Chronic fatigue syndrome in elite athletes: four case studies

Chronic fatigue syndrome (CFS) is one of the most controversial of conditions. It is barely understood, even within the medical profession. Researchers, doctors and patients struggle to agree on its name (it is also known as ME, or Myalgic encephalomyelitis). In the field of sports medicine the underrecovery/overtraining syndrome is more broadly recognised, with a whole-body maladaptation to perceived stress implicated. CFS can encompass a broad spectrum of symptoms but treatment remains a challenge and in severe cases, full recovery can be elusive. A report in Occupational Medicine journal concluded: "An analysis in 2005 of trials that followed patients for up to five years concluded that the recovery rate is 5%". Possibly due to the unclear mechanisms underlying this condition, there is no agreed best way to treat it.

In order to help others understand the issue we present four case studies of high profile fell runners who suffered from CFS, compiled from personal interviews with them. In two cases it was career finishing/shortening, and in two others a return to a high standard of performance was possible. Three of the cases were in the 1980s and one in the last couple of years.

DAVE CANNON
Dave Cannon was the first British Fell Champion, in 1970, and later went on to have a successful marathon career, with a 2:11 PB.

Cannon's chronic fatigue came on fairly suddenly, although he wasn't aware of the extent of the problem initially. He comments that he, 'always says it really started at the time of the Chernobyl disaster [1986]. I was working as a linesman and it was really stormy weather in Cumbria and it rained and rained. I was stuck up a pole for hours and I was getting absolutely drenched. I went home and had a bath and then a couple of days later I started to feel bad, as though I had flu. It was the usually feeling of having a cold through getting wet and all that.'

At the time that it happened he was 35 years old. He describes the symptoms. 'At the time I couldn't pick my arms up, and my ears zinged. I would crawl up stairs and just go to bed. My wife thought there was something seriously wrong with me.'

The longer this went on, for months eventually, the more frustrating it was that the doctor still said there was nothing wrong with him. But running was out of the question. 'No way. Just to work was a trial.'

In trying to pinpoint the trigger he wanted to back his theory up a little bit. At the time of those rainy days, his aunt lived at Threlkeld (in the Northern Lakes) and all her hedge was blue as if it had been dyed. 'My daughter had a horse a mile away from I lived and the stallion that was outside never sired another mare, but those that were inside were fine. We get our water from the Pennines (at Appleby) and they weren't allowed to sell sheep off those fells for ages because of the contamination of the water off the fells. I am sure that shower had an influence on me, whether it was the cause or not.'

Later on when he asked what had been wrong with him, basically he was told over the years he must have had so many antibiotics it destroyed his immune system. When he was younger he kept getting
tonsillitis, and taking anti-biotics to get rid of it. 'This may well have the root cause of the fatigue problems I had later. So although what I had at this time may have been flu or a cold, they reckon you can have a virus that is hidden in your system and the more you push yourself the more it multiplies, and the worse you feel. It is getting rid of this virus that is in your system that you have to achieve.'

When the illness hit Cannon was in a build-up period of training, moving back towards another marathon race. 'I was probably up to what I used to do, around 70-80 mile a week, but maybe not with the full depth of training. I got ill at that stage though.'

Immediately he went to the doctor and took anti-biotics, but it wouldn't go away. 'Because he was running for GB he also went to the GB doctors, but nothing came from any of it, which is why he went to homeopathy eventually.

There was an article in his local paper discussing "a new group of sufferers in Cumbria", and it was for ME (Myalgic Encephalomyelitis). He rang the person up that was holding the meetings and said he didn't really want to come to the meetings out would welcome any information. There were kids in wheelchairs and I thought that isn't what I have got. If I did not push myself I could still do day to day things, but there was no way I could train. I was a member of Gateshead Harriers at the time, since finishing fell running, and Max Coleby rang me up to ask if I had packed in running, said I can't train, I feel shit all the time. He said there is a lad in Gateshead whose mother was diagnosed with ME and she has been seeing a homeopath.'

