

For people with Pompe, travelling is a wonderful thing to do but planning can make all the difference for a successful trip.

Planning to travel:

Where to stay:

- Research the accommodation you wish to book, to make sure your needs can be met.
- Confirm whether ground floor accommodation, ramped access, a wet room, grab rails, shower chair, profiling bed, hoist, disabled parking, and charging points for wheelchair, scooter or medical equipment are available if you need them.

If you have questions, speak directly with the provider so there are no unpleasant surprises when you arrive. Ask for photos for clarification e.g. to make sure your wheelchair can fit underneath the sink, and that there's enough room at the side of the bed for you to transfer from your wheelchair.

Using transport:

If travelling by train in the UK, Passenger Assist is a service available to people living with Pompe. Just contact the train company you're starting your journey with, and they will arrange assistance to support you getting on and off trains and with connections. www.nationalrail.co.uk/



To find out if there are accessible vehicles when you're travelling, contact the taxi licensing office at the local council - they must keep a list of wheelchair accessible vehicles in their area. Drivers and operators have to help you to use their service. This could include help with:

- getting in and out of the vehicle
- finding the vehicle
- putting a mobility aid in the boot.

www.gov.uk/transport-disabled/taxis-and-minicabs

Travel insurance:

- It's a good idea to take out travel insurance for each person in your party at the time of booking your holiday. If you have a medical condition(s) you will need to go through medical screening. This will ensure that if something happens between booking and going on your holiday, and you subsequently need to cancel, you are covered.
- Remember that ALL medical conditions must be declared. Failure to do so, could result in hefty medical bills and it could also invalidate your policy.
- Shop around. It's worth getting 3 quotes.



Medical Equipment:

- Label all your medical equipment. This will have to be unpacked if going through security. Many people travel with ventilators, and you need to easily identify yours.
- Get a letter from your consultant explaining that you need to carry your medical equipment as hand luggage, even if you don't need to use when airborne.
- Make sure you pack adapters where needed abroad.

"People with Pompe, think outside of the box. The whole flying experience can be very stressful. Do remember there are other types of holidays, including cruises and driving. Ask questions and know your rights it's worth it overall!"

TOP TIP: Make a list of everything you need to take and plan every detail, check for travel delays and cancellations in case this affects assistance.

Assistance at the airport:

- Make yourself known to the Airport Assistance Team.
- Explain exactly what you need to enable you to get around the airport, and on / off the aircraft safely.
- You can get fast tracked through security.
- People with disabilities should board first and disembark last.

Blue Badge:

- People living with Pompe should take your **Blue Badge** with you if you will be hiring a car.

Medication:

- If you are flying, divide your medication into two bags, so should one get mislaid, you still have some medication.
- If you're thinking of travelling for an extended period and receive enzyme replacement therapy, you need to plan well in advance. Talk to your clinical team about what arrangements could be made to prevent interruptions in treatment.

I arrange a holiday around my infusions and there can be some leeway...My hospital team liaise with Homecare to provide an adjusted schedule of treatment in the lead up to and on my return.

TOP TIP: Make a list of all questions you want to ask your hotel or BnB. Get measurements for beds and turning circles. Give yourself plenty of time to do this and share with others if you rate the accommodation.

