

Meningococcal infection: What you need to know

**A guide for patients
from the National aHUS Service**



You have been given this leaflet because you are on Eculizumab or Ravulizumab therapy. These drugs are usually very well tolerated, but we know that being on either of these medications increases a person's risk of getting meningococcal infection (meningitis and septicaemia). This can be a life-threatening illness.

This leaflet explains:

- Why you are at increased risk of meningococcal infection
- How you can reduce your risk of getting meningococcal infection

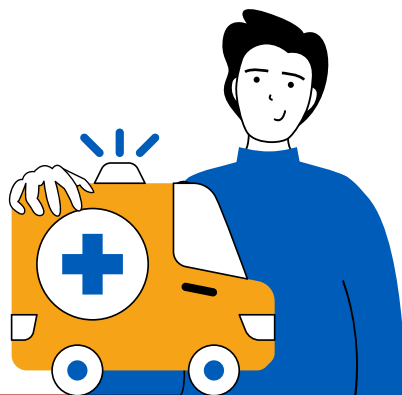
- The signs and symptoms of meningococcal infection
- What to do if you are concerned you might have meningococcal infection
- Where you can get more information

Risk of meningococcal infection as a potential side-effect of treatment

Eculizumab and Ravulizumab block your body's ability to recognise and destroy the bacteria which cause meningococcal infection, which means you are at increased risk of getting this. Meningococcal infection can be:

- Meningitis (inflammation of the lining of the brain and spinal column)
- Sepsis (infection in the blood)

These can be life-threatening illnesses and need treatment **immediately**.



How to reduce your risk

To reduce your risk of getting meningococcal meningitis and sepsis, when you start on eculizumab / ravulizumab treatment you will:

- receive vaccinations against the different types of meningococci bacteria strains
- be advised to take long-term oral antibiotics

You will need to keep taking antibiotics for as long as you are on treatment and for a period of time after stopping treatment.

TIP
Make sure you tell your friends and family that you are at increased risk of getting meningococcal infection so if you become unwell they can get urgent help for you

Emergency medical information

We have also included with this leaflet:


- A wristband for you to wear. This can alert other people that you are on eculizumab or ravulizumab and are at increased risk of getting meningococcal infection
- An "at risk" (of meningococcal infection) card. If you have symptoms of meningococcal infection you must attend the emergency department at your local hospital. Your "at risk" card should be shown to the staff assessing you.

TIP
Photograph both sides of your "at risk" card to keep on your phone to show healthcare professionals if you go to hospital



Signs and symptoms of meningococcal infection

You should also know what to look out for. Below are some of the symptoms of meningococcal meningitis and sepsis:

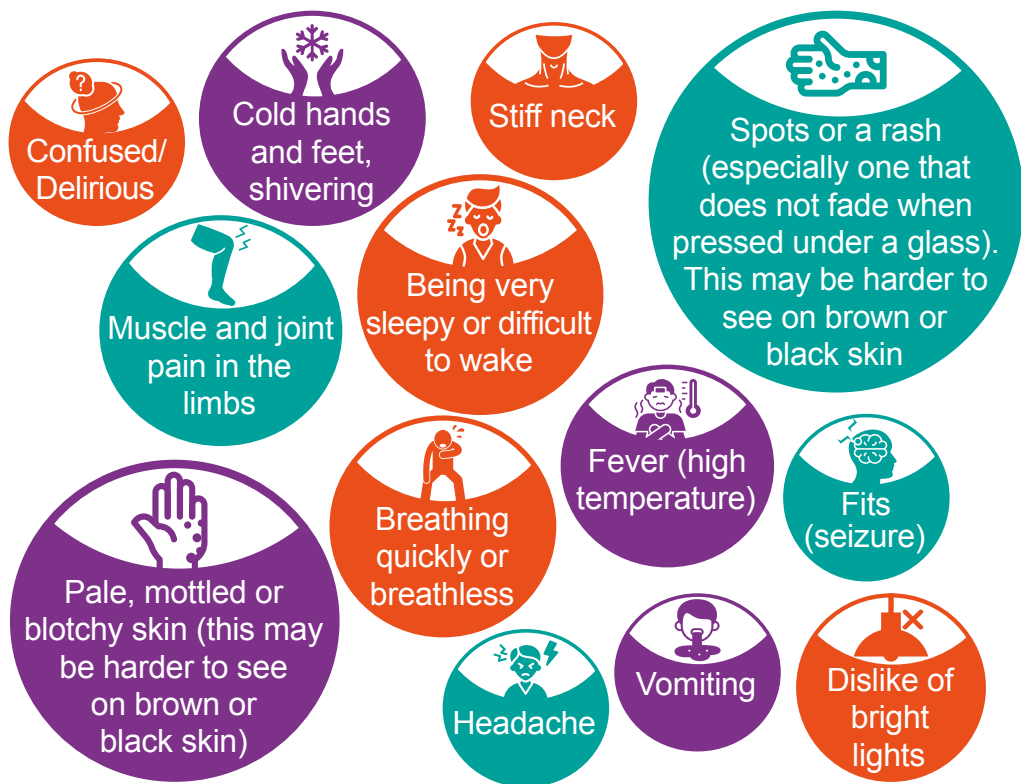
 Rash may not be present in all cases. If you are unwell, don't wait for a rash to appear. Get medical help immediately.