Cannon thought he should try that, and made an appointment to see Jan de Vries. 'I met him and he hardly spoke any English and I began to wonder if I was wasting my time. He cricked my neck and looked in my eyes. He said I want you to take six drops of this in the morning and six drops of this at night, and take one of these tablets every day. I was very sceptical. It cost about £20 for the consultancy and I thought well he is not making a fortune out of this. I went back every first Monday in the month and he always did the same cricking and looking, and changed the doses a bit. After a day I used to feel worse, but it was getting rid of all this crap.'

Eventually after 18 months de Vries said he didn't think Cannon needed to come any more. 'He says you will be fine now. I am convinced that he got me back to where I was. All he had done was build it back up.

By then I was 37 and I didn't want to start running again. I don't think my body would have taken it to be honest, not the amount of training I would have had to do.'

Cannon was told that it was all in his head at one point. 'I would take a day's holiday if I wasn't feeling well so I never missed any work. I had to work to pay for my family and that. I doubt work knew anything about it all.'

The stressors in his life at the time were simple things like working and training hard, and there was nothing in his family history that can be linked to the issue. He didn't really change his lifestyle when he was feeling bad (except adjust his exercise regime).

He feels that he has fully recovered. 'I wouldn't say that homeopathy would work for everybody, but as far as I am concerned it worked for me. I stopped taking the potions but I took an immune strength tablet for years afterwards. He says he has never had what you might call a relapse and his health has been fine in general but when he gets a cold it takes a long time to get rid of it.

Finally, when asked what (if anything) he would you have done differently, he replied, 'I don't think so, because I think I tried everything. It is difficult for a fully trained athlete, they are on the verge of illness all the time. Someone once said this when asked how much training you should do: "It is a bit like blowing up a balloon. You blow, you blow a bit more and then POP, back to square one".'

KENNY STUART

Kenny Stuart was three-time British Fell Champion, still holds some fell course records and also has a 2:11 PB for the marathon.

In Stuart's case the fatigue seemed to happen and then go away, and then come back and never went away again. It was about the time of his second marathon, which was 1987, when he was 31 years old. He says that the symptoms were just like the after effects of mild flu, as he explained. 'It was not so debilitating that you couldn't walk about but you were tired all the time.'

Kenny Stuart - Blisco 1983

PHOTO: © STEVE MATSON
I didn't have dizzy spells but was very lethargic, and I couldn't concentrate either. I found it difficult to drive and concentrate for long periods of time. The thing is when I started with these symptoms I carried on and tried to push through for six months. Every runner has been through something similar. This particular time I didn't get through it. It was very frustrating.'

The worst thing about it was that he ended up not being able to get back to running and not having a job as well. A year later he went back to retrain and do some college work, to get better qualifications in his line of work. 'I had this idea it might not happen again. I tried coming back to running once or twice after that and I got to a certain level, but knew I wouldn't be able to go on further. It was quite humbling actually.'

He thinks the trigger for his fatigue was through a combination of factors: a lowered immune system, probably stress as well, and trying to fit everything in at that time. 'I don't think I had this thing they called ME. I do recall that not long after this I had a test which suggested the symptoms I had were probably caused by a stomach virus, which went a bit further than that. I do recall running the Brampton to Carlisle 10 miler in 1988, which is a fast course. I hadn't run under 48 minutes and fancied my chances there. But there was a head wind which is unusual for there. I pushed and pushed and I knew at that time that I had a dicky stomach. I think that is actually where it properly started from. I hadn't told them about the stomach problem before the test and they had some idea it was in some way responsible.'

In terms of his training, it was at the end of a period of ten years where he had trained exceptionally hard throughout. 'Maybe I had not had enough rest periods. I ran right round the year. But it was not related to the change from fells to roads.'

He also thinks it wasn't anything to do with training and racing, as such. However, during the time I was running the London Marathon I was also having problems with pollen at that time of year. Rhinitis, the lot. Perhaps if I had packed my job in 18 months earlier it might have been different. Who knows? There was no work security really. A lot of lads who were running very well at the time had no responsibilities.'

He tried changing things in his life when he was feeling bad. 'I tried cutting out dairy products, different diets, gluten free for instance. I became convinced I was gluten intolerant. Now I am eating bread and I am not so sure about that. For a while I was also convinced that citrus fruits were causing some sort of problem.'

