

dbas^{UK}

THE UK'S DIAMOND BLACKFAN
ANAEMIA SYNDROME CHARITY



Me and my blood transfusions-

What should I know?

A booklet for people on regular transfusions

DBAS UK Registered Charity 1083179

Where does the blood come from?

Your blood transfusion will come from healthy volunteers who are rigorously tested. For further information: <https://www.blood.co.uk/>

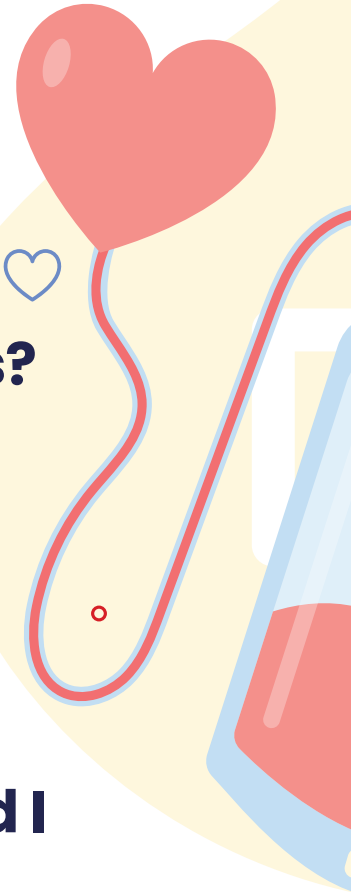
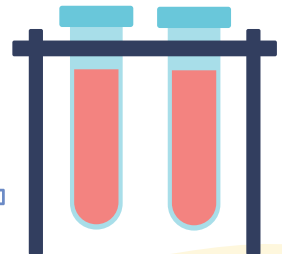
What are blood groups?

There are 4 main blood groups (types of blood) – A, B, AB and O. Your blood group is determined by the genes you inherit from your parents. Each group can be either RhD positive or RhD negative, which means in total there are 8 main blood groups. However there are numerous 'minor' blood groups which can cause problems in people with repeated transfusions.

- Blood groups define the specific type of red blood cells in your body. The most important ones to match between the blood donor and you are **ABO** and **RH +/–**.

How many units should I be getting?

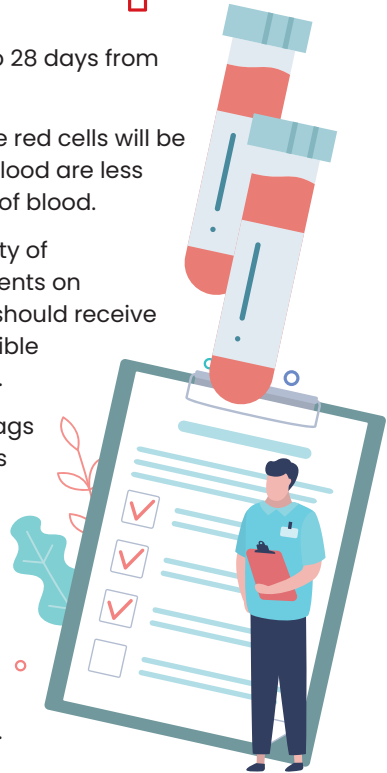
- Many people on transfusions have a target Hb that the medical team and you should aim for. In DBA **this is the lowest Hb** you should be allowed to drop to before receiving a transfusion. For example: "not lower than 100g/L".
- If you are dropping too low, you may need your transfusions more often.
- **Who should be making that decision?** This should be agreed between you and your consultant and documented in your notes.
- **What should I do if I feel I am not getting enough blood?** Please get in touch with DBA UK if you feel you need support with this.



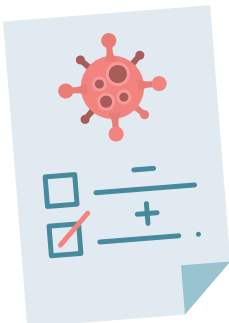
How fresh should the blood be?



