, sensitivity, and perceptiveness allow viewers to connect with the realities of severe ME on a personal and meaningful level."

Corina's series on 'Invisible Octopus' was the focus of her contribution to the exhibition. "The series on 'Invisible Octopus' started

with my marionette puppets and an octopus glove puppet I made with the help of Lorraine Shanahan (Lismore) in 2019," Corina explained. "I had mentoring via Arts and Disability Ireland with Master puppeteer Dr. Emma Fisher. During this time, I was introduced to shadow puppetry and ended up creating 'Invisible Octopus' - a twelve stanza video poem about life with ME."

The poster design and booklet were designed by David Murphy from Red Heaven Design. Editing of the poem was with Dolores Ronayne from Heilbhic, An Rinn. Working on 'Invisible Octopus' inexplicably forced me to examine and establish the truth about what is my normal. I moved into full time care in 2021, however the words and images in the poem still hold true. Sometimes with a newer meaning than originally created.

"[It was] an huge honour to be part of this mind altering exhibition. I believe art is the most powerful way to share our often difficult to comprehend illness. Many of us live hidden from society. The public's view of ME can still be one of 'tiredness'. This illness is indescribable in words. Images often go straight to someone's heart and mind and stay there to 'dissect', to ponder."

FUTURE EVENTS

It is expected that more online events will be organised to raise awareness of ME and severe ME. "ME Advocates Ireland (MEAI) have always held awareness events over the years on ME Awareness Day (May 12th) and throughout ME Awareness Month (May), on Severe ME and Remembrance Day (August 8th) and at other times," Moira said. "We hope to continue using art and holding other types of events as meaningful ways to raise awareness. The online formats allow us to reach people who may be confined to bed/home or otherwise unable to attend in-person events. We are exploring ways to expand the reach and impact of future exhibitions and other online events."

THANKS

Corina would like to thank the ME community: the 'community of hermits' all over the world, but especially her fellow advocates, who advocate for change from their beds. Thanks also go to all those who have followed and supported her journey. "You keep hope alive," she said.

Moira would like to thank the artists who contributed their work to the exhibition, and everyone who visited the online gallery and engaged with the work. "It means a lot to the Severe ME community," she said. "I deeply value the



communications and connections that took place between me and the creatives within the ME community before, during and after the curation process; it was both meaningful and special and at times deeply profound. Patients involved in the two exhibitions I held this year have shared that the curation process and the published exhibitions made them

feel seen and less hidden."

To explore the online art exhibition, there are three ways to view:

1. Video: <https://youtu.be/Ti5e1hzAZa4>
2. Slideshow Presentation: <https://bit.ly/4IX1f0e>
3. Exhibition via PDF Document: <https://bit.ly/41vwAzf>