Stuart feels he didn't really fully recover, although he doesn't feel that he has ever had what you might call a relapse. 'I could have got back to club running, but that is not what I wanted. My general health now could be said to be the best it has ever been. I don't have the rhinitis, and all the other asthma type issues. It is interesting to note that both Rosie and Emma [his daughters] in their teens got glandular fever. Emma in particular had bad eczema. There is something there in the family giving us some predisposition. They called it atopic. [Atopy is a predisposition toward developing certain allergic hypersensitivity reactions.] It is diagnosed by some sort of blood count. I had an MOT check over 10 years ago: I was diagnosed with tricuspid valve incompetence, but it is not a major problem.'

The Northwick Park report said he had, 'the murmur of tricuspid incompetence which is common in athletes of this quality', which is why it is not a problem as opposed to being a true tricuspid valve incompetence.

So what (if anything) would he have done differently? 'I shouldn't have run races when I was on the fells, i.e. to get championship points. When not well. On the Saddle Skyline for instance I had a mild bout of influenza, went down there and thought I would recover after the race. I had to drop out at High Cross. That knocked me back for a week or so, then I got stronger again. But I think the more times you go to that sort of bank, the more you get drained and it catches up with you. Another important thing is that I was never out of action through physical injury, or very rarely. If that had occurred now and again it might have been in a backhanded way a natural stopping place - to recover. I would definitely change my attitude now, looking back.'

"BY STEVE CHILTON & STEVE BIRKINSHAW"

Sarah Rowell is an Olympic marathon runner (with a PB of 2:28), who came on to the fells to win both the British and English Fell Champs in 1995 and 1996.

Rowell feels that with hindsight the first warning was sudden, but then in terms of recognising it, it was gradual. She recalls: 'I raced the Cardiff international cross country as part of the England team on 19 December 1987 and had a shocker. I continued training as normal for a week (well slightly lower, doing 68 miles), but the tiredness did not go away, plus I started feeling shaky, dizzy, floating, sick when running.' She was 25 years old at the time.

Her training mileage in the following weeks then went (in miles): 42, 23, 14, 40, 56, 60, 67, 82, 70, 82, 64, 23, 45, 35. 'I then had another 9 weeks where I was running 30-ish miles per week before realising that I had to stop, which I did for 2 months. After that I had another 11 weeks of no more than 50 mwp steady running, with the first 'sessions' being introduced in December 1988.'

Her first race back was her first ever fell race – Boxhill on 21 Jan 1989. By mid-1989 her mileage was back to normal, plus she had gone back to running twice a day on some days.

Rowell's symptoms manifested both physically and mentally. Physically she felt
below par and heavy legged, unable to sleep well despite feeling tired and waking up tired, feeling sick. In her head she was dizzy, lightheaded, and had a brain that felt fuzzy/foggy and not sharp.

‘The worst thing about it at the time was not knowing if I would ever get better – there was another well-known female endurance runner who I was aware of who 3-4 years on from first symptoms was still not able to run, that scared me.’

She reckons the trigger for her fatigue was a mix of physical and mental stress overload. ‘I was entering the last year of my PhD. I had had a second operation to try to save my running career in July that year, which looked like it had not worked, was running 70-100 mpw and racing most weekends – it was too much.’

The races she was doing before it happened were a mix of local and national. Her performances were fine until the international cross country [mentioned above], where in her own words she ‘bombed’.

She sought a diagnosis immediately. ‘I think I got a blood test pretty quickly, and have a note in my training diary saying I had a virus and nothing more. I sought further advice, mainly from my coach plus the doctor who had been overseeing my leg problems, Dr Ken Kingsbury.’

Rowell feels that you cannot separate the mental and physical aspects. ‘In terms of the cause, I do not think you can easily separate the two; I had a stress overload/over-recovery. As to symptoms, then both were prevalent.’

