

THINGS YOU SHOULD KNOW...

WHEN ADVOCATING FOR YOURSELF

1 **Active participation in care decision-making** can take place by amplifying your voice in the following ways:

- **Being an equal partner** in care decisions by sharing your opinions (when when you might not be asked or invited to do so)
- **Expressing your personal views** about what matters most to you
- **Highlighting your needs** and repeatedly doing so to ensure your needs are fully recognised
- **Explain and express your perspective** on care decisions to ensure you are understood
- **Making your treatment preferences well-known** and asking for these to be documented.





Be aware of different communication styles.

Learn to recognise that there are different styles of communicating that you might notice in the people around you and in yourself. Pay attention to the communication pattern that you might fall into and work out what you might need to work on through practicing different ways of responding or communicating to those around you.

2



3

Analyse your communication style and practice making changes.

Weigh up the advantages and disadvantages of the communications style you tend to use. Many advantages can be short term and related to underlying fears, worries or beliefs. The goal is often to prevent potentially negative outcomes. Pay attention to the advantages and try to aim for communication styles that result in sustained and long-term advantages.



Disadvantages can be identified by asking yourself about the long-term impact of this communication style on you, on the people around you and how you want your relationships to be. For instance, with healthcare relationships, you may avoid the discomfort of a difference in opinion by not speaking up or asking questions in the short-term, but in the long-term you may notice yourself feeling disempowered, even less confident to ask questions and inhibited by these feelings.

4

Make time to evaluate changes to your communication style.

To evaluate your communication style, you may find it helpful to consider the following questions before and after any interpersonal interaction that you are looking to change or review:

- What outcome do I want from this interaction?
- What do I need to do to achieve this outcome?
- If I don't get the outcome I want, can I revisit this?
- How can I cope with the feelings that might come up?
- What matters to me about this relationship in the long-term and does this matter more or less than the feelings coming up for me now?
- How would I like to feel about myself after this interaction? How can I achieve this?

**SOURCE: UKTS THALASSAEMIA MATTERS SUMMER 2021
COMMUNICATION: LEARN TO BE HEARD – DR. CHINEA EZIEFULA**

PAGE 24 – 29



#MONTHOFLEARNING



THINGS YOU SHOULD KNOW...



WHEN APPLYING FOR PERSONAL INDEPENDENCE PAYMENT (PIP)

1 What is PIP?

PIP is a welfare benefit that can help you with some extra costs if you have long-term ill-health or disability. You could get between £23.60 to £151.40 a week if you are aged 16 or over and have not reached state pension age. PIP is usually paid every 4 weeks.



It is important to note that PIP is not based on the condition you have or medications you take.

It is based on the level of help you need because of how your condition affects you. You will be assessed by a health professional to work out the level of help you are entitled to and will be reviewed regularly so it may be subject to change. Your carer could get Carer's Allowance if you have substantial caring.

How do I make a claim?

You can make a new PIP claim by calling the Department for Work and Pensions (DWP). Someone else can call on your behalf, but you will need to be with them when they call. Before you call, you will need your contact details, date of birth and national insurance number.

Call on **0800 917 2222**



For more information or guidance, you can contact the UKTS by emailing **office@ukts.org** or calling **0208 882 0011**

Try to be as factual as possible and provide answers from most of your days rather than the actual day of the interview. Often the days of the interview are much better compared to others. **You may find it helpful to keep a diary** over a number of days and write down a list of things you've needed help with or found difficult.

4

The more evidence the better. It is important to provide relevant information or information you already have that explains your circumstances.

5

This might include:

- Prescription lists
- Care plans
- Reports or information from professionals such as a GP, hospital doctor, specialist nurse etc



or any other information you think would be helpful in your application. The supporting evidence you send does not need to be recent.

