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'A Journey with James:' from mystery seizures to eventual diagnosis

Three years ago, James Shipley experienced his first of many seizures. He shares with Jorvik Radio how it took years of medical visits, counselling and support from family, friends and strangers to finally get him a diagnosis and start his road to recovery.

In 2018, 23-year-old James Shipley's shift in a Vancouver café abruptly ended when he woke up with two paramedics kneeling above him. He later found out that he had experienced a tonic-clonic seizure.

"[It's] basically the kind of seizure where your whole body is vigorously shaking. Every muscle in your body is going crazy", he explains.

When the episodes continued to happen, he cut his stay in Vancouver and subsequent travels short and flew home to the UK.



In a café overlooking a busy street in York, James shares what he has been through since that first seizure.

We learn that it would take over two years working with neurologists, specialist nurses and charities to uncover a diagnosis of Non-Epileptic Attack Disorder (NEAD) alongside epilepsy.

Since March 2018, James has experienced numerous tonic-clonic seizures and frequent dissociative episodes. He later tells us: "I have lost count of how many tonic-clonic seizures that I've had."

Physical non-epileptic seizures share some characteristics of epileptic seizures. However, they are not caused by the brain's electrical activity, but the body's preventative response to overwhelming stress, emotions, physical sensations, or memories. Other dissociative episodes are frequent for James, with sudden verbal confusion and dazed behaviour.

"It's basically my brain being overwhelmed by everything going on that it just decides the best thing to do is to like... freeze."

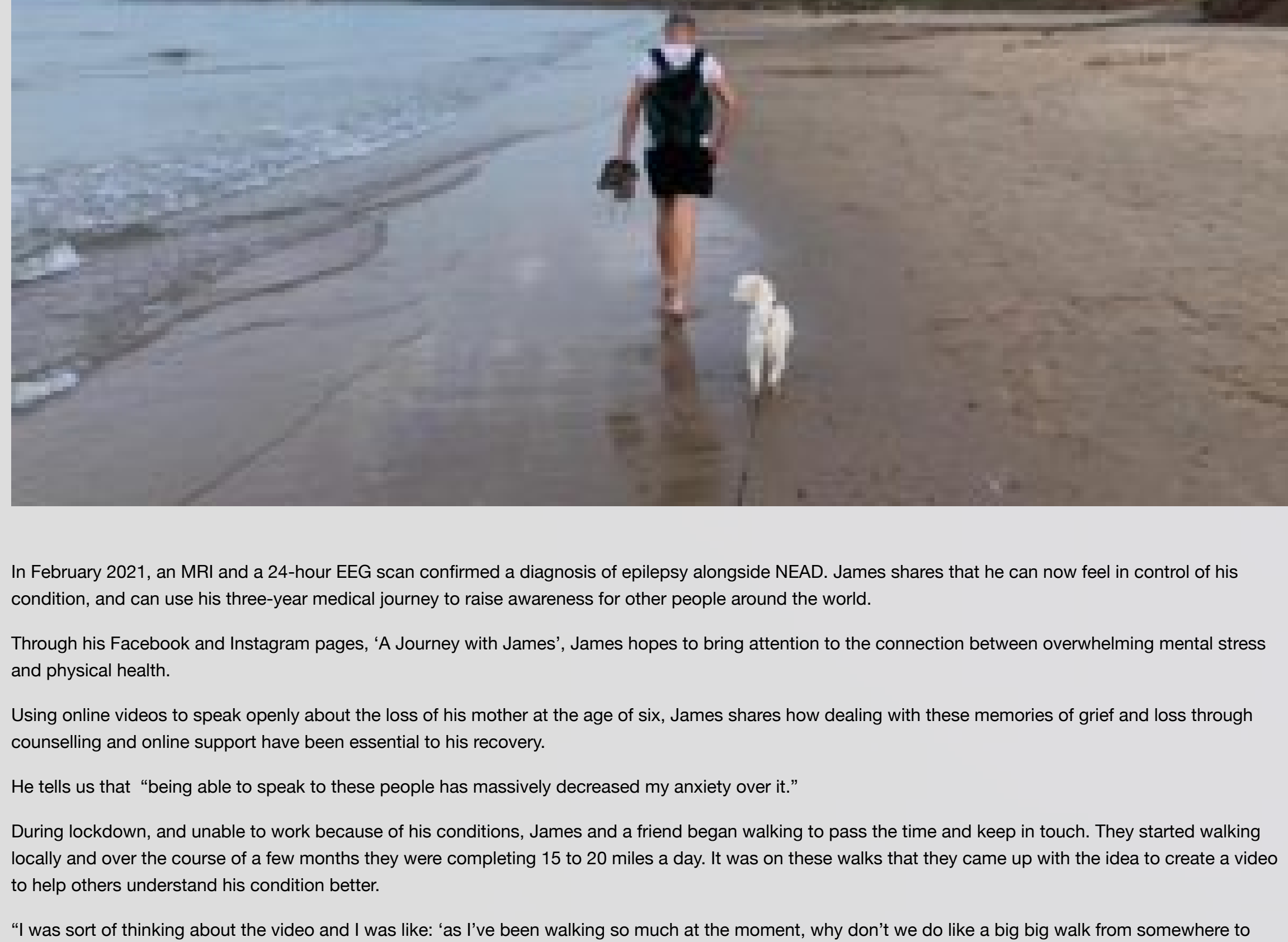
According to the charity FND Action, NEAD is experienced by 15,000 people in the UK. The charity estimates this number to be considerably higher due to common epilepsy misdiagnosis.

