



Moving to London & the UK with Type 1 Diabetes

— A Quick Guide for Australians



At any one time, the United Kingdom has half a million Aussies calling it home, and a half of those are in the fine old town of London.

Reality Check's Founder, Kate Gilbert spent almost two years living and working in London in 2004-06, part of it working for London's largest public hospitals. She shares what she learnt about how to negotiate the health system and getting onto the stuff you need when Type 1 diabetes has to come along on your travels.

A quick overview

- **Everything's free:** insulin (inc. Lantus and Levemir), blood test strips, doctors' appointments, everything.
- **The GP is the most important person in the UK health system.** Everything starts with him or her (and the costs of everything you need are charged back to them as well!).
- **Take several months' supply of everything (insulin, strips, etc.) over with you.** It might take a while to get set up on the system and you'll have better things to do with your first exciting months overseas than sit in

GP waiting rooms! You also need to have at least a semi-permanent address before you can get in on the UK system.

How to get into and use the system

1. Find somewhere to live.
2. Register with a GP.

As soon as you have an address – you normally don't need to provide any documentation of it – use this excellent website to find a list of your local GPs:

www.nhs.uk/England/Doctors/NearestSearch.aspx

NHS Direct (www.nhsdirect.nhs.uk) can also help you with a list of local GPs if you don't have easy internet access - call them on **0845 4647**.



Ring around the GPs and make an "appointment to register". They may tell you they are all full up. This doesn't just mean they have a lot of appointments full, it means they are not taking on any new patients at the moment. Just keep phoning down the list.

The weird bit: You have to live within the 'catchment' area of the GP clinic, so when you call they'll ask for your address. And once registered you are now attached to this GP. Yes, you have to be in the suburb where you live to see a doctor, even just to get a prescription. So it's also best to wait until you are living somewhere you plan to live for a while (unless it's an emergency or a family planning/contraception issue – see 'Special Situations').

At this registration appointment you will probably see the 'practice nurse', not a doctor at all. The nurse will take all your details and plug in everything to a computer. You are now registered on the system. A few months later you will get an NHS card in the mail (but this is not needed for

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anything except taking up space in your wallet!).

If you actually need to see a doctor or get some prescriptions for supplies, make this very clear to the nurse when you go in for your registration appointment. I managed to convince the nurse that I was desperate for insulin, so she printed out a script and reluctantly ducked in to get the GP to get it sign it for me. More likely, you'll need to make another appointment at a later date to come back and see the GP for supplies or whatever you need.

3. Get prescriptions from your GP for ALL your supplies

There is no equivalent of the NDSS (National Diabetes Services Scheme) that Australians are used to for ordering non-pharmaceutical diabetes supplies.

To get hold of blood test strips, ketone/urine strips and needles as well as insulin and everything, you need to get a prescription from your GP and take it to your local chemist.

4. Getting supplies from your chemist

This was my favourite part of the system ... when I dropped off my script for insulin or strips, the chemist used to ask, "Do you pay for your scripts?" I say no. And I don't pay. Voila!

It's actually not a rort at all: as people with a chronic illness we have what is called a "medical exemption" from paying anything.

In theory A) You have to fill in a special form to say you have diabetes, and your GP signs it too. A few weeks later you receive a card that proves you are entitled to free NHS prescriptions. It is not the usual NHS registration card but one specific to the medical exemption, and you can (in theory) be asked to pay an NHS charge if you cannot show the card. **B)** If the chemist is particularly thorough, they may ask you to tick the medical exemption box on the green form/prescription and/or present your card.

Note that this exemption from paying any fee will apply to any and

all medications you are prescribed, diabetes-related or not.

So, just keep saying no and ticking that medical exemption box!

5. Getting repeat prescriptions

The quantities of prescriptions for everything: insulin, testing strips, etc will be much smaller than you are used to. For example, one bottle of 50 strips at a time is very common. Have a red hot go at convincing your GP when you are asking for the prescription that you need more, but don't hold your breath. And unlike in Oz, every time you get a prescription filled, even if it's a repeat, it needs to go back to the GP to be signed off. Nightmare!

But wait, there's help out there! Many pharmacies have a 'Prescription Collection Service' where they will do all the paperwork and ferrying back and forth to the GP for you. You'll need to find a pharmacy which lists your GP as one that they work with on this, and that's convenient for you, and register for the Service there.