6

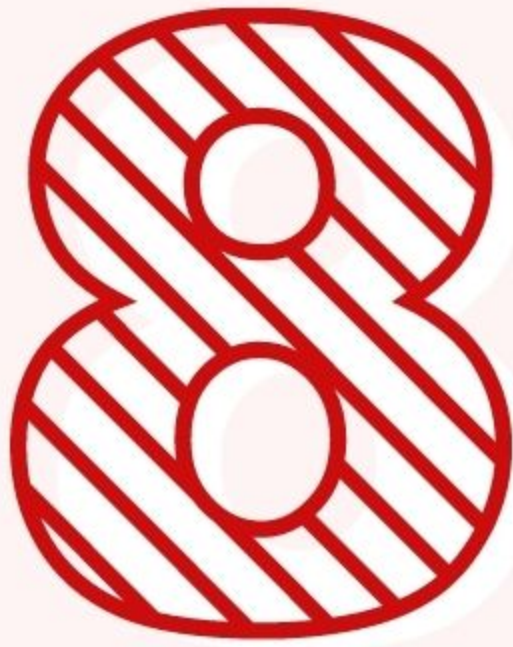
Give detail. Try to give as much detail as possible by covering physical, mental, intellectual or cognitive factors. Examples include:

- Preparing food
- Taking nutrition
- Washing and bathing
- Dressing and undressing
- Engaging with others
- Communicating verbally
- Moving around



**SOURCE: PERSONAL INDEPENDENCE PAYMENT INFORMATION BOOKLET 2019
& UKTS SOCIAL MEDIA POST**





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 crossmatching (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.



FOOD

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 between 95 g/l- 105 g/l



5

As blood transfusions usually takes 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.

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



SOURCE: WWW.UKTS.ORG:



THINGS YOU SHOULD KNOW...

IF YOU ARE A DENTIST



Dental decay studies have shown that patients with thalassaemia have a higher rate of dental decay. There are many reasons which contribute to this. Changes to the amount and protective quality of saliva can result in dry mouth, which increases the chance of getting dental decay.





2

Patients may be reluctant to attend if they feel the dentist does not understand their condition. However, patients may also be reluctant to attend as their thalassaemia care can become overwhelming and their focus shifts to coping and managing secondary complications of thalassaemia.

Dentists should be aware of their patients medical history and especially treatment with bisphosphonates for osteoporosis. Before bisphosphonate therapy is administered, patient's should be referred to maxofacial surgeons or tertiary dental care. Throughout treatment with bisphosphonates, patients should be regularly monitored by tertiary dentists to determine whether there are any changes as osteonecrosis of the jaw is a common but major side effect of bisphosphonate therapy.



Dental care can be expensive which is why patients are more likely to attend when something is wrong or there is an emergency. Unfortunately, at this late stage, dental decay can often be advanced, with the risk of infection and abscess spreading into the tissues of the face and neck. Sadly, dental extractions can be the only treatment due to late presentation and insufficient monitoring.

3

4

Dental care should be delivered as a coordinated **team approach**, ensuring close liaison between the dentist, the haematologist, and where appropriate, the paediatrician. The involvement and treatment provided will depend upon the severity of thalassaemia.





5

Most patients with thalassaemia can receive **routine dental treatment** under **local anaesthesia** from a local general dentist. This means that routine check-ups and treatments are mainly provided by the local general dentist, but referral may be required to specialist services in the community or hospital dental services. This will be for specific courses of treatment such as extractions if the patient receives regular blood transfusions.

Dental treatment under **general anaesthesia** should be avoided due to the risks associated with underlying anaemia. When general anaesthesia is absolutely necessary, it should be carried out as an inpatient procedure, with the patient admitted under joint care with the haematology team.



6

Other considerations may need to be taken into account in the following instances:

- If a patient has had a splenectomy, they may be at greater risk of infection following any invasive dental procedures (such as extractions or deep scaling); as such, antibiotics may be prescribed to reduce the risk.
- Some patients can be on treatment with anticoagulants so there is an increased risk of bleeding.
- Bisphosphonate treatment can cause osteonecrosis of the jaw.



**ALL INFORMATION FOUND ON OUR WEBSITE: WWW.UKTS.ORG
WHAT PARTS OF THE BODY ARE AFFECTED – DENTAL**





THINGS YOU SHOULD KNOW...

ABOUT DIET AND THALASSAEMIA

Nutrition can play a vital role for people who live with thalassaemia.

Although, nutritional interventions will not reduce the number of blood transfusions you need or cure the condition, it can help you maintain a healthy body weight. In addition, good nutrition can help manage some of the symptoms and prevent them becoming worse, as well as reduce the risk of developing chronic diseases like diabetes etc. that can affect your overall health and well-being.