 Symptoms can appear in any order

 You might not get all the symptoms listed

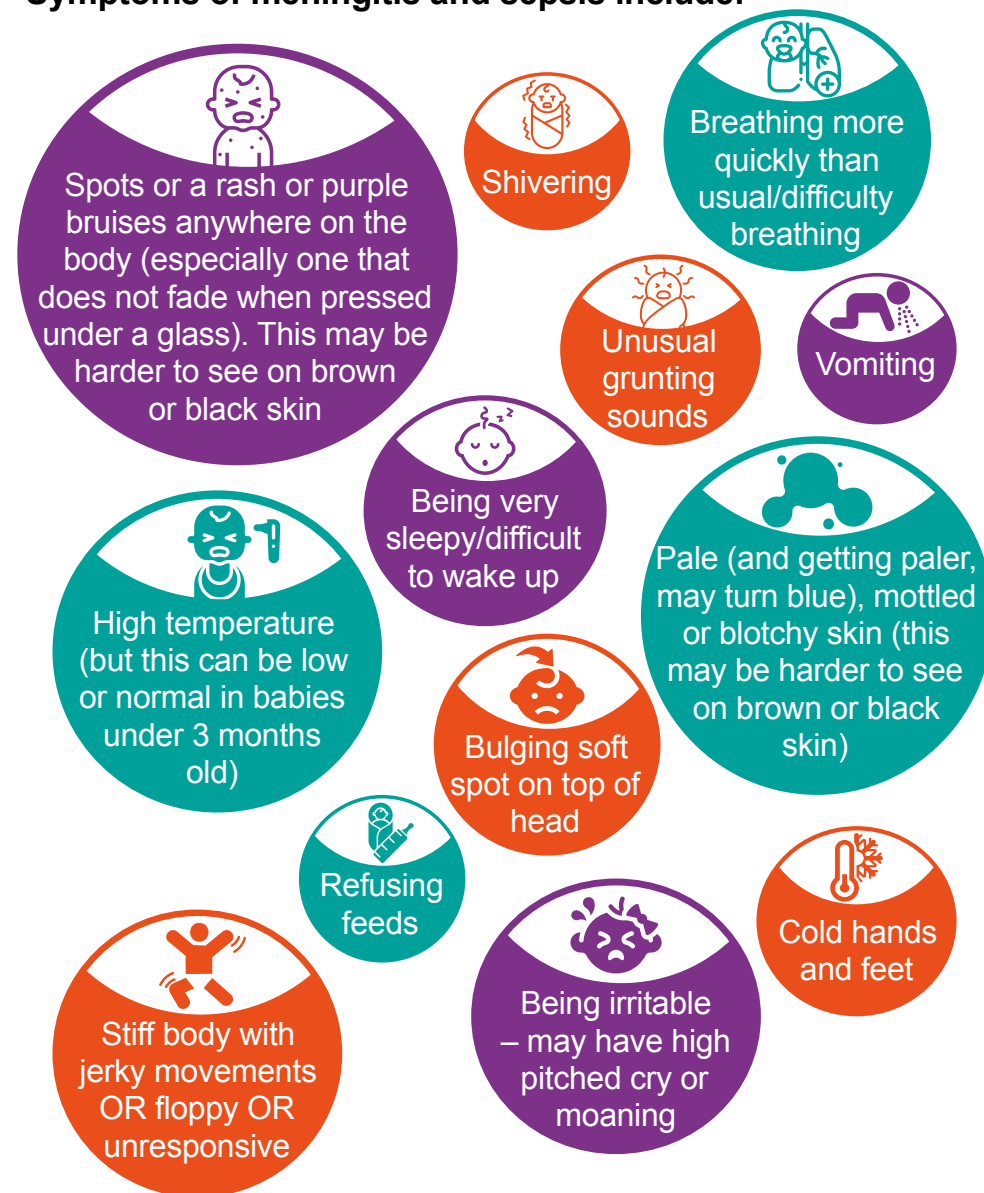
Children and adults

Symptoms of meningitis and sepsis include:



Babies

Symptoms of meningitis and sepsis include:



The tumbler (or glass) test

A rash can sometimes be a symptom of meningococcal infection. A useful test you can do at home is “the tumbler (or glass) test”.

If you / your child is ill and gets a new rash or spots, you can use this test.

- Look for tiny red / brown pin-prick marks (these may have changed into larger red or purple blotches).
- Press the side of the glass firmly against the rash .
- **If you can see the marks clearly through the glass, you should seek urgent medical help.** You should go to the hospital Emergency Department (sometimes called “Accident and Emergency”).
- Check the entire body.
- Be aware, the darker the skin the harder it is to see a meningococcal meningitis / sepsis rash on skin. You should check lighter areas like palms of hands and soles of feet or look inside the eyelids and the roof of the mouth.
- **Remember – a very ill person needs medical help even if there are only a few spots, a rash, or no rash at all.**



