



PAIN & GAIN

WORDS Anna Gardiner

IMAGE Jesse Wild

For some, riding a bike is far more than a hobby – it's a means of managing chronic conditions and keeping pain at bay

STEVE GOTOBED RIDING WITH MS

It's fair to say that sport and cycling has saved Steve Gotobed, 45 and the senior art editor of *Cycling Plus*, from losing the ability to walk. Diagnosed in 2007 with multiple sclerosis (MS) – a condition affecting the nerves, spinal cord and communication to the brain – Steve was told bluntly that he'd be in a wheelchair within 10 years. Although he'd been sporadically active beforehand, he was sceptical of throwing himself into any sort of physical training following his diagnosis.

Four years on, Steve was still coming to terms with the news. "I struggled to find ways to manage symptoms, was piling on weight and felt like I'd no control over my body. Then a friend roped me in to running a trail race, followed by a half marathon. I realised the enormous positive physical and mental effects that exercise had on me, and that I didn't need to be defined by my condition."

MS is different for everyone who suffers from it. Steve's own symptoms often include a debilitating feeling of "pins and needles meets sunburn", and numbness down his left-hand side. Steve describes it akin to how your arm or foot feels after lying asleep on it and then immediately trying to use it. "Running with this sensation is far from easy as there's no feeling of contact with the

ground, so I don't experience any proprioceptive feedback," he states.

After landing his current job in 2016, Steve had a fast introduction into the world of bikes, which opened up new possibilities for managing MS. The numbness and discomfort is less noticeable while cycling, and even dissipates it. "Cycling, with lesser impact on my body, allows me to exercise even more than I did before my diagnosis, which is ideal as the worst thing for this condition is inactivity. Being able to do sport daily makes me feel like I'm in control of my condition; although this might not be true of all MS sufferers, it's definitely my experience of it."

Steve rides solely for enjoyment and the therapeutic benefits rather than anything competitive. He put himself off long rides in 2017 after riding from London to Paris over three days with only six hours' sleep a night and four weeks of training. This wasn't ideal – tiredness makes his symptoms worsen – and he lost sensation in his left hand for six months post event. He now sees the bike as a tool of recovery; he can keep aerobic fitness without overloading his body if he sticks to manageable distances.

"Until now, I hadn't told many people about my condition – the way that someone looked at me once made me feel like I was contagious – but after 14 years I've stopped worrying about people knowing," he adds.

With the bike, Steve can exercise every day, always striving to push forward physiologically and psychologically, cycling in the face of MS.

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Right Steve's recipe for managing his MS? A hearty mix of road riding, commuting and, what else in 2022, gravel riding



Images: Jesse Wild

RICHARD BUTTERFIELD RIDING WITH CANCER

Richard Butterfield, 54, is used to discomfort. Riding the mountainous Haute Route Alps and Dolomites back-to-back is evidence of that. So, while his oncology team raised an eyebrow or two at Richard choosing to commute the 50-mile round trip from his home in Trowbridge to Bristol daily for treatment, his family thought nothing of it. "It's fair to say I am just a bit obsessed with cycling!" he says.

Richard was diagnosed with tonsil cancer in 2019. After his first assessment, his dedicated approach to training and racing saw him travel to France to compete in a gran fondo, shrugging off health concerns and making the most of the time away. "I didn't think to prioritise my health - and I really didn't think it was cancer. I was about 5% off my usual level but had a great race, finishing sixth vet," he recalls.

Yet it *was* cancer. On his return, he underwent neck surgery and radiotherapy, and again he rode throughout that period

of treatment, brushing off the fatigue caused largely by the radiotherapy. "Being fit made a difference to my recovery from surgery and radiotherapy - much of the advice around exercise in treatment assumes a sedentary lifestyle - but I was able to ride with the advantage of being a lifelong athlete."

He planned events for the following year as treatment seemed successful. However, Richard started struggling on local routes. An annual lung-function test showed a marked reduction from previous years. In March 2020 he learned that the cancer had spread to his lungs and was incurable. He was given a prognosis of 18 to 24 months to live. But he was largely asymptomatic.

Living with a terminal diagnosis is obviously an extremely difficult thing for Richard and his family. Covid has made that even harder. Richard is used to being able to travel freely through cycling, so the curtailing of freedom in lockdowns proved incredibly frustrating. In the periods where travel had been easier, he was keen to fill his boots, such as his visit to the Dolomites in July 2020.

On his return, he underwent chemotherapy, but continued to ride, carrying a portable infusion pump in his back pocket attached via a PICC line into his veins. Fatigue was rife, and some days just

making it out of bed was difficult, so his training was adaptable. But training had to continue, providing a constant in a changing world.

He completed the Rapha Festive 500 in December 2020 and, for a while, it seemed his body responded well to treatment. "I don't know what I'd have done without the bike," he says. In May 2021, as soon as travel restrictions lifted once again, Richard visited Nice, riding every day while his health held, then crossed borders for the Haute Route Crans Montana in the Swiss Alps. During this period, however, Richard noticed difficulty with words and a cancerous brain tumour was found. He underwent an awake craniotomy.

Still, he couldn't be kept down and just seven weeks later he was back in the saddle for a series of tough events: the Haute Route Alps and Dolomites back-to-back, then the Haute Route Ventoux later in the summer. New treatment has meant life and cycling has become more restricted, but Richard continues to train for his next challenge, which is always on the horizon.

