CASE STUDY

I THOUGHT I'D BE DEAD

MD sufferer Fergus O'Farrell spent his childhood expecting to die before he hit 30, says **David Young**, but he's now in his 40s, and enjoying life as a musician, artist and husband

Diagnosed at nine years of age with muscular dystrophy (MD), Fergus O'Farrell never expected to see his 30th birthday. But he has, and he continues to live a busy life, as he moves happily into his mid-40s.

“I always thought that I'd land somewhere in the 20s, at best,” Fergus says, revisiting his teenage world, and affording himself a smile.

“I suppose the prognosis back then could only stretch that far. Today, we seem to know so much more about MD.”

He continues: “I remember being diagnosed in primary school, because, for a while beforehand, we kind of new something was amiss. I was stumbling a little, and becoming clumsy.

“My folks were devastated. I didn't fully understand, but it really knocked them — especially my dad. My mum seemed to handle the news that bit better. After that, we just got on with it.”

Fergus was an active child, just like most others: running and racing with his friends; kicking ball; pedalling his bike. Naturally sociable, he joined in with everything. But others began to spot his difference.

“In school, my football team won a competition,” he recounts. “And we were all getting medals, but I didn't get one at the time — it was thought I didn't contribute enough. But I got it eventually.”

It is just another thing that Fergus has circumnavigated in his life with good grace. MD was quite the mystery in his childhood. And so, people easily mistook it for awkwardness or laziness, or plain old carelessness.

Now, it is understood that there are several forms of MD: the more severe types limit lives to childhood, while others, such as Fergus's, which is known as Emery-Dreifuss, allow a much longer span.

Named after professors in the UK and US who first described the disorder, Emery-Dreifuss is still quite early in its framing — only being properly classified as a separate disease since the Sixties. The experts do know that, like other forms of muscular dystrophy, the muscles tighten and shorten, and thus limbs become more difficult to move. However, in Emery-Dreifuss, these contractures occur before the muscles actually weaken, and hinder the smooth movement of the joints sooner.

In essence, the muscle fibres are degenerating and being replaced by fatty tissue; this leads to increasing difficulty extending the arms and legs, and this also consequently challenges movement, coordination and balance.

Someone with Fergus's MD would begin to walk on their toes during late childhood and early adolescence, while they would also display a difficulty in bending their neck forward.

“I was riding a bike until I was about 15,” Fergus explains. “But soon after, I had to give it up, and use a moped instead. That lasted for a couple of years before I had to concede that I hadn't the physical strength to lift it, or even hold it properly. My legs were first to go. But it was only a matter of time before my shoulders and arms were to follow.

“I used to get a piggyback up the stairs in the last couple of years of secondary school.”

Yet, Fergus's telling of how he coped, while those around him got on and did all the things he wanted to do, is shaped by defiance rather than fear.

“I was never scared,” he says. “I was pissed off, though — the bloody inconvenience of not being able to do what your mates were doing.”

'They wouldn't touch me with a barge pole. Record companies look for certain things. Using a wheelchair doesn't fit that bill'

Unable to pursue sport, Fergus immersed himself in music. And, in Clongowes Wood, he was where he could do just that — learning to cope by losing himself in hours of piano practice. “It was a great place,” he smiles, “ it's where I started the band — Interference — with my friends. I could play music for up to four or five hours a day.

“I didn't even want to do my Leaving Cert. I was so sure this was what I was going to do with my life,” he says, echoing the resolution of his youth. “But my parents encouraged me to sit the Leaving; my mother insisted. Once I got through, I headed for Dublin where myself and a few of my friends set up in the Winstanley Factory, opposite Christ Church Cathedral — to make music.”

And they did, gaining recognition and respect. “But with my MD, it's a slow and gradual losing of things,” Fergus describes, “so, over the years, it's been a case of bye-bye piano, and bye-bye guitar, just as I was mastering them. That's why I've taken up painting.

“I've also had to change how I sing through speech therapy, because I have less lung capacity,” he continues. “Oddly enough, it has made me a better singer. Learning how to use my throat muscles.”

Ever sanguine about his condition, Fergus holds no grudges, despite the music industry's prejudices: “I heard through others, they wouldn't touch me with a barge pole 'cause of the MD.

“That's just the way of it. Record companies are looking for certain things, and being in a wheelchair doesn't fit that bill,” he says, untroubled by the rebuffing.

It did not hinder his peers. A long-time friend, the Oscar-winning songwriter, Glen Hansard, invited Fergus to collaborate on the soundtrack to the movie *Once*. And when it all took off, Glen wanted Fergus to join him on tour in the US.

“It was great fun,” he grins. “Playing Radio City and the Philadelphia shows, and New York. Travelling is tough, but I love it. Even airplane food.”

These days, Fergus resides with his wife, Li, in a beautiful spot, overlooking Schull Bay, in West Cork. His parents are his nearest neighbours — their respective houses standing either side of his recording studio.

Li, a Chinese nurse, met Fergus while he was in hospital in Cyprus, 18 years ago. Succumbing to a second bout of pneumonia that year, Fergus was downbeat about life. Then,

MICHAEL MACSWEENEY/PROVISION

in his late 20s, he feared the worst.

"I was thinking — 'ah — that's it. This is the pits,'' he says. "As MD goes on, you become more and more prone to pneumonia — and I wasn't feeling good about the future. But then I met Li.

