Blood transfusions, reactions and blood matching: information for patients and parents

Why is this leaflet worth reading?

If you or your child has an inherited anaemia, transfusions may be part of life – occasionally, or regularly, or for years. Transfusion is one of the safest treatments in medicine, and in the UK it is very tightly regulated. Most people have transfusions for decades without a serious problem.

But reactions do happen, and the people who do best are the ones who know what to look out for and speak up early. That is really all this leaflet is for.

Tell your nurse straight away if you feel unwell during a transfusion – even if it seems minor, and even if you feel silly doing it. It is far easier to deal with a reaction that has just started than one that has been going for half an hour.

Why do reactions happen?

Your immune system is very good at telling the difference between "you" and "not you". Donated blood is, unavoidably, not you.

Everyone's red blood cells carry markers on their surface. The best known are the ABO and RhD groups – whether you are O positive, A negative and so on. But there are many other markers besides those, with names like Kell, Duffy, Kidd and MNS. Most of the time these do not matter.

They start to matter when you have transfusions repeatedly. Each time you receive blood carrying a marker you do not have, your immune system may learn to recognise it and make an antibody against it. This is called alloimmunisation. Once you have made that antibody, any future blood carrying that marker can be attacked – so each new antibody makes it harder to find blood that suits you.

This is more likely if you have had many transfusions, and it is more likely where the donor population and the patient population have different common markers. In the UK this particularly affects people of African, Caribbean, Mediterranean and South Asian heritage whose blood group patterns are less well represented among donors.

What is extended phenotyping and why does it matter?

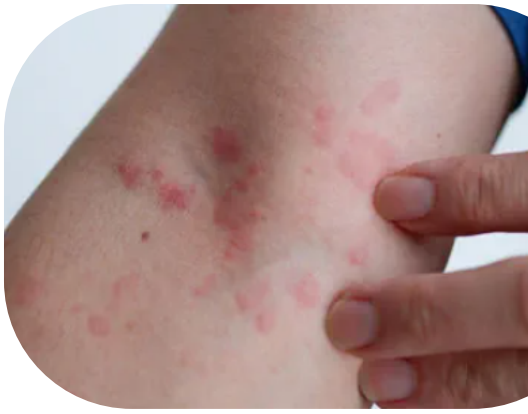
Extended phenotyping is a blood test that works out your red cell markers in detail, well beyond ABO and RhD. Genotyping does the same thing by looking at your genes, and is particularly useful if you have been recently transfused, because the donor's cells can otherwise confuse the result.

Knowing your full pattern means your blood can be matched more precisely – so you are given blood that avoids the markers your immune system would react to, instead of waiting to find out the hard way.

If you are likely to need transfusions long term, ask your team whether you have had extended phenotyping or genotyping. Ideally it is done before your first transfusion. If it has not been done, it is worth asking why.

There is a second reason this matters, which is worth saying: giving blood helps. Blood matched to people with rare inherited anaemias often comes from donors of similar heritage, and there are not enough of them. If your family and friends ask what they can do, this is a real answer.

What kinds of reaction can happen?



Feeling feverish or shivery The most common reaction. Usually mild, often just needs the transfusion slowed or paused, and treated with paracetamol.

Allergic reactions Itching, a rash or hives. Usually mild and treated with antihistamines. Severe allergic reactions are rare but are treated urgently.

Delayed haemolytic reaction This happens days to weeks after a transfusion, not during it, which is why it catches people out. An antibody attacks the transfused cells, and they break down. You may feel tired, look jaundiced, pass dark urine, or simply find that the transfusion did not seem to last. It is important to report this – it is easy to mistake for your underlying anaemia coming back. Extended matching is the main way this is prevented.

Acute haemolytic reaction Very rare, and serious. Caused by receiving incompatible blood. Symptoms come on during the transfusion: fever, pain in the back or chest, dark urine, feeling suddenly and severely unwell. This is why you are monitored closely at the start of each unit, and why the identity checks before a transfusion are done so carefully. If a nurse asks you your name and date of birth for what feels like the fourth time, that is the system working.

TACO (transfusion-associated circulatory overload) Breathlessness and swelling caused by too much fluid too quickly. More likely in older people or those with heart or kidney problems, and prevented by transfusing slowly.

TRALI (transfusion-related acute lung injury) Sudden difficulty breathing, usually within a few hours. Rare, and much rarer than it used to be, but needs urgent care.

Iron overload is not a reaction, but it is a consequence of transfusion over time. See our leaflet on iron overload from blood transfusions.

How are reactions prevented?

Your team does a great deal that you may not see: extended phenotyping and antibody screening, careful matching including the minor groups, removing white cells from donated blood (which greatly reduces feverish reactions), giving medicines beforehand if you have reacted before, transfusing slowly, and monitoring you closely – particularly in the first fifteen minutes of each unit, which is when the most serious reactions declare themselves.

Your part is smaller but genuinely matters: tell them if you have reacted before, tell them if you feel unwell, and keep your own record.

What can I do to help myself or my child?

Keep a record of your antibodies and any past reactions This is the single most useful thing. Antibodies can fade below the level a test can detect while your immune system still remembers them – which means a hospital that has never treated you before may test you, find nothing, and give you blood that your body will attack anyway. Your own record can prevent that. Ask your team for a card or a written list, keep a photo of it on your phone, and show it every time you are transfused somewhere new.

Consider a medical alert bracelet or card particularly if you have antibodies.

Say something if you feel unwell, during or after. Reactions in the days afterwards are easy to dismiss. Report them.

Attend your blood tests, including antibody screening before transfusions.

Do not take iron supplements unless your haematologist has told you to.

If you are being transfused away from your usual hospital – on holiday, at university, in an emergency – tell them your diagnosis, your antibodies, and where your usual team is. Hospitals do not automatically share these records.

Transfusion is a safe and effective treatment. Knowing what to report, and carrying your own record, makes it safer still.

When to seek medical advice

Tell your nurse or doctor immediately, during a transfusion, if you have:

- Fever, chills or shivering
- Rash, itching or swelling
- Back or chest pain
- Shortness of breath
- Dark urine
- A feeling of anxiety or of something being wrong – this is worth mentioning even without another symptom

Contact your team in the days or weeks after a transfusion if you notice:

- Increasing tiredness, or a transfusion that did not seem to last
- Jaundice – yellowing of the eyes or skin
- Dark urine
- Fever

Can we help?

CAN (Congenital Anaemia Network) is a charity specifically for patients with inherited anaemias. It was started by a group of patients and doctors, working together to tackle some of the problems of having an inherited anaemia – the lack of information and the loneliness of not knowing anyone else with your condition. We run events for patients to meet each other, as well as provide some additional information, support and services for patients who need that extra bit of help.

If you want to know more visit www.togetherwecan.uk or email us: info@togetherwecan.uk

Do you know your care should involve a specialist centre for inherited anaemias? These conditions are rare enough that few doctors see many of them and all patients with rare inherited anaemias should be under the care of a haemoglobinopathy specialist. Please read our 'How red cell services are organised in England' information sheet. If you don't know who your specialist service should be, please get in touch with us so we can help you find out.