

What should I do when I am unwell? (continued...)

When you are receiving treatment for vasculitis, you are at risk of picking up infections that may cause you to become very unwell, very quickly. If you think you may be seriously unwell out-of-hours (i.e. in the evening, overnight or at the weekend) then it is usually safest to attend A&E. Remember to tell the doctors there that you are receiving treatment for vasculitis.

For non-urgent problems, you may choose to contact your GP (usually the first port-of-call) or our vasculitis clinic directly.

Vasculitis is often a life-long condition and therefore it is always very helpful to establish a good rapport with your GP as they will be involved with your care over many years. That said, the treatment of vasculitis is highly specialised and your GP will often wish to talk to us about your case. At times (e.g. if we are seeing you very frequently for regular intravenous treatments) it may be easier for you to contact us directly if you have any problems / questions.

If you do need to contact us at any time then please contact Dr. Kluth's and Dr. Dhaun's (Bean's) secretary (Lynne: 0131 2421240).

Vasculitis Patient Information Sheet **Edinburgh Vasculitis & Lupus Clinic**

This leaflet contains some general advice regarding vasculitis and related conditions. Our advice will vary from person to person; we will therefore tailor this to the details of your case.

Where can I find out more about vasculitis?

We recommend www.thelaurencurrietwilightfoundation.org. This website contains factsheets on vasculitis and its various treatments. Please ask if you would like us to provide any written copies. It also provides access to sources of patient support.

For you, the relevant factsheet is:

- microscopic polyangiitis*
- granulomatosis with polyangiitis*
- eosinophilic granulomatosis with polyangiitis*

We will provide written information about some of the treatments that you may receive (e.g. cyclophosphamide or rituximab).

What can I do to stay healthy?

Avoid potential sources of infection. Treatments for vasculitis are designed to suppress your immune system. This means that you will be at increased risk of picking up infections. It also means that any infection that you do pick up could progress rapidly. We advise avoiding potential sources of infection. This might include asking visitors to stay away if they are unwell, avoiding public transport during busy periods and avoiding swimming in public pools. The risks of picking up infections are usually highest during the first three to six months of treatment; we will let you know when this risk has returned to a lower level.

Stop smoking. Vasculitis (and its treatment) increases the risks of heart attacks, strokes and some cancers over many years. For this reason, we strongly advise against smoking. Stopping smoking can be very difficult and we suggest talking to your GP about this as they can usually provide help and support.

Avoid alcohol or drink only in moderation. This is particularly important when you are taking steroid tablets because alcohol can suppress the immune system and predispose to stomach problems. We advise abstaining from alcohol whilst on high doses of steroids. On low doses (10 mg prednisolone per day or less) it is usually safe to drink alcohol in moderation.

Diet and exercise. The Lauren Currie Twilight Foundation website has factsheets on eating healthily (see above).

Stay up to date with immunisations. Immunisations are given by your GP. We almost always advise receiving immunisations against *influenza* (flu) and *pneumococcus* (pneumonia). Live vaccines such as the Shingles vaccine may not be safe, depending on what treatments you are receiving for vasculitis. We can advise you and your GP about this.

What should I do when I am unwell?

If you are unwell with fever, diarrhoea or vomiting then you should stop taking any diuretics ('water tablets') and drugs in the 'ACE inhibitor' family. Examples of these types of drugs include: furosemide, bumetanide, bendroflumethiazide, ramipril, lisinopril, enalapril, candesartan, losartan, irbesartan. In your case these are:

These drugs are beneficial for the kidneys and heart in the long-term, but can cause short-term kidney problems if you are dehydrated. Please also contact your GP and / or us to let us know that you have stopped taking these and to seek further advice.