2

IRON

It is recommended that transfused and non-transfused patients to have a **low iron diet**. You also have to decrease your intake of foods supplements with iron as well as food that increase iron absorption such as foods high in vitamin C.

Iron has two forms:

Haem iron which is found in meat and animal products e.g. milk.



Non-haem iron which is found in non-meat foods e.g. leafy green vegetables.



Haem iron is more easily absorbed compared to non-haem iron as non-haem iron needs to be dissolved before uptake.

In general, a low iron diet would contain **cereals (maize, whole-grain flour, beans) and root vegetables with little meat, fish or foods rich in vitamin C.**

3 CALCIUM

Foods high in calcium should be incorporated in the diet as it is important for bone development and management. Calcium is a crucial component in the diet for those with osteoporosis.



Calcium also reduces haem iron absorption.

- **Milk, cheese and other dairy products** provide about half of the calcium in the UK diet.
- Calcium is also provided by some **green leafy vegetables** such as **broccoli and cabbage** - please note that although spinach is a good source of calcium, it is also high in iron and therefore patients following a low iron diet should have less spinach in their diet.
- Other foods such as **fortified soya products and fish** eaten with the bones such as **sardines, salmon and whitebait** all contain food sources of calcium. If you are lactose intolerant, lactose free foods are still high in calcium



ZINC

4

Zinc, unlike iron, **is not stored in the body, therefore it must be consumed as part of the diet.**

Research has shown, that **a lot of people with thalassaemia are deficient in Zinc** and it is particularly important in patients receiving transfusions; a Zinc supplement is an option, however, please consult with your GP before taking it as the intake of Zinc can affect the absorption of other nutrients.

Foods that are high in zinc: Mainly found in meat and present in milk, cheese, eggs, shellfish, wholegrain cereals, nuts and pulses. For cereals and pulses, zinc's availability is limited by phytates.



5

VITAMIN E

Antioxidants are important in any diet, because as their name suggests, they have a role to play in keeping the amount of free radicals in check, in so doing antioxidants prevent oxidative damage in the body.

Antioxidants therefore plays an important role in the prevention of diseases such as coronary heart disease and cancer. In thalassaemia, because of the excess iron in the body, there is a higher risk of oxidative damage.

Vitamin E is an important antioxidant and has a role in immune function.

Vitamin E is mainly found in **vegetable oils such as olive oil**. It is best to add the olive oil towards the end of cooking, after the food is cooked or on raw vegetables because heat can destroy the vitamin E content of food.



SOURCE: WWW.UKTS.ORG/NUTRITION





THINGS YOU SHOULD KNOW...

ABOUT THALASSAEMIA INTERMEDIA

People with beta thalassaemia intermedia, like those with major, inherit a thalassaemic (or poorly functional) beta gene from both parents, but for one reason or another can manage and often keep very well without the need for regular transfusions. There are various reasons why some people who have two beta thalassaemia genes produce an adequate amount of blood while others do not.



A person with intermedia may have two genes which are **only mildly under functioning** (?+ genes) so that they can produce sufficient haemoglobin to live comfortably on.

Alternatively, they may have inherited a **combination of other genes** which interact with beta thalassaemic genes and somehow improve their function or otherwise improve the amount of useful haemoglobin they can produce.

2



3

People with beta thalassaemia intermedia will often run a haemoglobin level between **7 and 9g/dl**; that is they are **moderately anaemic** but at this level are usually asymptomatic and thrive and grow normally.

4

The **spleen** is commonly much **enlarged** in children with this condition, and blood “pools” there, so that **splenectomy** is often offered to maximise the haemoglobin level that can be achieved.

After splenectomy, **prophylactic penicillin** is given to prevent serious pneumococcal infection, and daily folic acid tablets also help to keep up the haemoglobin level as the bone marrow, which is working overtime, needs increased supplies of this vitamin.



It is **usual** for people with intermedia to need **transfusions** at some times in their lives. Infections can lower the haemoglobin so that blood transfusion is necessary, and transfusions are commonly required during pregnancy too. Leg ulcers are a frequent problem and these can be difficult to treat, again often requiring transfusions to heal fully.

