

What is Paediatric Inflammatory Multisystem Syndrome (PIMS)? Information for young people

Paediatric Inflammatory Multisystem Syndrome (PIMS) is a new condition that happens weeks after someone has had the virus that causes coronavirus (COVID-19). It causes inflammation (swelling) throughout the body which is one way your immune system fights off infection, injury and disease. This information sheet from Great Ormond Street Hospital (GOSH) describes what we know about PIMS, how it was treated while you were at GOSH and what you need to think about now you're ready to go home.

Although most children and young people who develop COVID-19 have no symptoms or very mild ones at the time, we now know that a small number develop Paediatric Inflammatory Multisystem Syndrome (PIMS) a few weeks afterwards. These are mostly young people in adolescence, but children can get PIMS too. As PIMS is a new condition, we are learning about it all the time – you are helping us to understand more so we can diagnose and treat other children and young people better in the future.

What causes PIMS?

Even though it is a new condition, doctors have already worked out a lot about it – we know it is caused by your immune system which fights off the virus but then over-reacts to affect other parts of your body. We need to do more research to work out why some children and young people develop PIMS but others don't. As well as at GOSH, research is being carried out all over the world to find out more about PIMS.

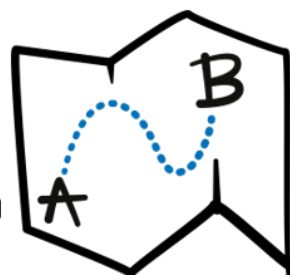
How is PIMS diagnosed?

You may already have had nose and throat swabs to confirm you had COVID-19 but PIMS seems to develop after the virus is infectious. The doctors need to rule out other more common conditions that cause similar symptoms – this includes things like Kawasaki Disease, Sepsis and Toxic Shock Syndrome.

Unfortunately, we don't have any specific blood tests to diagnose PIMS so the doctors look at the symptoms to work out if you have it. The doctors will use blood tests to look at the levels of inflammation in your body as well as checking how various parts of your body are working. Together, these results along with your symptoms let the doctors confirm you have PIMS so they can treat it.

What are the symptoms of PIMS?

The main symptom of PIMS is a high temperature that lasts for a few days.



You might also have other symptoms such as:

- A rash
- Tiredness and weakness
- Tummy pain or cramps
- Red and cracked lips
- Swollen hands and feet
- Peeling skin on your hands and feet
- Headache
- Red eyes
- Muscle aches and pains
- Diarrhoea and vomiting
- Swollen neck glands
- Unexplained irritability

If you think you have any other symptoms, that may or may not be linked to PIMS, tell your clinical team.

How is PIMS treated?

We are still learning how to treat PIMS in the best way possible – our aim is to ‘turn off’ your immune system to stop the inflammation and then to ‘reset’ it to reduce the risk of long-term damage.

PIMS is treated with a combination of medicines:

- **Intravenous immunoglobulin (IVIG)** – This is taken from blood donations, checked for infection and then given to you as an infusion (drip). IVIG contains lots of antibodies – the proteins in the blood that fight off infection.
- **Corticosteroids** – You have these as an infusion or by mouth as tablets or liquid. They are a man-made version of a hormone (chemical messenger) in your body that calms down your immune system. As corticosteroids damp down your immune system you might be more at risk of some infections, especially if you are having high doses. When you no longer need corticosteroids, you may need to gradually ‘wean’ or ‘taper’ them rather than stopping suddenly. This helps your body start to make its own steroids again.

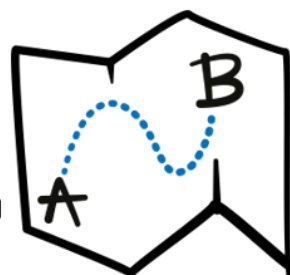
- **Anti-clotting medicines** (aspirin and dalteparin) – aspirin makes your blood less ‘sticky’ so it’s less likely to form clots. You will usually stop taking this after six weeks if the doctors are happy that your heart is working well. Dalteparin is given as an injection and makes your blood thinner. Typically, you only have this while you’re in hospital.
- **Stomach medicine** – Corticosteroids and aspirin can irritate your stomach, so you will probably have another medicine to take alongside them to protect your stomach lining.
- **Biologic medicines** – If IVIG and corticosteroids don’t work well on their own, you might have infusions of biologic medicines called ana-kin-ra and toci-li-zu-mab. These also ‘switch off’ your immune system.

As we are running several research trials at GOSH, you may have had other medicines to test new ways of treating PIMS.

Going home after PIMS

Now that you are getting better, we are planning for you to go home again. The clinical team will only do this when they are sure that you are improving and will stay in touch to keep an eye on you when you’re home. As PIMS affects all areas of the body, you might still have some symptoms when you go home, including:

- Trouble concentrating or ‘brain fog’
- Thinning hair or hair loss
- ‘Up and down’ emotions including angry outbursts
- Sleeping difficulties
- Rashes and skin peeling
- Changes to your hearing
- Tingling hands and feet
- Loss of smell and/or taste
- Swallowing difficulties or voice changes
- Diarrhoea (runny poo)
- Changes in appetite
- Muscle weakness and tiredness



- Tummy pain
- Problems with your heart, kidneys or breathing

PIMS can affect your mind as well as your body so be aware of your mood once you get back home. It's normal to feel anxious, moody and irritable. This is down to PIMS as well as the everyday disruption that COVID-19 has brought to everyone.

