

## Destination Barcelona ... or Not

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The 12th International Conference on Home Mechanical Ventilation, sponsored Journées Internationales de Ventilation à Domicile (JIVD), was held in Barcelona on March 27 and 28, 2009. I was excited to present my poster among the 96 accepted at the meeting.

In 1991, I sustained a complete C3-4 lesion with paralysis and loss of sensation below my neck and today use a trach. The previous HMV conference I attended in 2005 had opened up a wide range of contacts with people in other countries who face similar challenges in independent living.

Planning a visit to Spain presented something of a challenge. Our initial enquiries about rail transport were with Rail Europe, which had a problem understanding my basic requirements.

They were unaware that the overnight direct rail connection between Paris

and Barcelona does not accommodate wheelchair passengers who are unable to leave their chairs. An alternative route via Montpellier is similarly unavailable to wheelchair users. However, the JIVD Secretariat offered to arrange vehicle transfer from Perpignan, France, to Barcelona.

Two of my carers and the poster had gone ahead and arrived safely in Barcelona three days earlier. My own journey with two carers began well and uneventfully. We left Stirling at 10:30, reaching London at 15:58. The onward arrangements were to collect our Eurostar tickets at St. Pancras (successful) and the Rail Europe tickets, which were to be left for collection at the Eurostar office. They had not been left.

The person who had dealt with these plans had gone off duty, but another person assured us that these arrangements were NEVER made. Since we had the reference numbers for our journey from Lille and had arranged to stay overnight there, we concentrated on enjoying Eurostar and the 50% reduction on first class travel for wheelchair users.

Once in Lille, we found that our Eurostar-booked apartment/hotel, which we understood was about a three-minute walk from the station, was three stops away on the Metro. No taxis would transport me and my wheelchair! The travel information centre at Lille Europe did everything that was possible to help, and even gave us a coloured print-out of the



Liz at home with attendant.

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area, identifying the 20-minute walk between the Metro exit for our hotel. While these details were being clarified, we joined the queue to find our tickets.

It proved impossible for SNCF, the French National Railway Service, to confirm these reservations and therefore to give us tickets. The reference numbers provided by Rail Europe did not correlate with SNCF data, nor did a search using our names.

Our train departure to Perpignon was for 11:57 the next day, and there were no wheelchair spaces available to us. We chose the only option that seemed available: a wheelchair space on the train to Perpignon departing at 08:47, for which we purchased tickets.

As we left the Metro to walk to our accommodation, we got trapped in the closing doors. It was then after 23:00. The concierge had departed and entry was by telephone instructions. After giving your name, a series of numbers (in French) were provided. These were pinged into a keyboard to open the door. Once inside there was another system to open a box in which were keys to the rooms.

There was no way we could get to the station to catch the early train to Perpignon the following morning. We appreciated the efforts of two ambulance drivers to attempt to lift me and my chair into their vehicle, but they found it impossible. We set off again on foot to the Metro to hopefully find our lost tickets at the Rail Europe office.

Once back at Lille Europe, we presented the correct reference for our reservations from Rail Europe. SNCF confirmed that these were still incorrect, and we bravely watched the Perpignon train depart without us. We ate in the Irish Pub at the station, explained to the Secretariat that we would not be able to join them, and purchased Eurostar tickets for our return to Scotland.

It was very disappointing not to meet other delegates and discuss my poster.

The important aspects of life for me include freedom of choice, being able to enjoy my life as much as possible for as long as possible, and minimizing avoidable complications.

I have plans to visit my sister in Holland soon, using ScotRail, which has experience of my wheelchair travels. They provide me a corner to share with the bicycle space, and it comfortably accommodates me, my wheelchair and two companions.

By using only overseas rail travel carriers that accept wheelchair users, I am confident in extending my journeys. ▲



Liz uses the BREAS PV 501 at night and has a Laerdal resuscitator attached to her chair with her portable suction device and bag of back-up bits.