- Blood is safe to be given up to 28 days from when it is taken from a donor.
- The 'older' the blood, the more red cells will be damaged, so 'older' units of blood are less effective than 'younger' units of blood.
- According to The British Society of Haematology guidelines, patients on recurrent blood transfusions should receive 'young' units as often as possible (ideally less than 10 days old).
- The guidelines also say the bags of blood should be as large as possible, specifically for older children and adults.
- It is ok to ask for this and to check that this is happening. Sometimes there are good reasons why this can't be achieved every time, but this should be discussed with you.



What is cross-matching and why does it take so long?

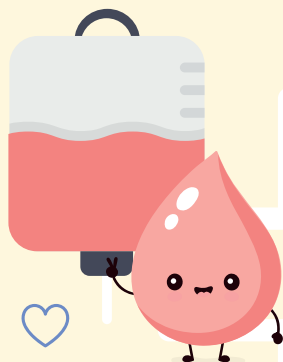


Cross-matching is carried out in the transfusion lab to make sure that the specific donor blood that will be used during a transfusion does not react with a patient's blood. In cross-matching tests we are looking to see if there are any antibodies in the patient's blood that may react with the red cells to be transfused.

- To ensure safety, this has to be repeated in full for every single transfusion as close as possible to the transfusion day.

How fast should my blood be given?

- The rate of transfusions for children will be calculated by the child's age, weight and overall health, but each unit of blood will take no longer than four hours. As a child grows more blood is required, so multiple units (bags) will be needed.
- Some adults may be able to have a unit of blood over 1 hour. This will be calculated by the medical team based on your age and overall health.
- On average, people receive their blood units over 2-4 hours.



What are blood antibodies?

- With increased blood transfusion your immune system can make antibodies against one of the donors' blood cells.
- The better the donor recipient match, the less likely antibodies will form.
- Once antibodies form, they can destroy future transfusions which makes it harder and harder to match.

What are transfusion reactions?

While having your blood transfusions, the clinical team will be taking your blood pressure, pulse and temperature to monitor for signs of a reaction. Reactions are extremely rare, but if you are concerned or feel unwell, speak to the team immediately.

- **Immediate** : this is extremely rare and results from an ABO mismatch.
- **Delayed** : this happens a couple of weeks after a transfusion if you have antibodies. Symptoms are tiredness, jaundice and dark urine. Please contact your medical team as you may need to be reviewed.
- **Hyperhaemolysis** : very rare rapid destruction of the transfused blood and your own blood cells requiring urgent medical treatment.



Should I be getting irradiated blood?

- This is for people who will be having a bone marrow transplant– speak to your hematology team if this applies.



Why do I have to be asked my name and Date of Birth every time?

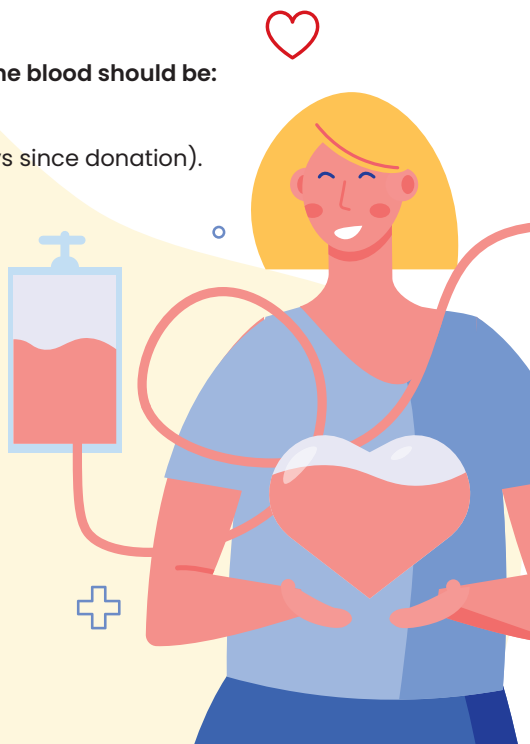
- This is for safety and ensuring the right unit is given to the right patient every single time. This practice has reduced transfusion reactions over the years. The nurses are always grateful for your patience.
- Please feel free to speak up if you have any concerns