Her work and concentration were both affected. ‘In many ways I was lucky in that I was doing my PhD and had only loose supervision from my supervisor, so on bad days I could just drift. Concentration was an issue, and I can remember at least one occasion when I ended up down in Eastbourne town centre with no idea why I was there – it was like being in a mental fog all the time.’

She expanded on trying to make lifestyle changes to deal with the situation. ‘I am someone who works best off 8 hours sleep a night (I still do, which is not great for ultra-long events!). I would find going to sleep easy, but did not sleep well and would therefore wake up tired. To help with this I stopped drinking diet coke in the afternoon/evening (I do not drink tea or coffee) to reduce caffeine intake, and I did not drink that much alcohol anyway. Plus I took prescription sleeping tablets for quite some time.’

She then made the decision to stop trying to run. ‘I am however someone who feels better for even a decent walk – which meant I had to balance the minor buzz of feeling good from a walk, with the follow-up ‘hangover’ of feeling awful, fuzzy brained and tired.’

She does now feel that she is fully recovered. ‘But I would say it took 10 years for the dizzy days to completely stop.’

She also feels the she had what might be called relapses. ‘Lots of times, recovery was like a wave, with the down parts slowly getting further apart and not as bad, but in the early days there were a number of times when I can remember feeling very scared that it had come back fully – the longest I can recall a bad period lasting once I was on an upward curve was 7-10 days.’

Two other later occasions stand out for Rowell, both from the period when she was running superbly on the fells. ‘In 1995 I did the British and English Championships for the first time and was focused on doing well at the world mountain running championships in Edinburgh that year on a course which suited me. I think I won every race I ran that year apart from the Worlds, where I had a poor race. I trained too hard going into it, plus I guess the stress of knowing the course suited me and I was fit. My diary notes that I was tired, sleeping, feeling shaky the two days before the race. A week later I set the record at Dalehead which still stands.’

‘Then in 1996, the day before the Ian Hodgson, we went to recce it. I lasted 3 miles before feeling too dizzy and ill to continue, I went back to my tent and slept. I was able to race the following day OK, and my diary records, “so overall felt normal, a massive high and relieve afterwards”, showing how worried I had been.’

Looking back now, she feels she would have done things differently. ‘Not tried to fight it, but to have accepted that my body needed rest and taken the 2 months rest straight away – I am sure I would not have taken a year to get over it had that been the case.’
STEVE BIRKINSHAW

Steve Birkinshaw is an elite fell/ultra-runner, having won the 5-day Dragons Back race and run the Wainwrights in a new record of six and a half days.

Birkinshaw started having problems after completing the Wainwrights run, in 2014, when he was 47 years old. 'I knew I had not felt right since completing the Wainwrights but after a couple of week’s rest I carried on running. Then it was a fairly gradual decline, as I was being beaten by people in races I normally beat and I would also finish the races sad, cold and shivery instead of feeling great. I also started to feel really shattered the whole time and noticed I was struggling to concentrate at work.'

He rested for a couple of weeks then felt OK, so started running then the fatigue suddenly hit. Then he got into a repeated cycle of rest, running and fatigue. He listed a disturbing list of the symptoms:

- Persistent exhaustion. When it was bad it was an effort to go for even a short jog.
- 'Brain fog'. Not being able to think straight or concentrate and my short-term memory was absolutely awful. This normally cleared around midday and by the evening I felt almost back to normal. When the ‘brain fog’ was bad I would find it impossible to write a simple email or even remember a simple instruction.
- The persistent wish to go to sleep even when I had just had been in bed for 8-9 hours.
- Disturbed sleep. I would wake up in the middle of the night and not be able to get back to sleep.
- Regular headaches.
- Feeling really dizzy. Light headed like I was going to faint.
- High resting heart rate.
- High blood pressure.
- Occasional fast but erratic heart beats.
- Really emotional. If something upset me I would not get angry, just upset and prone to crying.

He feels the worst thing about it was what he calls the ‘brain fog’. He was really struggling to complete his work and getting stressed by it, with the stress then making his symptoms worse. ‘I got to the stage where I thought it did not matter about being able to run long distances again as long as I could think clearly. I was also worried about the strange heart beats and I thought I might suddenly have a major heart attack.’

