Swimming with MND

The sudden onset of motor neurone disease stopped Alex Francis in his tracks. But cold water swimming has had a positive impact on his physical and mental wellbeing. By **Liz Lowe**

Alex Francis, a father of two, was diagnosed with motor neurone disease in May 2019, aged 42

The first winter swimming outdoors can be daunting, but Alex Francis had a compelling reason to brave the falling temperatures. "There was a realistic possibility I wouldn't last six months," he says, "so it was like each week was a gift."

Alex, a father of two, was diagnosed with motor neurone disease (MND) in May 2019. MND attacks nerves in the brain and spinal cord: this prevents messages being sent to the muscles, causing them to weaken, stiffen and waste. The disease progresses rapidly, killing a third of people within a year and more than half within two years of diagnosis.

Growing up on Hayling Island, Alex enjoyed the water, but never thought of himself as a swimmer. In his thirties he became, by his own admission, "a bit obsessed" with running, tackling challenges like the seven-day 255-kilometre Trans-Alpine Run alongside wife Laura.

Then, age 42, MND stopped him in his tracks. "I started falling over," he recalls. Initially the falls occurred after several hours' running, but that soon changed. "I remember I was going to run for 40 minutes, and two minutes in I tripped on a manhole cover, and that was that," he says.

Cycling also became problematic, so Laura suggested Alex visit outdoor swimming venue Vobster Quay. She arranged for open water swimming coach Richard Smith, who has a background in sports science, sports therapy and rehabilitation, and working with disabled athletes, to be there.

Richard currently volunteers one-to-one support for Alex and firmly believes, "it's not what you can't do, it's what you can do". With Alex, his approach is holistic and aimed at maintaining quality of life. "I've always tried to coach the person, coach positivity and set goals," says Richard.

Alex learnt front crawl and began regaining lost cardiovascular fitness. Within a few months he completed his first 750-metre circuit of Vobster, which Alex remembers "felt like a big deal".

Two friends of Alex's, Sarah and Jolene, joined him for those first sessions before offering to be his regular support crew, enabling him to swim once or twice a week. "Neither of those guys had swum through the winter before, we just sort of found ourselves there each week, and we kept checking the temperature and we were still getting in," remembers Alex.

The water allows him to move in ways which aren't usually possible, but that's just one facet of a potent mix of benefits. Swimming provides a mental release too, says Alex. "The combination of cold and being in the water, it's a very strong stimulus and it really focuses your attention for a little while: you can't think of anything else, and that can be really good. It's like a reset."

Sharing the experience with friends is uplifting and meaningful for everyone. "We laugh at each other when we're really not enjoying it so much, when we're all shivering trying to get warm afterwards or trying to fumble around in dryrobes and that kind of thing," Alex says. "It's a really special thing to be there with them," he adds. "It's not just my vulnerability, it's theirs as well. You go into the cold and you see a more open version of each other."

Vobster Quay's closure during the first lockdown of 2020 had a big

Photography: James King

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impact. When Alex returned to the water, he was largely reliant on a wheelchair, and front crawl was no longer an option. "I'd lost so much strength and mobility, particularly in my arms and hands, and felt I wouldn't be safe face down," he remembers.

With Sara, Jolene and now another friend, Neil, for support, Alex switched to backstroke and began to enjoy his new perspective. "I'm looking at the sky, I'm seeing the birds, I'm in the weather, I'm noticing things that I never had time to notice before," he says.

"The goals shifted to maintaining as much functional movement as possible," explains Richard. Alex's swim sessions follow a routine: acclimatising, relaxing and enjoying the sense of freedom afforded by the water, and then some exercises. He sometimes wears a buoyancy belt to hold him upright in the water.

The exercises target three key areas: improving the range and quality of functional movement, neuro-muscular stimulation, and maintaining and developing muscle strength. Designed to support actions required for everyday life, the exercises have had an immediate positive impact. "Alex is developing movement and power that he hasn't had for months," Richard says.

By December 2020, Alex was able to complete a 350-metre cold water fundraising swim, a distance he hadn't swum for ten months. He raised nearly £5,000 for the MND Association.

The research around the impact of exercise on people living with MND remains inconclusive, but Alex clearly experiences both physical and mental benefits. "I'm convinced this area offers some exciting prospects for rehab and research into how MND can be slowed down," says Richard. He hopes there will soon be answers to questions such as whether Alex's increased strength is due to the recruitment of dormant muscle fibres or whether their work is actually restimulating neurons and muscle fibres that have degenerated.

A 2016 study (published in Human Molecular Genetics, Volume 25) explored the use of cold-water therapy with spinal muscular atrophy mice (SMA is a childhood form of MND). It found evidence that hypothermia therapy prolonged lifespan, increased body weight and improved motor coordination. The MND Association believes it's an area that warrants further investigation.

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A short film documenting Alex's journey is due for release in early March 2021. The aim is to raise awareness and prompt more research, as well as inspiring others to try open water swimming.

Scientific data aside, hearing Alex describe his swims is evidence enough of the positive effects. He remembers a recent dip, just before Christmas: "It's not a normal experience to see heavy rain hitting water close up," he says, "you see these raindrops hit the water and bounce and catch the light and you can feel it on you. It's magical." OS

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