5

6

Some people with thalassaemia intermedia who have been monitored during early childhood have been **shown not to grow as quickly as expected**, and to develop marked bony changes in the face resulting from bone marrow expansion, causing prominent cheek bones and upper jaw bone sometimes with dental problems. In these individuals a **regular transfusion regimen** has sometimes been instituted. This brings with it the side effects of transfusions seen in patients with thalassaemia major.

People with intermedia absorb **large quantities of iron all the time from their diet**, so that even when not receiving a lot of transfusions, they may need to use some Desferrioxamine by pump for periods in their lives.

7



SOURCE: WWW.UKTS.ORG/THALASSAEMIA-INTERMEDIA





THINGS YOU SHOULD KNOW...

ABOUT IRON CHELATION

Why do I need to take my iron chelation?

Iron chelation therapy is essential for individuals with transfusion dependent thalassaemia also for those with thalassaemia intermedia who have developed iron overload either due to intermittent transfusions in the past or due to increased dietary iron absorption.



In all people, Iron moves from one area to another bound to a protein which makes it safe. In individuals with a moderate to severe form of thalassaemia, this protein is rapidly fully loaded with iron leaving the harmful excess iron to move around in the blood freely. This free form of iron causes serious damage to how the major organs such as the liver and heart work.



There are two goals of iron chelation therapy; the primary goal of chelation therapy is to maintain safe levels of body iron and the secondary goal is to rescue patients who have developed toxic levels of iron resulting in organ damage. Unfortunately once iron overload has occurred the removal of excess iron is slow and may need several years of excellent compliance to treatment to completely clear the iron.

2

There are three drugs used for iron overload but in four regimes:

3

Desferrioxamine (Desferal)
Deferiprone (Ferriprox)
Deferiprone and Desferrioxamine in combination
Deferasirox (Exjade)



IRON CHELATORS THE RUN DOWN!

4

Desferrioxamine:

- **This was first used in the 1960's** but has been mainstream treatment for iron overload since the late 1970's.
- **It is a good liver and heart iron chelator**, however due to issues with compliance and concerns around toxicity it is used less often.
- Desferrioxamine has to be **given either subcutaneously or intravenously via an indwelling device such as a Hickman Line or Port-o-cath.**
- In general the recommendation is to **take Desferrioxamine on 5 nights a week as a 12-hour infusion.**
- Patients with more severe iron loading either in the heart or liver often receive Desferrioxamine as 24-hour infusions.
Desferrioxamine can push the ferritin down quite rapidly and it is important to monitor the liver iron regularly to make sure that toxicity related complications do not develop and that the Desferal dose is not reduced too quickly if the liver iron is still high. Desferrioxamine is excellent for stabilising and reducing free iron and therefore good in acute heart failure or if there are abnormal heart rhythms. (Long term data for over 50 years).





Important things for you to know: Desferrioxamine

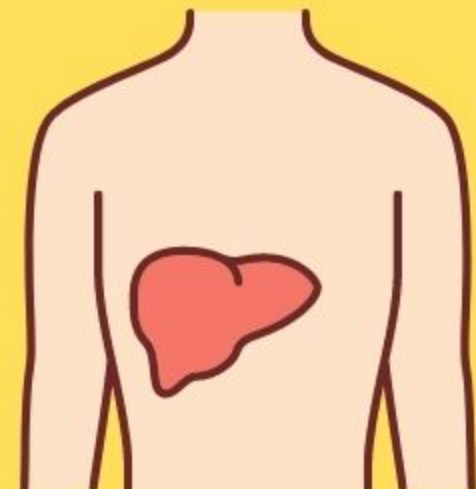
- **Desferrioxamine is only effectively working for as long as the pump is attached.** It is therefore important to ensure that the pump does finish before it is removed in the morning and not to leave any infusion in the balloon or syringe otherwise the full dose is not administered.
- It is important **to not do 2 pumps in a day if you have 12-hour pumps!** Many patients do this in order to avoid 2 needles BUT by doing this you get effectively double the dose in a 24-hour period!
- If there are **reactions** at the sites of the infusion **let your doctor know**, we can have a small dose of hydrocortisone added into the infusion to reduce the reactions or increase the volume of water so it is less irritating.