Once registered, you can drop in or phone them to say you need more insulin or strips or whatever and they'll tell you when they can get the paperwork done and the stuff in for you – normally 2-3 days. I used to use a pharmacy in my Tube station that was open late and on weekends so was nice and convenient to be dropping in regularly. (They were sad to see me go home!!)

Note: The pharmacy may try to sell you some membership/loyalty scheme to go with this service but you don't have to buy or pay or sign up for anything to use it.

6. Seeing an endo/diabetes specialist

In the UK specialists are called 'consultants'. If you are planning to stay a while and want to see an endocrinologist, ask your GP to write you a referral to a diabetes consultant. It will be at a hospital near to where you live, and may take a few months to get an appointment.

There are a few websites that list specialists and specialist clinics and give an interesting range of details about their expertise, training and waiting lists.

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Try Dr Foster's Find a Consultant (www.drfooster.co.uk/localServices/consGuide.asp) or Specialist Info (www.specialistinfo.com/directory.php).

7. Complications screening

If you don't want to go through the rigmarole of getting into the public hospital system or the wait is too long, and maybe like me you have an email/phone for your endo at home for any questions anyway, another option is to use your GP to get your complications screening done. This is all pretty similar to how the public health system works in Australia.

Eyes – Ask them to refer you to the local diabetes and eye clinics – there is a national service called DECS (Diabetes Eye Complication Screening) with strict targets and protocols, so as soon as you are referred in to one of these clinics the care is likely to be very good – and very similar to what we are used to in Oz.

HbA1c, Cholesterol, Microalbuminuria (kidneys) and other blood and urine tests – Your GP can write you a script for a blood test or urine collection. You will then need to take it to a public hospital near where you live – the GP will tell you which one, you often have a choice but like everything it will be near your home or registered address. Have the test then phone the GP to get the result. They may want you to come in to get the result, but you might have some luck if you persist a bit and ask to speak with the practice nurse and say you are happy to get the result over the phone.

Blood pressure, neuropathy testing, peripheral pulses check – Your GP can do all of these check ups and should even have a recall system to call you in to do these, and make sure you have had eyes and blood tests described above, done once a year. At the end of the day it's your health, so you may need to prompt them and be proactive about getting it all done.

Common problems & a little hard-won wisdom

Can't find a GP who's not full? Phone your local Primary Care Trust – Use this website: www.nhs.uk/England/AuthoritiesTrusts/Pct/ and ask them to tell you which GPs in the area are not full. They have to find you a space somewhere (even if you're Australian). Some have a specific service to help with this (e.g. Tower Hamlets PCT's Find-A-Doc service at <http://www.thpct.nhs.uk/index.aspx?pid=93>) but all will be able to help you in some way.

Can't get enough strips? If your GP refuses to prescribe more than 50 strips at a time and this is causing you problems (eg you're going travelling and need more to keep you going), the best bet might be stockpiling – just getting your script filled using the Boots Prescription Collection Service described above a few times a week before you go! Another option is to contact your local PCT (<http://www.nhs.uk/England/AuthoritiesTrusts/Pct/>) and get them on the case – ask to speak to the diabetes nurse or the diabetes team. Or as suggested at the beginning, bring heaps over with you from home.

Ended up with a useless GP? You have three options:

- **Complain** – write to your PCT (see above) if you are seriously unhappy with the care you receive. They generally have very efficient and through complaints procedures and will be happy to hear from you.
- **Find a new one** - Pretty time consuming to go through the whole registration process again but you do have the right to change GPs if you want.
- **Get over it and get on with it** – It can be quite a shock to be an anonymous pawn in the system if you have got yourself a great network and D team back home. If you're only going to be in UK for a couple of years it might be just worth not stressing too much about having a fabulous GP, but just taking the lead on your care yourself, getting what you need from the GP and getting out of there.

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Special situations

Emergencies.

Break a leg? Run out of insulin?

Head to your nearest big public hospital with an Accident & Emergency (A&E) department. In emergencies, you can go to any A&E – you do NOT have to be in the same area as your home.

The emergency phone number in the UK is 999.

There are several different "no appointment necessary" services to deal with a range of minor emergencies. The services include walk-in clinics and phone support and are detailed on the NHS website at this link:

www.nhs.uk/England/NoAppointmentNeeded/Default.cmsx

Family planning and Contraception.