You may have noticed that you became weak and tired when you became unwell. The physiotherapy you then received enabled you to do the correct exercises so you could regain the strength and fitness of your muscles. You may have been sent home with exercises to complete in order to help your recovery. We know that exercise is vital for your health and so it is very important that you remain active and participate in sport and physical activities, such as daily walks.

Take your time to recover and don't try to do too much at the start – gradually build up how much you do and don't feel bad if you have 'bad' days as well as 'good' days. The key is to balance your activity – don't do so much on a 'good' day that you then have several 'bad' days to recover.

We will give you the opportunity to talk to our psychologists – they can listen to how you're feeling as well as helping you find ways to help yourself get better.

Frequently asked questions

Can I go back to school?

Yes, you can if you feel well enough – you're likely to feel pretty tired for a while after having PIMS so don't overdo it. You could talk to your teachers about gradually building up your time at school until you are completely recovered.

It's up to you how much and what you tell your friends and family about being ill. Sharing your experience can help so keep the lines of communication open!

What about seeing family and friends?

There is no need to 'shield' or stay isolated if you've had PIMS. Although you're not infectious, you should still follow Government guidance about meeting people outside your household. Have a look at www.gov.uk/coronavirus to check what you can do where you live – things might have changed while you've been in hospital.

You should follow Government guidance if you come into contact with someone who has (or may have) COVID-19.

What about contact with infectious diseases?

The medicines you had to treat PIMS damp down your immune system so you should avoid contact with anyone with chicken pox, measles and tuberculosis. If you think you have been in contact, call your clinical team at GOSH as we may need to make sure you've not picked up an infection.

I'm due a vaccination – should I have it?

It's important to keep up with your routine vaccinations when they're due. However, the medicines you had to treat PIMS can affect how well they work so talk to your doctor about when best to have them.

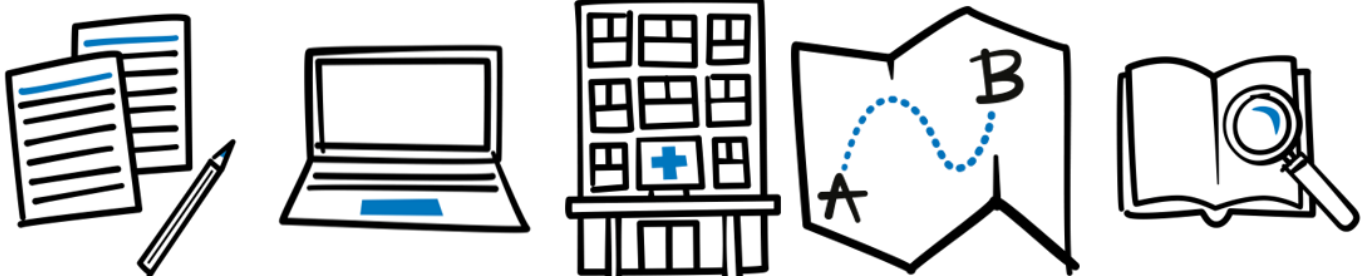
For example, if you had IVIG, we recommend waiting three to six months before vaccination. If you had a vaccination in the weeks before you had PIMS, you might need to have a booster if you've received IVIG.

We recommend you have the inactivated flu vaccine (injection rather than nasal spray) even if you have it within six months of having IVIG.

If you had anakinra or tocilizumab, you should wait at least six months to have any live vaccines.

Can I get PIMS again?

When you have an infectious illness like PIMS, your body makes 'antibodies' to it so you are protected from it. Although we know people who



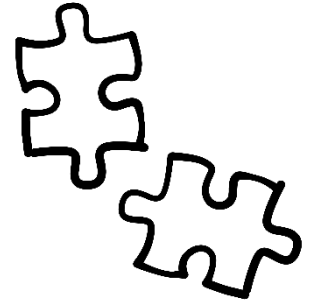
have had COVID-19 and PIMS make antibodies, we're not sure how long they last. We know it is extremely unlikely that you could get PIMS again.

However, if you show symptoms that might be COVID-19, you should self-isolate following national guidance. If you start to feel the same as you did when you had PIMS, ask your family to take you to your local hospital to be checked – remember to tell them that you have had PIMS. They can always contact your clinical team at GOSH for advice.

Research into PIMS

Learning about PIMS, improving the way we care for young people with PIMS, and sharing knowledge is a priority at GOSH. This goes hand-in-hand with research, and whenever possible we aim to include patients with PIMS in our research studies.



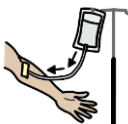


Thank you if you have already taken part in these research studies. If there are studies that you can take part in in the future, we will be in touch and invite you to join.



Further information and support

If you have any questions about PIMS, please contact the Clinical Nurse Specialists for Infectious Diseases on 07718 251 317. You can also contact the team through MyGOSH once you have registered. Further information about MyGOSH is at www.gosh.nhs.uk/your-hospital-visit/mygosh

All about PIMS

	PIMS is an illness that some children and young people get after they've had coronavirus.
	Your immune system works hard to fight off the virus – it can cause inflammation or soreness all over your body.
	You will have various medicines to damp down your immune system – this stops the inflammation.
	You can go home when you are getting better. The doctors and nurses will call you to see how you are feeling at home.
	You will probably feel tired and weak for a while afterwards. Don't try to do too much.