5

Deferiprone:

- This has been in **clinical use since the 1990's.**
- Several studies have shown it to be **very effective for clearing heart iron especially in conjunction with Desferrioxamine infusions.**
- It is taken three times a day in either a **tablet or syrup form.**
- Deferiprone **does reduce ferritin in the majority of patients but there may still be raised liver iron levels.** In this case patients are often given combination therapy to control the liver iron. This usually means Desferrioxamine on 2 to 3 nights a week.



Important things for you to know: Deferiprone



- **Side effects can limit a person's ability to take Deferiprone** in particular the gastrointestinal (nausea and vomiting) effects and joint pains. In some cases a condition called agranulocytosis can occur, so you need to monitor your white blood cells regularly to avoid developing this!
- Most of the nausea and vomiting side effects do settle down so persevere with it and discuss with your doctor if there is anything that can be done to help manage them.
- **Always take the tablets three times a day** as the short half-life means the medicine is removed from your blood soon after taking it. If you miss doses or only do it twice a day you have less hours of chelation and the Deferiprone is less effective.
- **Always try to get your full blood count checked as advised (weekly).** If you develop a fever and sore throat stop the Deferiprone and have a blood test to make sure your blood count is OK.
- **If you are planning to start a family you need to stop Deferiprone 3 months prior to a planned pregnancy.** If you accidentally become pregnant on Deferiprone stop this straight away.



6

Deferasirox:

- **This has been available for clinical use since 2006** and has been shown to be effective for both liver and heart iron in stable patients. **It is available in a dissolvable or tablet form and is usually taken once daily.**
- **Deferasirox can be given at an iron-reducing dose where the dose is slightly higher than iron loading** from the blood transfusions in order to bring down the body iron, or it can be given at a maintenance dose where the aim is to maintain a stable body iron.
- **There is now good data from clinical trials showing improvement in heart iron** so it can now be used in stable patients with iron loading in the heart. Careful monitoring is required of kidney function and nausea, vomiting, diarrhoea and taste can affect compliance.





Important things for you to know: Deferasirox

- Most of the nausea and vomiting and diarrhoea side effects do settle down so persevere with it. **You can take Deferasirox with food and it often helps if you leave the tablets for half an hour (in lukewarm water) to allow them to disperse properly in water before drinking. This makes the drink less chalky and gritty.**
- **Kidney and urine tests should be monitored monthly and if the ferritin falls very quickly the kidney tests are more likely to go up.** In this situation reducing the dose or having a short break is advised and this does correct the tests back to normal.
- **Exjade can also cause gastrointestinal issues** as well as other side effects, you must let your haematology team know.
- **If you are planning to start a family you need to stop Deferasirox 3 months prior to a planned pregnancy.** If you accidentally become pregnant on Deferasirox stop this straight away.



7

Using chelation therapy as prescribed and with appropriate monitoring to help adjust treatment in a timely fashion is critical to ensuring that you live a long a healthy life. It is really important the critical tests such as MRI monitoring for hepatic and liver iron and blood tests such as glucose tolerance tests are done on a regular basis as many complications especially cardiac failure and diabetes can be avoided if there is timely changes in treatment. Remember it is your health and your life that is put at risk by missing these important tests and more importantly by missing treatment!



SOURCE: WWW.UKTS.ORG/ IRON-CHELATION-THERAPY

DR FARRUKH SHAH

CONSULTANT HAEMATOLOGIST

RED CELL DISORDERS UNIT WHITTINGTON AND UCLH HOSPITALS

LONDON



THINGS YOU SHOULD KNOW...

NUTRITION FOR CHILDREN



Bones

Calcium is an important nutrient for building and maintaining bone and teeth strength. A diet high in calcium will increase storage of calcium in bones which can prevent bones becoming weak, fracturing and leading to osteopenia (reduced bone mass) and osteoporosis. The peak time for storage is during the teenage years. It is during this time that the bones reach their adult length and strength. Therefore, ensuring that children and teenagers consume enough calcium is so important as this will influence their bone strength and health when they are older.