The Family Planning Association auspice walk-in clinics, mainly in community health centres, around London and the rest of the UK. This is an excellent service, completely separate from the NHS and your GP. That means you can go to any service, any time, anywhere, unlike NHS/GP where you must be in the area where you live and registered/referred. You can get help with ordinary contraception (including free condoms and the Pill), emergency contraception, sexual health treatment and advice, and all that sort of stuff. The clinics are free.

Visit www.fpa.org.uk or call **020 7608 5240** to find your nearest clinic and times.

Insulin Pumps. Pumps aren't as common in the UK as they are in Australia. You have Buckley's chance of actually getting a pump (though being pregnant, or telling your doctor that you are about to get pregnant has been known to expedite the process – sorry, guys).

NHS supplying: If you already have your pump you may, with a lot of time and effort, be able to get the

NHS to supply your infusion sets etc. Like everything, the costs have to be covered by your local area health service, called a Primary Care Trust (PCT). Your GP won't know anything about it so the first step is to see a consultant (endo) at your local hospital. It will also be well worth your while calling your local PCT and asking to speak with the Diabetes Nurse Educator on staff. If they don't have one, then your chances aren't looking great from the outset. If they do, then she or he will be able to tell you whether they have ever funded insulin pumps before and how to go about it.

Once/if you are approved, you will need to either contact your hospital or in some cases contact the pump company direct to order supplies, but your PCT will pay for them.

Take it with you: Personally, I brought all my stuff over and then had a friend bring me another suitcase full to keep me going. It was going to take more time than I had to get everything worked out with the NHS. This is a pretty common option for many Aussie pumpers in London.

Pump-specialist Endos: If you get really stuck, it might be helpful to know that the largest insulin pump service in the UK (approx 100 pumpers) is at Guy's Hospital (see www.gstf.nhs.uk, near London Bridge station), under the lead of Professor John Pickup and a pump nurse. You can phone them on **020 7188 7188**. You'll need your GP to write you a referral letter to see Professor Pickup – which they may not do as strictly they should only refer to consultants within their local area. Another option is in Kings College Hospital. Professor Amiel has been prescribing pumps for many years and has a team familiar with them. But I understand Prof Amiel has a very long waiting list.

Buy direct: Another option is to self-fund. You can buy supplies direct from the pump companies but they request a letter from your doctor to 'prescribe' it. Will likely cost £70-100 a month.

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Pump support and advocacy groups:

INPUT is a group helping people in the UK get funding for their insulin pumps. They have a website: www.webshowcase.net/input/ or you can contact John Davis on phone:

01590 677911 or email: input@care4free.net.

You can also get in touch with **Insulin Pumpers UK** for advice: <http://www.insulin-pumpers.org.uk/>

Lantus and Levemir are both covered by the NHS just like any other insulin.

Children. Sorry, not my bag but if you have a child with diabetes or are under 18, I hope this sheet has been helpful as an overview of how the system works – and to the best of my knowledge, and a tiny bit of working with the paediatric diabetes specialist at our hospital it is all very similar but please do some further investigation.

Places to start: www.diabetes.org.uk, www.jdrf.org.uk, www.nhs.uk.

Helpful stuff to understand

- **NHS** – National Health Service is the enormous government-funded organisation which runs healthcare throughout the UK. Private care and private health insurance are growing in popularity but are still a VERY small part of the system. The Brits are very proud of, and committed to, having a health system based on need not the ability to pay.

- **Consultants** – the term they use for all specialist doctors including endocrinologists. So when they offer to refer you to a consultant, you're not getting some fancy business management advice, just an endo!

- **'Trust' is a word you'll hear a lot** - they are organisations created by the NHS. 'Primary Care Trusts' cover a suburb or two and manage all the GP surgeries, and things like maternal and child health centres, community centres, quit smoking

programs; 'Hospital Trusts' might just be one hospital, but are often one organisation that manages a couple of hospitals in a local area.

- **Primary Care Trust (PCT)** – Organisations within each local government area that manage local health services – they oversee all the local GPs and are a good port of call if you have any number of difficulties. Some even have diabetes nurses on staff who do things like work to train up the practice nurses in all things diabetes, make sure the GPs have recall systems for complications screening etc.

- **NHS Direct.** A web and 24-hour phone service staffed by nurses to provide basic health advice. Visit www.nhsdirect.nhs.uk or phone **0845 4647**. Can also tell you where any number of different local health services are from GPs to A&Es.

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And to Dan Dunkley for the lovely photo - the view from our office window.