

M.E. and long haul – the road less travelled

By Fiona Agombar

The best moment of my life occurred last March. The Taj Mahal was more wonderful than I could ever have imagined – like a giant wedding cake studded with precious jewels. Tears rolled down my cheeks. But I wasn't just crying because it was so beautiful. I have had M.E. for 14 years – and for the first five of those I was severely affected. I never thought I would be well enough to travel to India but earlier this year I did just that.



'We made it!'

Fifteen years ago, my mother and I made a pact. One day we would travel to India together and see the Taj Mahal. Then, after a hefty bout of glandular fever I ended up crippled with M.E. For some time I was in a wheelchair. Reluctantly, I told my mother that the deal was off.

Over the next few years, thanks to judicious pacing, yoga and good diet, I made a partial recovery. Slowly I began to pursue my love of travel again, always allowing days either side of the journey to recover.

Assisted travel

Eventually I was well enough to try flying – but never outside Europe. At airports, I made friends with the ground crew and learned always to ask for assisted travel where they provide a wheelchair or buggy, so that I didn't use up precious energy with walking.

Finally in the summer of 2003, after a few weeks at a fantastic yoga retreat in Spain, my health seemed robust enough to consider the impossible. In September I announced to my mother that we would make it to India the following Spring.

Having made partial bookings with the tour company, I immediately relapsed for eight weeks. What was I thinking? I couldn't even travel into London, let alone all the way to Delhi!

Advice for the journey

I can only describe what I went through before the journey as a rollercoaster of fear and excitement. However, a friend with M.E. had lived in India and reckoned that the food and climate would suit me so well that I would be better there than in the UK. 'Have lots of ayurvedic massages' Trish urged, 'they are so cheap there. Try Indian head massage and don't be afraid to take sleeping tablets to help you survive the plane journey.' She also recommended a supplement called melatonin which helps jet-lag by resetting your body clock. Good advice, as I was to discover.

A more mildly affected M.E. friend who is a veteran of long-haul travel advised me to take lots of snacks for the journey, and to book into a hotel so that I could have at least 48 hours of undisturbed rest before going on anywhere else.

Meanwhile, my pal Erika worried about me getting 'Delhi-belly' and was less enthusiastic: 'You'll be on the loo all the time!' Her advice was to upgrade my seat to 'super economy' on the way out, so that I'd have extra leg room to make the journey more comfortable. Some AfME members have even secured a free upgrade by faxing a doctor's note or medical certificate about their disability to the airline in advance.

Slow and steady helps you pace

I decided to go out two weeks in advance of my mother so that I could rest before we started touring together. With the help of a wonderful Indian tour company called Trans Indus, we designed an M.E.-friendly package at a very reasonable price. While we were putting the itinerary together, I noticed points such as a train that left at 5am, or a stopover of only one night after a long journey. These were amended to make them more M.E. friendly – so that I was, literally, pacing my schedule.

The next decision I had to make was whether or not to have vaccinations or take anti-malaria drugs. There were points of view on both sides of the debate, but in the end my personal choice was not to have any inoculations in case they caused a flare-up of my symptoms. (It's less of a risk not to have vaccinations if you avoid malaria season and high-risk areas off the beaten track).

I emphasise personal choice because other travellers with M.E. disagreed with me on this, one having lived in an area where she'd seen people die of malaria. Instead I took artemisia, an anti-parasitic herb sold as Eradicidin Forte by Biocare, and lots of acidophilus or 'friendly bacteria' to prepare my gut for any



Riding high: Fiona and her mum flagged down a passing elephant

bugs. Recent clinical trials in Thailand have shown artemesia to be 90% effective – more than the standard drug, Chloroquine.

As I finalised my carefully-laid plans, my mother and I had a massive row, caused by nerves on both parts. We couldn't afford to have separate rooms, so there was even more pressure on me to 'be well'. While she worried about spending money on a trip where she might end up having to nurse me, I was nervous about sharing a room with someone quite chatty, when sleep was so essential to my health.

Meanwhile my husband booked me into a hotel near Heathrow so that I wouldn't have to make an extra journey to the airport before the flight. Luckily it only took seven and a half hours to Delhi and, thanks to the upgrade, the journey was pretty relaxing. As soon as I got off the plane there was a wheelchair to whisk me through immigration and Arrivals. There, I was met by a rep from Trans Indus, who took me to a hotel where I stayed for two nights, following my friend's advice to rest up.