Vitamin D is also important for bones as it helps the body to absorb calcium. The main source of vitamin D is from the sun and is found in small amounts in food sources. As it is getting darker earlier and the weather is not as sunny, vitamin D levels are likely to decrease, and this can result in the development of different symptoms e.g. fatigue, muscle weakness. It is of increased importance for individuals with darker skin complexions, as the increased melanin in the skin reduces the skin's ability produce vitamin D from the sun. Check with your consultant as they typically prescribe vitamin D3 supplements based on individual test results if required.



Encouraging children to **exercise** and carry out weight bearing exercise such as running, walking, skipping, dancing and playing sport will increase the density of the bones and make them stronger.



Growth

Undernutrition is a factor that contributes to stunted growth in children with thalassaemia major. Therefore, ensuring children are eating enough is so important as it plays a massive role in their growth and development. **Zinc** also supports growth and development.

4



Protein also plays a role as it supports repair and growth of muscles. It is important to note that every child has specific needs that are individual to them. For nutritional advice that is tailored to a child, please ask a GP to be referred to a dietician.

5

Iron

Iron rich foods do not have to be completely avoided for children with transfusion dependent thalassaemia who are prescribed regular iron chelation therapy. It is recommended to keep iron consumption under 10mg/ day.

ALL INFORMATION FOUND ON OUR WEBSITE: WWW.UKTS.ORG





THINGS YOU SHOULD KNOW...

ABOUT THALASSAEMIA TRAIT



1 What is thalassaemia trait?

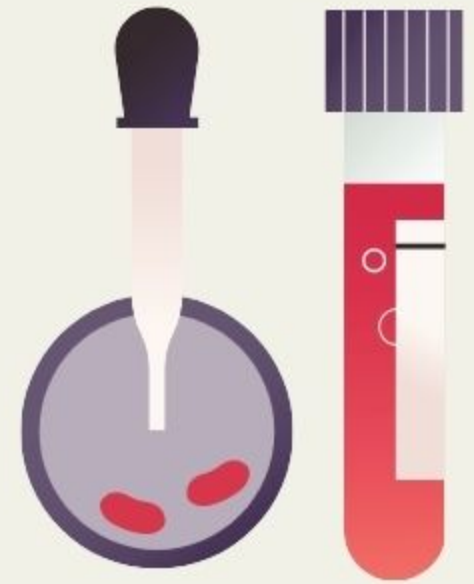
If you have been diagnosed with the thalassaemia trait, this is simply another way of saying that you carry the genetic trait for thalassaemia. A genetic trait is a kind of message or code contained in your body. You may pass this code on to your children, and they may pass it on to their children.



2 Why should I be concerned about thalassaemia trait?

Even though the thalassaemia trait has **no symptoms** and **cannot directly affect your health**, it can indirectly affect your health and directly affect the health of your children. Doctors may mistake your thalassaemia trait for a different condition and prescribe unnecessary and potentially harmful tests or treatments.

Also, when two thalassaemia trait carriers have a child, there is a **one-in-four** chance with each pregnancy that the child will be born with a serious blood disorder



3

Thalassaemia trait testing

Finding out if you have the genetic trait for thalassaemia begins by **determining the size of your red blood cells.**



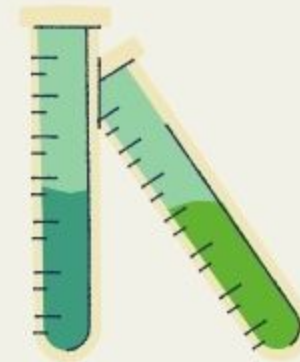
If you have a routine blood test known as a **Complete Blood Count** already on file at your doctor's office, ask your doctor to look at the **Mean Corpuscular Volume (MCV).**

The MCV reading determines the size of your red blood cells. For adults, if the MCV reading is less than **75** and you are not iron deficient, you may be a trait carrier. For children, the MCV reading may be lower and varies according to their age



If your MCV reading indicates that you may have the thalassemia trait, your doctor should then perform additional tests to confirm that you have the thalassaemia trait and to determine what kind.

Although the MCV reading is a good indicator of whether a person may have either the alpha or the beta thalassemia trait, finding out for certain if you have either trait involves additional tests





Prenatal testing for thalassaemia

4

If you have alpha or beta thalassemia trait and are considering having a child or are already pregnant, your partner should be tested to see if he or she has the thalassemia trait. If you both have thalassemia trait, there are several things you can do.