James explains that he was first prescribed anticonvulsant tablets, a medication used to treat epilepsy, yet his symptoms and episodes didn't stop. He started noticing that some of his episodes were triggered by certain feelings and memories. Initially, neurologists and GPs didn't believe there was a link.

"I just had it in my head that I was making this up because of what GPs had said to me," he tells us.

Since February 2019, James, friends and family have documented his episodes and symptoms for his neurologists through videos and diaries—recording over 450 dissociative episodes varying between 1 and 10 minutes. This documentation eventually helped medical professionals find the right diagnosis two years after his first episode. James considers himself fortunate and tells us that it takes an average of five years to diagnose NEAD.

He believes his current neurologist and specialist nurse have been a huge factor in his recovery. "I value them both as they have been a huge support for me...I see my nurse as a best friend. Just hearing her voice has calmed me down during difficult times in my life."



In February 2021, an MRI and a 24-hour EEG scan confirmed a diagnosis of epilepsy alongside NEAD. James shares that he can now feel in control of his condition, and can use his three-year medical journey to raise awareness for other people around the world.

Through his Facebook and Instagram pages, 'A Journey with James', James hopes to bring attention to the connection between overwhelming mental stress and physical health.

Using online videos to speak openly about the loss of his mother at the age of six, James shares how dealing with these memories of grief and loss through counselling and online support have been essential to his recovery.

He tells us that "being able to speak to these people has massively decreased my anxiety over it."

During lockdown, and unable to work because of his conditions, James and a friend began walking to pass the time and keep in touch. They started walking locally and over the course of a few months they were completing 15 to 20 miles a day. It was on these walks that they came up with the idea to create a video to help others understand his condition better.

"I was sort of thinking about the video and I was like: 'as I've been walking so much at the moment, why don't we do like a big big walk from somewhere to somewhere else,'" he explains. "We decided to do it for the two charities that have helped me the most: York Mind and FND Action."

James says that the support he has received since posting his first video on Facebook (https://www.facebook.com/watch/?v=307415980673149) last year has been overwhelming.

"I literally thought it would be a video that would be seen by family and friends, just like close family and friends. [We] would raise a few hundred pounds, and we'd do the walk and it would be great fun and a great experience."

His original video posted on 'A Journey With James,' Facebook page has nearly 17,000 views.

"I've spoken to so many people right across [the world]. Someone in Australia watched a video and messaged me..I never in a million years was expecting that kind of thing."

"I still will get occasional messages and people being like: 'thank you for making this video.' It's mad." His most recent message came from someone in Canada the morning of our interview.



His videos have also brought attention to his fundraiser walk. Originally scheduled for September 2020, it was postponed to this year. The influx in support from friends, family and strangers across the led James to change his fundraising goal from £500 to £3,000.

Having grown up in York, he had always known of York Mind but says he never thought of using their services until he found out there was a 10-month waiting list for counselling through the NHS.

"I just know that if I'd never heard of [York Mind] I wouldn't even think to go there. I probably would have just put myself on the 10-month [NHS] waiting list."

Within weeks of contacting York Mind, James was receiving counselling. But he thinks more could be done in the NHS to improve waiting times for mental health services.

"I do appreciate that [NHS support] is there, but at the same time, you know, things need to change within that," he says. "There are people in situations where there's a 10-month waiting list and, you know, things will be made worse in that time."

For James, having quick access to counselling through York Mind was crucial for his mental and physical health and he wants others to benefit from their services.

"The support I got from them on all fronts was what I needed," says James. "To keep York Mind active and having that short waiting list, it needs to have money put back into it."

James is also raising awareness and funds for FND Action, a charity focused on supporting those experiencing functional neurological disorder. He learned about the charity while researching his symptoms.

"I just remember one day it came up and I just went through their website and it linked to their Facebook page...They had support pages where you could join and speak to other people."