Richard's raised over £16,000 for cancer charities. Read more on his blog at tinyurl.com/RBFDBlog.



“Being fit definitely made a difference to my recovery from radiotherapy - much of the advice around exercise in treatment assumes a sedentary lifestyle - but I was able to maintain decent training with the advantage of being a lifelong athlete”



Images Jesse Wild



Right Such is Richard's determination that he even rides with a portable infusion pump in his back pocket attached to his veins via a PICC line

CLAIRE DAVIS
RIDING WITH FIBROMYALGIA

Claire Davis, 40, is a muscular six foot with a Mohican haircut. She has, however, lived with fibromyalgia for many years. Little is known about its cause, although it's thought that there's an imbalance of chemicals within the body and a disruption of pain messages throughout the central nervous system. Symptoms include widespread pain, fatigue, sleep issues and, often, associated mental and emotional distress. More recently, Claire has also been diagnosed with Ehlers-Danlos Syndrome (EDS), a genetic condition that affects soft tissue. Most days she manages symptoms as varied as irritable bowel syndrome, widespread muscular pain, cluster headaches, dislocation of limbs and chronic fatigue. Diagnosed with fibromyalgia 15 years ago, she was left to muddle along and rely on painkillers. She was initially nervous about exercise and didn't know if she should push through the discomfort barrier. But she didn't want to rely solely on prescribed analgesics, so she became more active. Slowly she gained confidence to try different sports, including triathlon. Days when she felt too exhausted to run, she would go for a swim or a gentle cycle. Claire soon found that exercising daily lessened the symptoms of fibromyalgia.

Being active has had massive psychological benefits, too, and backs up a 2021 NICE report that chronic pain conditions should be treated with exercise programmes, talking therapies and acupuncture alongside medicated pain relief. She also appreciated the sense of freedom that cycling brings and the opportunity to explore the wilderness of her home in Scotland. Her condition can make her feel isolated and alone, but with cycling she loves accessing remote areas. If she is having a bad day she will make sure she gets on the bike, as it's often the solution. "If you wake and feel exhausted, change your plans. Don't throw the day away. Just cycle around the block, then the next village, then the next one," she insists. Claire finds cycling so beneficial that it's at the heart of her two jobs: teaching Bikeability, the cycle skills training course, in schools during the week and her own cycling guide business at the weekends (claire-davis.com). She's also taken up ultra-cycling. After a life-changing solo south-east Asian cycling experience a few years ago, she's now training for the Trans Alba - a fearsome event covering over 1,000 miles and over 70,000ft of elevation, self-supported around Scotland. She's found that training with her condition's actually helped: "I'm used to doing things when exhausted and experiencing pain daily. In ultra-endurance events you have to learn to overcome those feelings to complete them anyway." Lockdowns have highlighted how important

cycling is to manage her pain. Being less active meant she had to take more analgesics, oxygen therapy and injections for migraines. But now she has the Trans Alba to train for in the build-up to her 40th birthday and enjoys the social life that her cycling brings. As Claire says simply, "Cycling makes me happy."

Below Claire's currently training for the Trans Alba challenge in Scotland



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KEVIN ROBERTS
RIDING WITH PARKINSON'S

Kevin Roberts, 66, has always been fit and active. He played professional football for three years, and then semi-professional, before retiring from football at 34. Exercise has always been a key part of his life and he made it part of his work when he became a retained firefighter in his early 50s. Although he commuted by bike, cycling for pleasure was never a feature of his life while he was able to keep fit playing golf and tennis. Over time, he noticed dexterity issues. He found it difficult to write, had ongoing pins and needles, and muscular aches and pains. Parkinson's was the diagnosis, aged 57. It's a disease that attacks nerve cells in the brain, which leads to the reduction of dopamine. Dopamine plays an important role in regulating movement of the body and its loss causes stiff limbs, involuntary shaking and depression. Parkinson's is a progressive disease but Kevin's consultants are surprised at how well he is managing his condition. Riding his bike, he believes, is the reason his symptoms are kept at bay. When he is on the bike, and for a period after, his symptoms disappear and he's comfortable

Below An e-bike's given Kevin that little bit extra support to head out and tackle the beautiful but hilly Northumberland countryside

in his body. He agrees that it doesn't quite make sense why he loses his balance after walking a few hundred yards but can comfortably cycle 25 to 30 miles. One of the side effects of Parkinson's is muscle wastage, so the constant resistance of pedalling is strengthening physically, as well as keeping neural pathways going. He finds that stress exacerbates his condition. He lives in beautiful, hilly Northumberland. Initially, the thought of battling hills along his routes would unnerve him and put him off heading out. His symptoms would then spiral due to the double whammy of stress and lack of exercise. So he bought an e-road bike and his cycling and attitude have been transformed. His bike motor acts like a tail wind - it still needs pedal resistance - but he can now take on any hill on his route without worrying whether his muscles can take the load. He loves the freedom and solitude of cycling, choosing to bike solo. Like other conditions, he doesn't know how he will feel physically day to day and would rather do as much or as little as he can than go on planned rides. Sportives and other organised events hold little appeal because he feels the competitive nature and riding in big groups would be too much stress and would make his symptoms worse. Riding a bike for him is all about physical longevity and the mindfulness that it brings. "The scenery, the relief from pain and discomfort - it's so vital and, for me, feels better than any medication. There's no point being down about my Parkinson's. Cycling through it and life would be all the poorer without it."

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Image Justyna Kolodziej

Image Gavin Forster