Summary:

If you are on regular blood transfusions, the blood should be:

- As extensively matched as possible.
- As 'young' as possible (less than 10 days since donation).
- As large a bag as possible (depending on age and health).
- Sometimes the transfusion lab cannot achieve all these and will prioritise your safety.
- **Feel free to show this leaflet to help assist your management and care.** Please don't forget, many of the staff on transfusion units won't be aware of these guidelines as they only apply to very few people with rare diseases.
- Please contact DBA UK if you have any concerns.



8 things you should know before a child has their transfusion...

1

Before every transfusion, your child will need to have a blood test to find out what their haemoglobin and other blood cell levels are (purple top) and for cross matching (pink top) which is to ensure the blood is compatible. These tests are usually done a few days before the transfusion.



2

It is important that your child is well hydrated before doing these tests to ensure the levels are as accurate as possible - dehydration can sometimes cause haemoglobin levels to be slightly elevated.

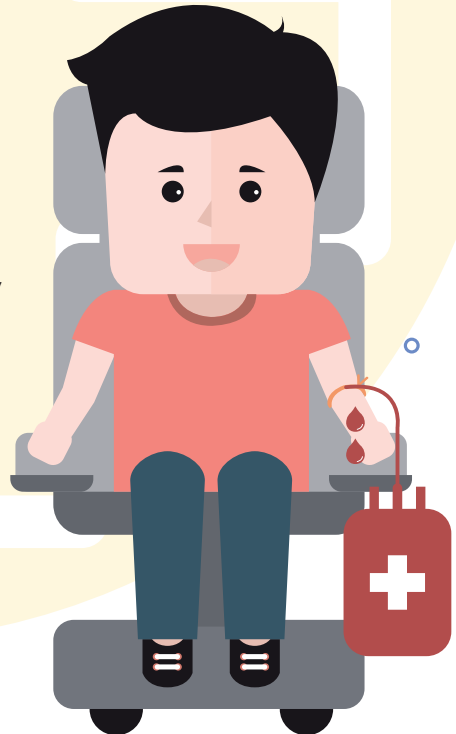
3

Dehydration can also affect cannulation. It is important your child has enough to eat and drink before their appointment. Keeping their hands warm also helps their veins to show up!

If they use a numbing cream, remember to apply this at-least 30 minutes before their appointment.

4

If they have started a regular transfusion programme ensure their pre transfusion haemoglobin levels are kept above 100 g/l



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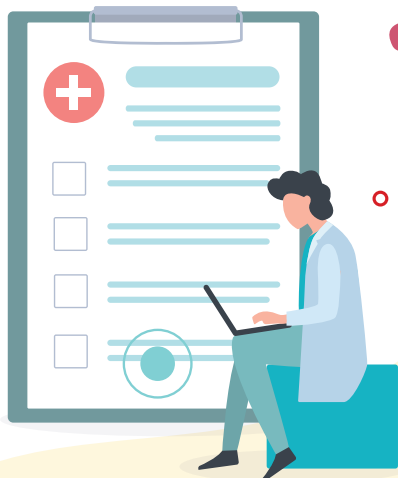
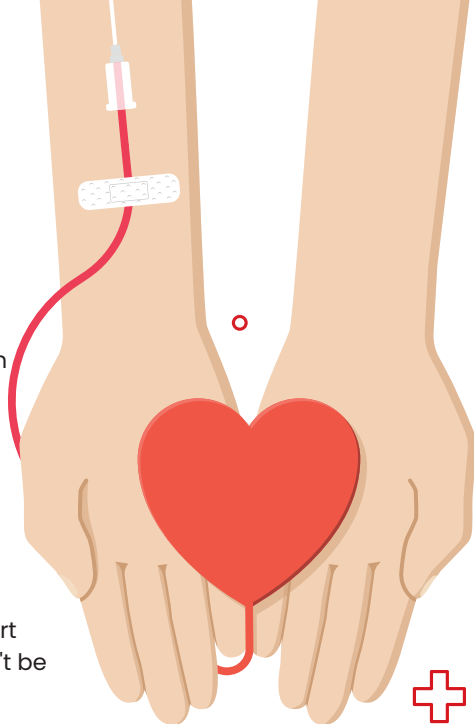
As their blood transfusions can take a few hours to complete, ensure your child has a lot of books, games, toys and food they like to get through the appointment.

