

# Pre-departure counselling and an email contact service for patients with epilepsy faring abroad for long periods of time

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The fate and management of 50 patients with epilepsy is described whilst they undertook varied gap year experiences in various countries. Despite initial apprehension on my part almost all had no change in their epilepsy (or had actual improvement) and it turned out to be a positive experience for all. With the ready availability of email it is suggested that the home clinic keeps in touch with gap year students whilst they are away and provides them with basic information and an assessment before they go, information which they can then take with them.

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## INTRODUCTION

In the United Kingdom more young people than ever take extended leave in a country, or countries, different from their usual domicile (the gap year). Some travel widely; others take temporary jobs in one country in order to extend their stay in it to be able to know it better. In years gone by, only the rich unemployed did this, usually men: some of our greatest literature derives in part from this practice of a year or more spent, from at least the 17th century, “finishing” in Italy or France despite famine, pestilence and war. But now rich and poor, young (and sometimes not so young) people of both sexes do this and journey much farther afield to opposite ends of the world or journey through the third world before settling down to mundane life at home. Most do it just before or just after university, or other training; but some do it much later in life when “the gap year” can bring their skills and experience to a needy world. But what if the “gap traveller” has epilepsy? Does this bring problems, injury and other disasters? Should we encourage young people with epilepsy to undertake a gap year, with all the difficulties they may encounter in foreign lands?

About 8 years ago I realised, with the spread of email throughout the world, that it would be possible

to keep in touch with people with epilepsy from our clinic as they journeyed about the world and began to offer them our email address with the adage “keep in touch”. Most did and from their experiences has gradually developed the service we now offer to our patients going abroad on gap experiences today. I perhaps naively assumed that all epilepsy clinics did this, but discovered, on talking to workers in other clinics, that this was not so and that our “email clinic” is unique. Since the early days, of course, all patients are now given our email address and an increasing number use it, as do general practitioners and others: but this is a brief account of email correspondence with our patients abroad.

## THE USERS

Fifty people have used the service whilst abroad in the last 8 years, the youngest 17 and the oldest 58 (mean age 22) (Tables 1 and 2). Their epilepsy is shown in Table 1. Seventeen were male and 33 female (this does not reflect the actual numbers or sex or age ratio of all those going abroad during this time but merely those that chose to use the service at least once: women may be more cautious (or more polite) than men; men may

Table 1: Patients and seizure frequency (prior to travel).

Type	Frequency			
	Nil	1–2 years <sup>a</sup>	Monthly	More than monthly
Simple partial	0	0	0	1
Complex partial	9	3	3	0
Tonic-clonic	20	2	1	0
Absence	2	0	1	0
Myoclonic <sup>a</sup>	0	0	3	5

<sup>a</sup> All these had juvenile myoclonic epilepsy but were free of tonic-clonic seizures.

Table 2: Where did they go?

Spain	2 <sup>a</sup>
France	3 <sup>a</sup>
Italy	1 <sup>a</sup>
Germany	1 <sup>a</sup>
Australia	20
New Zealand	1
America (North)	3
Travelled to several countries <sup>b</sup>	19

<sup>a</sup> Year abroad as part of university course.

<sup>b</sup> All took antimalarials for at least part of the journey: 16 took doxycycline prescribed by us.

chose to be more independent and cut more ties with the homeland than women).

Initially, we just gave some advice about malarial prophylaxis to those going to relevant areas plus the email address to all: but latterly, as we have gained experience, we have extended the service to include (for those that want it) an up to date pre-departure physical and epilepsy assessment plus advice about malaria and other diseases, depending on where the person is going, and a letter, which the patient carries with him/her, detailing his or her history, diagnosis and investigations. This has the advantage of making sure that the patient is also familiar with his or her medical history and investigations if medical help is needed. The letter can also be faxed or emailed to relevant authorities if the patient loses it.

## MEDICATION

Different countries may not always have the medication that the patient uses or, even if they do, it may not be the same preparation: also, patients may find that medication that is free here is not so abroad. So usually between ourselves and the patient's general practitioner, we ensure that enough is taken to cover the entire trip (or parents or friends send an amount, whilst the patient is abroad, to a secure address from which it can be collected). This does of course, depend on the country or countries to which the patient is going. Instructions are given about splitting supplies so that the patient is never without medication but also

Table 3: Medication being taken on departure.

Monotherapy	38	<sup>a</sup> Lamotrigine 17, valproate 12 Carbamazepine 6, levetiracetam 3
Polytherapy	11	Lamotrigine and valproate 4, carbamazepine and lamotrigine 2 Levetiracetam and lamotrigine 3, valproate and levetiracetam 2
None	1 <sup>b</sup>	

<sup>a</sup> Lamotrigine is our drug of first choice.