Birkinshaw feels doing the Wainwrights was the trigger, as up to then he felt good, and ever since then he has known something has been very wrong. His training at the time would consist of at least 10 hours a week on the fells, but he had been doing that for at least 10 years. Before it happened he had been competing in a mix of long fell races, orienteering events and mountain marathons. He admits that he usually did well in the longer ones and less well in the shorter ones.

He eventually went to the GP about a year after his Wainwrights run when he was starting to struggle badly. He had tests but nothing unusual was found. ‘I had more tests four months later when I was at my worst. All these tests also came back negative. To start with I thought I had had a virus, but after it carried on for so long it was diagnosed as chronic fatigue (which is the diagnosis you get with my symptoms once everything else has been ruled out). Atrial fibrillation was diagnosed about 6 months later when I managed to get an ECG whilst an episode was happening.’

He spoke to his GP and was referred to speak to an expert in cognitive behavioural therapy. ‘In many ways talking to my peers was more useful as many (such as Sarah Rowell) told of having similar problems, but they had recovered by changing their lifestyle.’

Once he had problems concentrating then he would get stressed because he could not do the work he needed to do, which made the symptoms worse, so there was a downward spiral. ‘Normal I run to relieve stresses in my life, but I was not really able to do this satisfactorily. I was also giving talks about my Wainwrights run which I found stressful and so made the symptoms worse.’

Birkinshaw is fortunate to be able to work from home most of the time. ‘So although I had real problems concentrating I was better in the evening, so just about managed to keep on top of my work by working late. With hindsight I probably should have gone off sick for a while and I would have recovered faster.’

He notes that he did not have any real stressors in his life at the time, although giving talks about the Wainwrights run was a bit stressful. ‘But other than that no particular stresses until I started to feel bad, then I got stressed so much that I could not concentrate.’

He decided he needed to make some changes in his lifestyle when he was feeling bad. ‘When I was at my worst I realised I needed to make some dramatic changes. So I started to live the ultimate healthy lifestyle. No alcohol, lots of healthy food, regular 8-9 hours sleeps, gentle runs, very little caffeine. I try to avoid snacking (particularly sweet food), and avoiding stressing about work.’

Birkinshaw is not sure if he is fully recovered. ‘Sometimes I have days when I feel completely normal. Other days I have some “brain fog” but it is nowhere near as bad as it was. Sometimes I get “hot flushes” in my chest and arms and sometimes I still feel light headed. A recent test showed I still have high blood pressure. I have done some longer harder runs and sometimes I have felt OK and sometimes I have really struggled. Basically I am happy with where I am. I might recover fully and be able to push it as hard and be as fast as before, but I might never get there. However, I can live a normal life and go out running every day.’

Several times he feels he had what might be called a relapse. ‘A couple of times I have thought I was completely OK but then I ran too much and the “brain fog” re-appeared. It then took nearly a month to feel good again.’

Birkinshaw concluded that he might well have done things differently. ‘After I finished the Wainwrights I should have listened to my body and let myself recover properly. If I had had an easy six months I may have
been completely OK and never suffered the chronic fatigue and atrial fibrillation.'

CONCLUSION
The parallels in the four cases studies are fairly obvious. We are not qualified to give definitive advice, so will just finish with some thoughts, the current evidence and some further reading.

These are four people who have pushed their bodies to the limit. As well as training and racing hard and over long distances, they were working, and eventually the mental and physical strain on their bodies was too much.

Overtreaining and under-recovery as a form of chronic fatigue implicates the whole body. The regulation of stress hormones from the brain, adrenal and thyroid glands can be altered, therefore disturbance in mood, memory, cognitive processing, digestion, sleep and hormonal function can occur.

Athletes who are highly motivated, especially those who know how to push their bodies 'beyond the limit' may be particularly at risk. Pushing too hard can undermine the body's capacity to adapt and strengthen with training stimulus, especially combined with inadequate recovery and the stresses of everyday life outside of training. The symptoms of long-term complete tiredness and struggling to concentrate are very similar in all the cases. All ignored the symptoms to start with but eventually dramatically reduced their training and made changes to their lifestyle and gradually improved although the final outcomes do differ.