"The more I read about it the more I was like, 'this sounds similar to what I'm going through.' And it was when I spoke to my neurologist and they said, 'Yeah, you do have this' that I started to Google and look at their website more and more."

James explains that through resources provided by FND Action, he was able to learn about his condition and connect with others with similar experiences.

"I just want to help them...The more that people talk about [non-epileptic attack disorder], the more people that can help."

James wants others to be able to benefit from their research, resources and support. He hopes that money for FND Action will allow them to continue their work and gain visibility as an organisation.

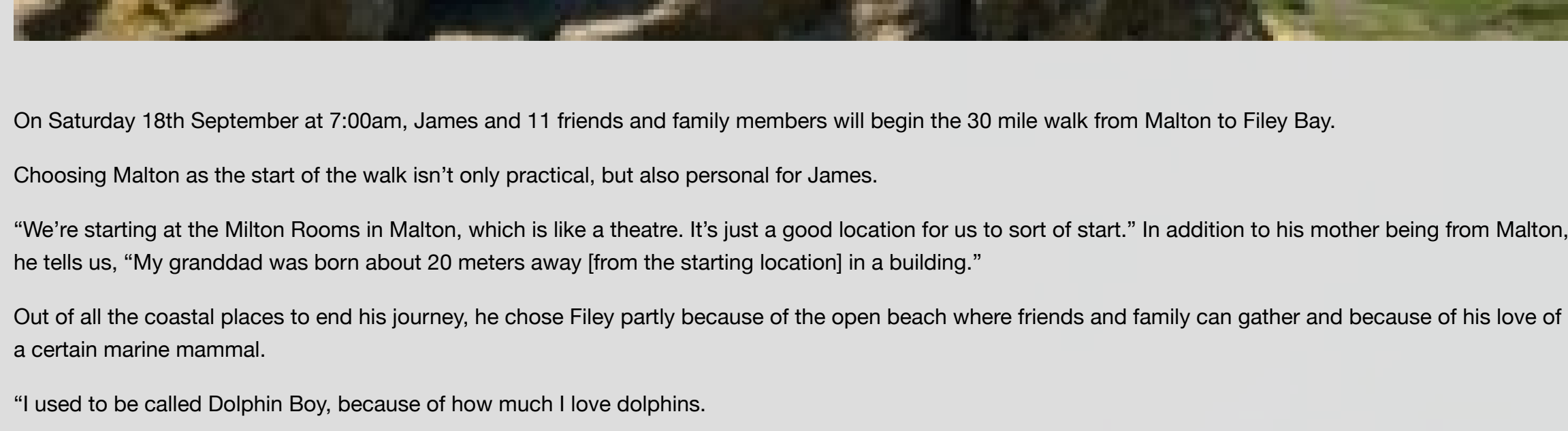
"I spoke to the director of the charity and it literally is one woman and a team of volunteers...I get along with her really really well, and they've just been able to move into an actual office."

He has since released more videos on his social media pages hoping that others with similar experiences may find it helpful to explain what they go through.

"If I'd had a video I could just quickly show someone and say 'this is what it is' years ago, it would have been something that could have helped me a lot."

"It just got stuck in my head that I was making this all up, and to speak to other people with it I was like, wow."

With the right diagnosis and support, James is finally getting control over his life again. He's now 26 years old, working as an NHS Track and Trace administrator (his first job since his seizures began) and has become a lockdown entrepreneur, opening his own baking business.



On Saturday 18th September at 7:00am, James and 11 friends and family members will begin the 30 mile walk from Malton to Filey Bay.

Choosing Malton as the start of the walk isn't only practical, but also personal for James.

"We're starting at the Milton Rooms in Malton, which is like a theatre. It's just a good location for us to sort of start." In addition to his mother being from Malton, he tells us, "My granddad was born about 20 meters away [from the starting location] in a building."

Out of all the coastal places to end his journey, he chose Filey partly because of the open beach where friends and family can gather and because of his love of a certain marine mammal.

"I used to be called Dolphin Boy, because of how much I love dolphins."

"There have been dolphins seen around that part of the coast recently. I have a dream to, like, get there and we just see dolphins," he tells us while laughing.

After the past three years of personal ups and downs, various diagnoses and a pandemic, his walk on Saturday with friends and family in support is sure to feel like a personal victory. Any dolphins that choose to greet him at the finish line will be an added bonus.

You can find videos and posts on his 'A Journey with James' Facebook (https://www.facebook.com/ajourneywithjames/) and Instagram (https://www.instagram.com/ajourneywithjames/accounts). You can also support his fundraiser for York Mind (https://www.yorkmind.org.uk/) and FND Action (https://www.fndaction.org.uk/) on his Just Giving (https://www.justgiving.com/team/Ajourneywithjames) page.

Interview and article by Rebecca Mendoza and Roisin Alston