<sup>b</sup> This patient used an effective behavioural method for controlling her seizures and chose not to take medication.

always has some in reserve in case a personal supply is lost for any reason.

If it is judged (a joint decision between patient and doctor) that seizures are likely, then a small supply of clobazam 10 mg is taken for emergency use: for patients going to remote areas or who are more likely to have seizures and who will have a companion with them a small supply of rectal diazepam is given and the companion instructed in its use. Eight supplies of clobazam have been taken of which four have been used: nine supplies of rectal diazepam have been taken of which one has been used once (appropriately).

Table 3 shows the medication that the patients were taking. Patients going on long flights across several time zones were advised to take clobazam 10 mg on the flight to ensure some sleep and 10 mg the first evening after arrival: but most patients going to the Pacific or the other side of America took short flights with intermediate stops and extended the journey.

## ALCOHOL

All patients were given some information about safe drinking levels (alcohol was not prohibited) and the potential interaction between unwise amounts of alcohol and anticonvulsants was emphasised. No alcohol-related seizures were reported.

## SEX

A few patients travelled in the company of pre-existing sexual partners (not all were together at the end of the trip) and some were taking oral contraceptives or their partners were. All were advised to be cautious about new sexual experiences abroad particularly in AIDS prevalent areas, and to use reliable condoms with new partners even if taking the pill: those women taking carbamazepine were warned of the interaction between the pill and carbamazepine. As a result of the experience of the first 50 patients, women in future will be instructed in and supplied with post-coital contraception, as, although no pregnancies or infections occurred, pregnancy risks were sometimes run.

Table 4: Breakdown of incoming email content.

“Descriptive”	180 <sup>a</sup>
Reporting seizures	9
Reporting other medical events	1
Requesting medical advice	4
Requesting additional medication	3

<sup>a</sup> Including five patients reporting that they had broken the only medical prohibition I gave them to avoid scuba diving.

## MALARIA

All patients going to malarial areas were given appropriate antimalarial medication (we use 100 mg doxycycline: those taking carbamazepine took 100 mg twice daily) and instruction about avoiding mosquito bites, appropriate clothing, mosquito nets, etc. Three patients changed their travel plans after departure and went to malarial areas unexpectedly: one had two seizures almost certainly caused by an unthinking local prescription of chloroquine.

## HEALTH ADVICE

Standard advice was given about using clean water (with sterilising tablets in unsafe areas), eating cooked food, etc. No problems of diarrhoea (which might have had consequences for anticonvulsant medication) were reported even by those that travelled off the beaten track.

## EMAILS

One hundred and ninety-seven emails were received over an 8-year period from the 50 patients (Table 4). Almost all were descriptive of what the sender was doing or had experienced: comparatively few were related to medical questions or problems. I realised after a while that we had probably been put on the mailing list of the sender and were one of several regular receivers of information. Since parents often were not, I assumed this meant that we could be trusted with uncensored information and felt flattered. Some patients hardly used the service at all: almost all used the message service much more in the first few months of being away and it was often hard to tell when they were back. Eleven contacts were made to my email address by foreign medical authorities asking for further medical details or advice about the future management of the patient—all were answered.

Table 5: Seizure changes whilst away.

Frequency unchanged <sup>a</sup>	32
Frequency improved	15
Frequency increased <sup>b</sup>	3

<sup>a</sup> Including those already seizure free.

<sup>b</sup> One due to an inappropriate antimalarial, one to relationship stress and one to local valproate medication (relieved by “English” valproate being substituted).

## SEIZURES—DID THEY GET WORSE?

No, they did not. Apart from three patients (Table 5) all patients retained the same seizure frequency, or it improved. Seizure increase usually had an identifiable cause and did not last. It may be of course, that patients neglected, their minds elsewhere, to report seizures (and parents were no longer reporting them) but the lack of seizure activity is encouraging.

## DISCUSSION AND CONCLUSION

All these 50 patients returned “having had a good time” with broadened horizons and knowledge. None regretted the experience, even the bad times, and all reported improved morale, self-knowledge and perspective as a result of going. Those that had reported an improved seizure freedom whilst abroad continued this good state on return to England. We conclude that, with support, people with epilepsy need not fear a gap year experience and should be encouraged to take one if they want to. Careful clinic review before they go, advice about hygiene and health and a contact email are a valuable part of helping them whilst abroad (and helping foreign medical advisers). It is useful if they are usually supplied with necessary medicine from this country and if they have personal responsibility for a summary of their condition and treatment. With the ready use of email everywhere perhaps more effort should be made to keep in touch with patients when they go abroad.

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