Medical authorities now agree that it is a genuine, discrete condition, even though its causes are debated. 'In sport, there needs to be an emphasis on early identification of athletes suffering excessive fatigue and underperformance by the athlete and coach,' says Dr Rebecca Robinson (a consultant in sports and exercise medicine): Frequent viruses, decreased sleep and decreased appetite or weight can also be warning signs. A thorough range of investigations is needed to ensure another medical cause is not present (such as anaemia or glandular fever).

Following a diagnosis of chronic fatigue or overtreaining syndrome a supportive approach to the athlete is very important. Low mood is a common feature of the condition and frustration for the athlete is understandably linked to the many unknown aspects even experts in sport and medicine acknowledge, as well as the missed goals when training seems to go awry. Therefore supporting the athlete to step back from short-term goals and also address other life stressors, prioritising physical and mental health is crucial.

An article in the Guardian** quotes respected sports psychologist and running author Tim Noakes (University of Cape Town, South Africa), and also outlines the variety of medical responses and controversy that surround CFS. Oversimplifying his argument, Noakes believes the answer to the condition lies in the brain, and says it may be that, "the central governor has got its settings wrong. It's overestimating how fatigued you are'.

The article goes on to say that Noakes’ work, "also raises the question of whether cognitive and behavioural therapies could be used to slowly push back the brain’s draconian limits. If interval training works for athletes by teaching the central governor that ever-greater levels of exertion are safe, might it also work for patients with chronic fatigue syndrome?"

Peter White at St Bartholomew’s Hospital in London was developing similar ideas about chronic fatigue. To try to reverse the changes the brain was signalling, he developed with colleagues an approach called graded exercise therapy (GET), which is intended to work like an ultra-gentle form of interval training. White also uses cognitive behavioural therapy (CBT), in which therapists work with patients to challenge negative ideas and beliefs that they have about their illness.

The report noted at the top of this article also commented on CBT and GET, concluding that, "there is increasing evidence for the effectiveness of cognitive behavioural and graded exercise therapies."

Our reading of the medical material that we have consulted, and having discussed the issues with a couple of practitioners, leads us to three conclusions:

That overtreaining appears to be a strong precursor for such syndromes, and that once set in it’s very hard to recover from (even through retraining).

Training through illness is unwise and can possibly affect your heart health.

Long term endurance training (in particular for ultra distance) can essentially stretch the heart's chambers, leading to the 'athletic heart' phenotype - dilated essentially. Whether this leads to further problems (e.g. Arrhythmia) is also determined by the genotype, which much research is still going into.

Finally, in reference to this last point, an experiment is starting later this year to monitor 100 ultra-marathon runners for damage to their hearts. Martin Huffman, professor of physical medicine and rehabilitation at University of California Davis says that the study, with Liverpool John Moores University, will test existing evidence that the runners had an "increased risk for certain types of cardiac arrhythmia". Huffman, an ultra-runner himself, suggests there should be a focus on addressing conditions that, whilst devastating, affect highly fit people relatively rarely compared to the epidemic of physical inactivity which is a far greater risk to health.

LINKS
http://www.basem.co.uk/ - athletes affected should seek sports medicine advice, and perhaps get their support team to use the British Association of Sport & Exercise Medicine website, where you can find links to NHS and private options http://www.meassociation.org.uk/specialist-services-throughout-the-uk/ - contact details for specialist services. Note that, while athletes can contact any of the services for information, referrals for assessment, diagnosis and treatment must be made by your GP or the professional responsible for your health care
Steve Chilton is the author of Running Hard: the story of a rivalry [https://itsahill.wordpress.com/] and Steve Birkinshaw is author of There is no map in hell [http://stevebirkinshaw-wainwright2014.blogspot.co.uk/].

* 'A systematic review describing the prognosis of chronic fatigue syndrome.' http://www.ncbi.nlm.nih.gov/pubmed/15699087
** www.theguardian.com/society/2016/feb/15/it-was-like-being-buried-alive-victim-of-chronic-fatigue-syndrome