"We're married 14 years," he exclaims. "And it's been the best thing in my life. To have someone to share things with — what were the chances? Me from south-west Ireland, and Li from south-west China.

"The daily battles are the simple things," he says. "Stuff like toileting. But a nightly dose of Senokot usually sorts that out. And Li helps me through the day. I've got a pressure-relief-system bed, with a computerised mattress. A hoist — the works. So Li doesn't have to lift me," he explains.

Candidly, he details that it wasn't because of his MD that the couple didn't start a family. Although the hereditary possibility of a son having his father's condition was explored.

If MD were to occur at all, it might have been in a grandchild — the chances being quite low. The choice not to take the parenthood path was more to do with the vagaries of being a musician.

"Music — it's a rough game. Often I wonder if I'd have been better off being born tone deaf," Fergus offers with a grin, "I might have made a few more bob." That's O'Farrell for you. ■

See www.interference.ie

RUDE HEALTH

JABS FOR THE BOYS

I feared flu vaccines given by pharmacies would cause trouble, says **Maurice Gueret**. It's surely a job for doctors and nurses

I mentioned an old arthritis rub fit for a President before Christmas and have been inundated with queries about sourcing its ingredients. Oil of Wintergreen is the one that seems to have caused the most trouble, but I am happily informed that it is available, particularly in older, family-run chemist shops, where the skill of compounding old remedies has not been lost. BBC television ran a fascinating series last year about a Victorian pharmacy, highlighting the wonderful breadth of knowledge and talent pharmacists once had about devising and making up traditional remedies. I'm a great believer in the real benefits that modern prescription medicine has brought to healthcare, but it is a shame that so few pharmacies still offer to compound personal homespun remedies for their patients' minor everyday ailments as they once did. Fish blubber oils and surplus vitamins are a very poor substitute.

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On the subject of arthritis, I had a very nice email from a gentleman in Limerick who told me of another old remedy, not a rub, but one to be taken orally. It came, he tells me, from America and the ingredients are a bag of raisins (white or golden ones, not dark) and a half bottle of gin. The raisins should be inserted into the gin until the bottle is full and the bottle is then closed for at least one week. The dosage is anything between seven and nine raisins per day. To my knowledge, there have not been any medical trials published on this treatment, and as I have yet to personally succumb to arthritis, I cannot make any informed personal comment either. But I would suggest that if you can get the gin content approved by Mr Gay Byrne and his Road Safety Authority, it'll do you very little harm.

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You are familiar with the old adage about your health being your wealth. Well, in Ireland, the converse is also true. Wealth can buy you earlier appointments, more clinical time, better communications, comfortable surroundings and infinitely better hospital food. Yes, even in so-called 'public' hospitals, the menus offered to private patients are often starkly different to those admitted to public wards. Apartheid has been institutionalised in our health service for generations now and you'd be very foolish to listen to political waffle about the introduction of a single-tier health service. It won't be happening any time soon. Your Government knows it. It's just that they won't admit it, yet.

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There was a brief time when equal access for all could have been a reality. Micheal Martin TD was Minister for Health and tens of billions of tax revenues were funnelled through his Hawkins House piggy-bank. For a man who talked a lot about optics, the word vision was completely foreign to Mr Martin. Obsessive about spin and puff, he forged an entire career from the studious avoidance of nettle-grasping. If it looked like a turd, and smelled like a turd, Mr Martin would ask someone else to handle it while he commissioned a report on the application of shine. His department sponsored snooker tournaments in Citywest hotel while he spent his efforts moving smokers outside licensed premises and collecting international awards for fresh air. Health workers knew they were on to a good thing. Everyone from health board members to senior doctors, trolley porters to ward sisters, queued up outside Micheal's office for pay rises, bonuses, reduced hours, expenses, grants and allowances. Trade unions started to believe in Santa Claus again. No demand was too extravagant. Bits and pieces of health facilities were opened up under his watch, a few extensions here and the odd attic conversion there, but Martin's reign left little of substance. The number of local public houses in Ireland entered into catastrophic decline and the number of smokers remained exactly the same. A legacy as empty as the party he now leads.

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At the tail end of last summer, Health Minister Dr James Reilly declared that he was allowing chemists to inject flu vaccines in the autumn. I was a bit puzzled, because not a single pharmacist had been trained at the time to give injectable medication. We now know that hundreds of customers were subsequently given a children's dose of the vaccine and had to be recalled for reimmunisation. A blame game has begun and an inquiry is under way to find out how training was sanctioned, approved and conducted. I shall have a lot more to say on this matter, if the final report appears in public. But there are three immediate matters that are troubling me, and I worry that they may not be covered in the report. Why was HIQA, the Health Information and Quality Authority, not given the mandate to conduct an inquiry into this serious public health matter? Why was the pharmacist's trade union (the IPU), and not the regulator (the Pharmaceutical Society), involved in such an important matter as the training of pharmacists in conducting invasive procedures such as vaccination? And finally, when Dr Reilly sanctioned the delivery of flu vaccines in pharmacy shops, had he satisfied himself that they would be trained adequately and that their training would have adequate medical supervision? The debacle is a public relations disaster for Irish pharmacy. Some of the pharmacists who feel particularly hard done by are those who chose not to get involved in flu vaccination because it was a field in which nurses and doctors had particular expertise. Flu vaccination is important for at-risk groups and those who work at the coalface of the health service. It should be delivered cheaply and conveniently — by those who have been vaccinating you for generations. ■

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