Meningococcal meningitis / sepsis rash on skin



Rash does not fade even when glass pressed firmly against skin

What to do if you have signs, symptoms, or are concerned you might have meningococcal infection

It is vital that you seek **urgent** medical help and assessment, because this illness can get worse very quickly.

You or your family member should tell the healthcare professional looking after you:

That you are on Eculizumab / Ravulizumab – so are at increased risk of getting meningococcal infection

You can also show them your wristband and “at risk of meningococcal infection” card

That you will need to be assessed quickly

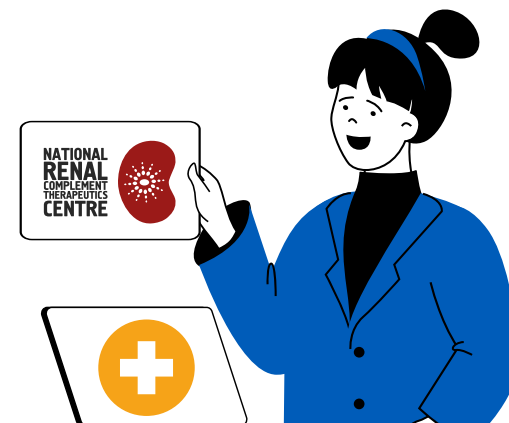
Further information

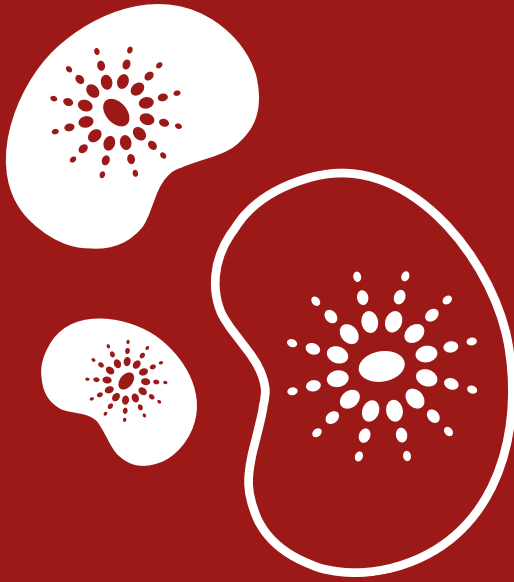
For further information about meningococcal infection you can look at the following websites:

<https://www.nhs.uk/conditions/meningitis/>

<https://www.meningitis.org/>

<https://www.meningitisnow.org/>





**National Renal Complement
Therapeutics Centre**

**Building 26,
Royal Victoria Infirmary,
Queen Victoria Road,
Newcastle upon Tyne
NE1 4LP**

Tel: 0191 28 20385

Our Website



www.atypicalhus.co.uk