

Press Release

Shape Shifting Emma – radio documentary UCC98.3FM

“My body is crooked, twisted and unreliable but inside I am well thanks to this eye-gaze computer which allows me to express myself. I honestly think I wouldn’t have made it this far if it wasn’t for this amazing machine. I feel I am being true to myself in writing this blog.”

Emma lived in Kinsale, Co Cork, with her husband Jonnie, and their children Rowan and Alannah. In October 2010 Emma was diagnosed with Motor Neurone Disease. Emma lost the ability to speak early on in her disease and since 2012 communicated using eye gaze technology. She used this technology to regularly and painstakingly post thoughts on her blog called ‘Shape Shifting Emma.’

Emma worked in collaboration with Jo Pickup (Producer) on this documentary until she passed away on Friday 27th February 2015, she did not live to see its completion. She was 47 years old.

In each of the five half hour episodes, Emma’s blog is narrated by an actor, Orlaith McManus. Emma’s story begins in September 2012 and she sets the scene by outlining the symptoms of her disease and the care that she receives. We learn that each blog entry is laboriously written with her eyes using a special eye gaze computer. As each episode unfolds we discover more about Emma, her family, friends, hopes, fears, frustrations and triumphs. The tone is intimate and the beautifully paced performance of Orlaith McManus enhances the emotional shades of the writing. Listeners are drawn into a highly personal, first-hand, on-going account of what it is like to live with Motor Neurone Disease and be trapped inside a body that does not work, without a voice.

“At night, in my dreams, I still walk and talk. God be with those times!

*I feel like saying to everybody: “don’t you realise how f**king lucky you are to be able to do those basic things like walking and talking?” It is so crap that I can’t. People don’t seem to realise how lucky they are.”*

The blog entries are interspersed with reflections from Emma’s husband Jonnie, her Mum, brother and sister and close friends about the strength of her spirit and the effect of the diagnosis on her life. Her husband and mother talk of their devastation at the news of her diagnosis and of the Emma they knew before her illness. Her sister and brother talk of childhood memories and how they maintained their closeness despite geographical and medical obstacles. Her friends talk of her inspirational spirit and strength. They all talk of Emma’s determination to keep being an involved mother, her ability to laugh, her gentleness and her feisty spirit.

“My sister Lucy lay on the bed with me to rest together. I said ” I think I’m dying “, she replied “ no, you’re resting “. Good on ya Lucy, even though my body felt traumatised and weak, your comment really helped me.”

In Ireland one person is diagnosed with Motor Neurone Disease every four days. There is currently no cure. Life expectancy is three to five years after onset.

Motor Neurone Disease (MND) is a progressive neurological condition that attacks the motor neurones, or nerves, in the brain and spinal cord. This means messages gradually stop reaching muscles, which leads to weakness and wasting. MND can affect how you walk, talk, eat, drink and breathe. However,

not all symptoms necessarily happen to everyone and it is unlikely they will all develop at the same time, or in any specific order.

The Irish Motor Neurone Disease Association (IMNDA) is the only organisation of its kind in this country. It was set up in May 1985 to provide care and support to people with Motor Neurone Disease, their carers, families and friends. There are currently over 320 people living with MND in Ireland. MND is often referred to as the 1,000 day disease as most people die within 1,000 days of being diagnosed.

This year the Irish Motor Neurone Disease Association marks thirty years of providing care and support to people living with Motor Neurone Disease. More information on all of the events and campaigns can be found on the Irish Motor Neurone Disease Association website www.imnda.ie.

Kieran Hurley, Station Manager, UCC 98.3FM commented, “This programme is a rare opportunity for 98.3FM to broadcast the highly personal experience of an Irish citizen, and those immediately affected by Motor Neurone Disease. It is an extremely high quality programme, beautifully paced and poignant. The audio landscape is intimate, warm and familiar.”

Jo Pickup, Producer said “Emma’s blog is the heart and soul of this programme. She describes with highly articulate language the despair she feels as Motor Neurone Disease totally robbed her body of its natural functions; the frustrations of being dependant on carers for even the simplest and most intimate of tasks and how changes in her body almost always mean deterioration. But she also describes the joy she feels when she is cuddled by her children and their small but thoughtful actions, her love of music and the warmth she has from being loved and cared for by family and friends. It is heartbreaking that Emma did not live to hear her words come to life.”

Orlaith McManus said, “It was a privilege to be asked to be a part of this project and to be Emma’s voice. Her writing is truly inspirational and her moving journey affected me greatly. When I first read Emma’s blog I both laughed out loud and was moved to tears.”

Episode summary

In each episode, Emma’s blog is narrated by an actor and is accompanied by her family and friends as follows:

- Episode 1 Emma’s husband Jonnie talks frankly about how they met, married and had their two children, about the early signs of MND and their devastation at receiving Emma’s diagnosis.
- Episode 2 Emma’s Mum Antoinette, brother Simon and sister Lucy-Jane recall memories from Emma’s childhood and teenage years, and how they find it hard to accept that Emma is no longer in their lives.
- Episode 3 Emma’s local friends tell how Emma first noticed that something was amiss with her health and her incredible fight to stay well and alive.
- Episode 4 Emma’s long-time friends from Dublin recall the fun they had together in their twenties, how they see Emma in her children and their loss of a great friend.
- Episode 5 Jonnie talks about Emma’s strength and her fight against the symptoms of MND, he tells stories from their journey together and finally how Emma died in February 2015.

The music at the start and end of each blog is 'Gold' by Interference – this music was chosen by Emma for the programme. Interference are an Irish group whom Emma knew personally in her early twenties.

Emma's son Rowan announces the start of each episode.

Summary

- UCC98.3FM are broadcasting Shape Shifting Emma a five part radio documentary comprising half hour episodes – to be aired at 5pm each weekday evening starting Monday x September 2015. All episodes will also be available as Podcasts from the UCC 98.3FM website.
- Each episode consists of Emma Fitzpatrick's blog narrated by an actor (Orlaith McManus) interspersed with testimonies recorded with her family and friends.
- Emma was diagnosed with Motor Neurone Disease in 2010 and quickly lost the use of her voice. In 2012 she started using an eyegaze computer which allowed her to communicate, and she started posting on her blog called Shape Shifting Emma in September 2012. Emma's blog can be read in full at shapeshiftingemma.wordpress.com.
- Emma died on 27th February 2015 during the making of this documentary.
- This year the Irish Motor Neurone Disease Association marks thirty years of providing care and support to people living with Motor Neurone Disease. More information at www.imnda.ie.

ADDITIONAL INFORMATION

About UCC98.3FM

UCC 98.3FM is Ireland's only 24/7 student and community radio station.

Jo Pickup – Producer

Jo was the Producer, Researcher, Interviewer and Editor of Shape Shifting Emma, and worked in collaboration with Emma until her passing in February 2015.

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Kieran Hurley – UCC98.3FM Station Manager

Kieran Hurley is an experienced producer who has over 30 Sound and Vision projects to his name.

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Orlaith McManus – Actor

Orlaith is an experienced amateur actress who has appeared in large number of varied productions most recently 'Two' by Jim Cartwright at the White Lady in Kinsale.

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