As they become older, involve them into this process as much as possible and normalise transfusions.

6

Speaking to other families who are also going through this can sometimes make the experience a little more pleasant. The emotional support of having a support buddy can't be understated.

Try to book transfusions with other families – not only will you have support, the children will also have a playmate too! If this does not happen regularly, check in with each other – they may be struggling too. Contact us if you need to find other parents in your area.



7

Keep a diary of what your child's pre transfusion levels are and how much blood they receive at each appointment.

8

If you have any concerns or questions, speak to the DBA team.

Writing notes prior to the visit helps to ensure you remember everything.

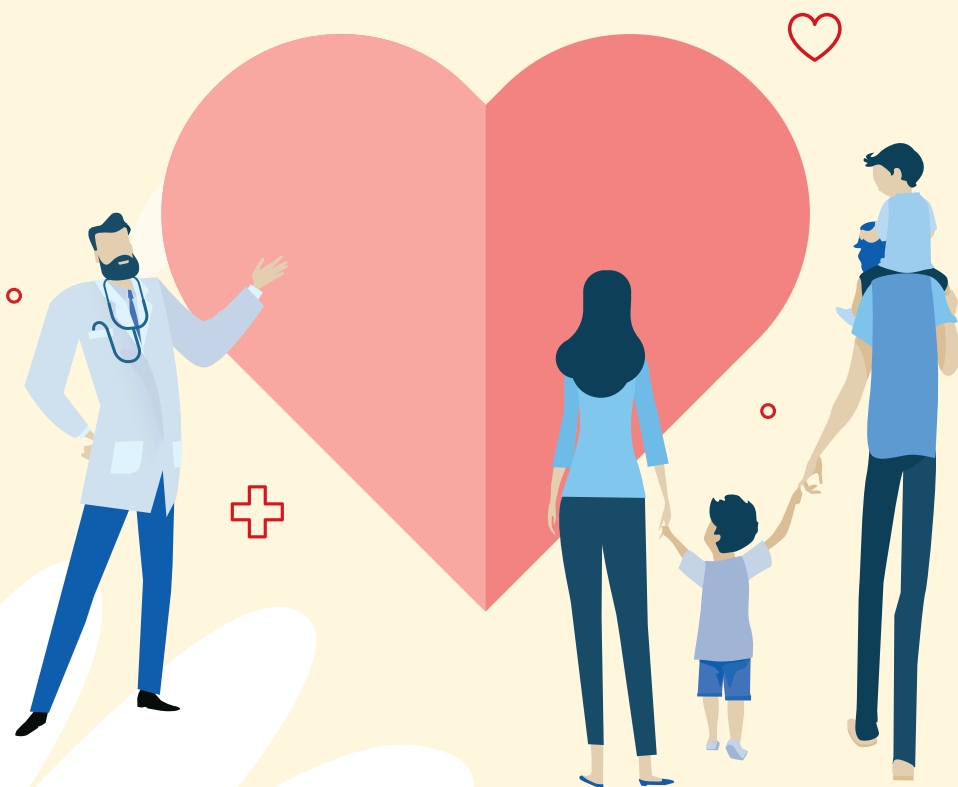


This factsheet has been put together by **DBA UK** with the help of doctors and nurses in England, children with aplastic anaemia and their families. Special thanks to Noemi Roy for her collaboration with DBA UK.

With kind support and guidance from the **Aplastic Anaemia Trust**. Check out www.theaat.org.uk/marrowkidz for further information.

www.diamondblackfan.org.uk

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