Inform your obstetrician about your thalassemia trait. Discuss what it might mean for your unborn child.

If you want to determine whether your unborn child has any form of thalassemia, there are two kinds of tests you can request

- 1) Amniocentesis
- 2) Chorionic Villus Sampling (CVS).

1) AMNIOCENTESIS

Amniocentesis is performed in the second trimester of pregnancy, after about 15 weeks of gestation. Using ultrasound as a guide, the doctor withdraws 2-3 tablespoons of amniotic fluid from the mother's womb through a very thin needle inserted in the mother's abdomen. Fetal cells that are floating free in the amniotic fluid are then analyzed for the thalassemia mutations.



2) CHORIONIC VILLUS SAMPLING (CVS)

CVS can be performed somewhat earlier than amniocentesis, at about 10-11 weeks of pregnancy. In this test, the doctor removes a small sample of the chorionic villi, or the cells that will form the placenta. The cells are removed either with a thin needle inserted in the mother's abdomen or with a thin catheter inserted in the vagina. These cells, which contain the same genetic information as the fetus, are analyzed for the thalassemia mutations. If you are interested in either of these tests, ask your obstetrician to refer you to a prenatal testing center.



If you are unsure what your carrier status is...

Get screened for the gene!



Many people originating from the Mediterranean area, the Middle East, Africa or Asia carry the gene for thalassaemia.

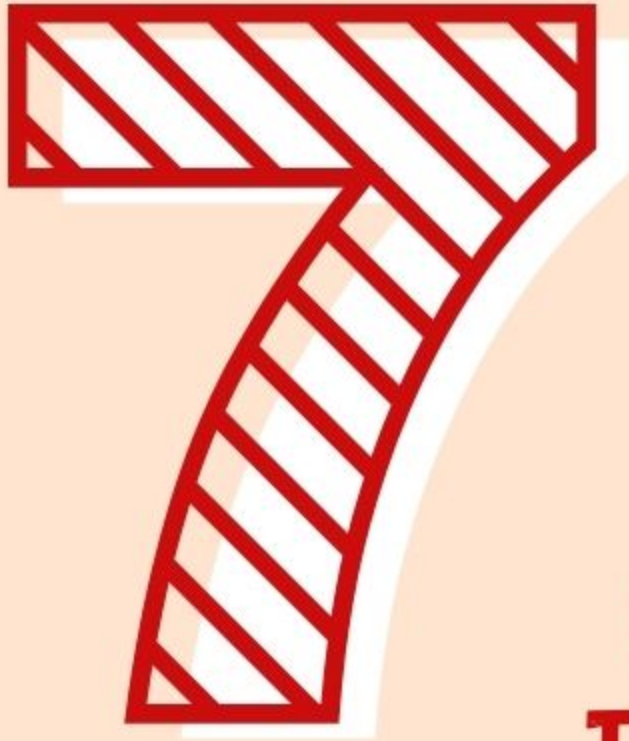
Due to migration, thalassaemia can still occur everywhere in the world so it is important for everyone to get tested!

Anyone can get tested at any point in their lives. To access this, you need to **request a test from your GP or local sickle cell and thalassaemia centre.**



**SOURCE: WWW.UKTS.ORG/ INFORMATION AND RESOURCES
- WHAT IS THALASSAEMIA TRAIT LEAFLET**





THINGS YOU SHOULD KNOW...

DOCTORS WHO HAVE PATIENTS TRANSITIONING INTO ADULT CARE

1

Treat the young person as an equal partner in the process and take full account of their views and needs.



Involve the young person and their family or carers, primary care practitioners and colleagues in education, as appropriate.

2



3

Support the young person to make decisions and builds their confidence to direct their own care and support over time.

Fully involve the young person in terms of the way their transition is planned, implemented and reviewed.

4

5

Address all relevant outcomes, including those related to:

- education and employment
- community inclusion
- health and wellbeing, including emotional health
- independent living and housing options



Involve agreeing goals with the young person

6

7 Include a review of the transition plan with the young person at least annually or more often if their needs change.



**SOURCE: TRANSITION TO ADULT SERVICES
ESSENTIAL TRAINING LEVEL 1
SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST**