'Living within the confines of M.E. for so many years made every new experience extra special'

Heightened experiences

Now my Indian adventure really started. The train journey to Rishikesh was very funny as I shared my overnight sleeper with three Indian men who were absolutely charming, looked after me – and all snored! Thanks to the advice about taking sleeping tablets and using earplugs, I did manage to get some rest though. I was then taken to a stunning guesthouse high above Rishikesh in the Himalayas, overlooking the Ganges. To me this paradise-on-earth had an extra sweetness to it; living within the confines of M.E. for so many years made every new experience extra special. Here I joined a yoga retreat and also made lots of friends of different nationalities. The Ganges, known locally as the Ganga, is said to be a Goddess who fell to earth and became a holy river. It certainly felt very spiritual to me – high up in the mountains the water is green and crystal-clear, fringed with the whitest of sand.

After ten days, refreshed by the yoga, clean air and excellent healthy food, it was time to leave and make the tortuous journey north to meet my mother at Amritsar. I was cheered along the way by meeting a hand-reared baby elephant called Yogi who was very cuddly. Memories of Yogi helped me accept the mini-relapse I then had at Amritsar, which meant a frustrating day in bed. Mum was great and totally accepting of my limitations. The old fear of 'I can't do this – I'm going to be too ill to travel', was overcome by doing meditations on the Bhagavad-Gita (an Indian holy text we had studied

by the Ganga) and the next day I travelled 16 hours south by train with my mother to Agra.

Adventuring within my limits

The weather was now warming up and I was blooming in the sunshine and clear blue skies. Only if you have M.E. can you appreciate the sense of wonder and achievement I had at finally seeing the Taj Mahal shimmering majestically in the sunshine. Because of my illness, every experience was heightened – I took joy from just being there. For the next two weeks, my mother and I had a driver, Santoosh, and we worked out a system where I lay down in the back of the car, while she sat up front and chatted to him.

'Now I know that I can manage a major trip, the world is my oyster and not my jailor'

We had many adventures along the way – from riding an elephant and a camel, to meeting a Royal Maharaja, and consulting an astrologer who told me I had 'good health for all my life'. Hah! What did he know? In addition, we ate delicious food, and as I was careful not to drink tap water or have ice cubes in drinks, I had no tummy upsets.

Some days were bad for me and meant I had to duck out of sightseeing and rest, feeling weak as a baby monkey compared to the vitality of my 72 year-old mother. But it was worth it. The ayurvedic treatments helped my health reach another level and apart from a massive nose bleed at the Lake Palace hotel in Udiapur, where I was told my body was creating too much 'pitta' (heat) from the food and climate, my health was pretty good.



Streetlife: local musicians have a blast

Breaking out of the glass cage

I fell slap bang in love with India – with the people and their devotion to ‘the Creator’, with the Hindu culture, noisy trains, colourful markets, and delicately spiced food – not to mention all that sunshine. One month on and not only is my health still a couple of notches up but my confidence has also soared. Now I know that with careful planning I can manage such a major trip, the world is my oyster and not my jailor.

Dr Clare Fleming once likened M.E. to being trapped in a glass cage and, for the first time in 15 years, I broke through the confines of that cage and expanded in mind, body and spirit. As for the astrologer, my yoga teacher has pointed out that he could be referring to my spiritual health rather than just my physical state.

Was it worth the angst and aggro of organising the trip around M.E.? Yes, yes and yes! I can't wait to go back.



Passage through India: travelling the old-fashioned way

My tips for travelling

Plan your trip and flight times carefully, factoring in lots of rest breaks and avoiding extreme temperatures

Take high-protein snacks for energy with you and drink lots of water during the flight

Request assisted transport at airports as soon as you check in (or better still, in advance). Be assertive about the effects of your disability and ask if you can book a front row seat for more leg-room

Discuss vaccinations or anti-malaria treatments (including herbal alternatives like artemesia) carefully with your GP or travel adviser, or for further information, visit www.masta.org. Biocare can advise on their products – for contact details, see page 26.

I chose to travel during the non-malaria season but you need to consider the risk of life-threatening diseases compared to the toll injections and medicine may have on your M.E. For more information, see ‘Dear Doctor’ in *InterAction* 42 about the pros and cons of vaccinations – (photocopies free from the Wells office on request)

Take an eye mask and earplugs to help block out light and noise when you need to rest e.g. from www.shop.store.yahoo.com/earplugstore/

If sleep is a problem, ask your doctor for sleeping tablets to help you survive longer flights or adapt to a new time zone without getting overtired. The sleep hormone melatonin can help deal with jet lag and is available from the USA via www.immunesupport.com

Avoid ice and water unless bottled. Check that the seal is opened in front of you

Visit www.flying-with-disability.org for more useful travel tips including advice on travel insurers for people with health problems

And finally – pace, pace, pace. It's tempting when sightseeing to think that you can do a bit extra or walk a bit further – but of course, you risk a relapse. I insisted that sightseeing tours were split over two days and that I always had at least a day's rest after travelling

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