Thalassaemia and Trait: An International Guide to Higher Education Policy

Higher Education, Health and Wellbeing

Maria Berghs
Unit for the Social Study of Thalassaemia and Sickle Cell,
De Montfort University,
Leicester, United Kingdom
Maria.Berghs@dmu.ac.uk

Higher Education and Thalassaemia

Issues affecting employment trajectories often begin in schools and Higher Education (HE) which is why it is important to ensure reasonable adjustments or accommodations for students to allow inclusion in education. The 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is applicable to students who have a medical condition like thalassaemia. In the CRPD, Article 24 affirms the rights of persons with disabilities and serious medical conditions to education. All states must ensure non-discrimination and equality of opportunity and inclusion in education and life-long learning. It is up to the authorities in higher education institutions, inclusive of tertiary or post-secondary educational institutions such as vocational settings, colleges and universities, to ensure this inclusion.

Good practice: People living with thalassaemia should be encouraged to follow their educational dreams and employment aspirations. They can be aided in this through mentorship and seeing examples. Encourage people living with thalassaemia, who have gone to HE, to come and talk to those pupils thinking about it. If you are a teacher or lecturer, motivate your students and talk through their fears and aspirations. In our research, we found that there was always that one key teacher who believed in the abilities of a student or gave them some extra support. That could be foundational for setting that student on the path to HE and later employment.

What are Thalassaemias?

People with thalassaemia have mutations in the DNA cells that make-up haemoglobin. Haemoglobin is needed for red blood cells to carry oxygen around the body. In the mutations, the alpha or beta chains that make up the haemoglobin molecules become affected or reduced leading to **Alpha-Thalassaemia** or **Beta-Thalassaemia**.

Symptoms and Treatment

People with thalassaemia can have **symptoms such as anaemia** which is makes thalassaemia an energy-limiting condition. This means having anaemia can cause fatigue, feel weak, have shortness of breath, heart palpitations and pale or yellow skin. Another issue that can affect people with thalassaemia is that they can need regular blood transfusions to treat severe anaemia but this can mean that iron builds up in the blood causing issues to major organs of the body and hormone production. Symptoms are progressive and can include losing weight, feeling weak, having abdominal pain, lack of periods and joint pains. Too much iron can also affect the major organs of the body and is dangerous. Iron chelation is used to treat this **iron-overload in the body** and typically comes in two forms: 1) Deferoxamine and 2) Deferasirox. Deferoxamine is given under the skin through a pump that has to be worn for 8 to 12 hours a day. This might need some care and attention such as not engaging in physical exertion. Deferasirox can be taken in tablet form but has to be taken regularly. Adherence can be an issue as students may forget to take their tablets during studies, work and busy social lives.

What is Alpha-Thalassaemia?

There are four genes that make up the alpha haemaglobin chain. You inherit two from each parent. If you inherit one gene, you carry the **Alpha-thalassaemia gene or have the trait** but have no

symptoms. People with two genes have **Alpha-Thalassaemia minor** may have anaemia leading to fatigue. **Haemoglobin-H** means that you have three genes and can have a range of symptoms from moderate to severe. If a student has a moderate version of Haemoglobin-H that means that from time to time they might have anaemia and need blood transfusions. A student with a severe form of Haemoglobin H would have a need for regular transfusions.

What is Beta-Thalassaemia Major?

Beta-thalassaemia major is a serious inherited blood condition in which the red blood cells are nearly empty of haemoglobin, the key part of the blood that carries oxygen around the body.
The first life-saving step of treatment involves having blood transfusions every 3-4 weeks for the rest of their lives. This extra blood introduces extra iron into the body that the body cannot get rid of easily. The second step of treatment involves taking medicines that get rid of the excess iron. Depending upon the individual's suitability for particular medicines, some students may take these orally, either by tablet or in a drink, whilst others may have to have injections that are delivered slowly over 10-12 hours, 5-7 days a week.

Sickle Beta-Thalassaemia

There is a form of Sickle Cell Disorder, a serious inherited blood condition, that people get when they inherit sickle cell and beta-thalassaemia. It causes red blood cells to form sickle-like shapes causing blockages which can cause a severe pain called a crisis. It also affects the amount of haemoglobin that a person has in the blood or none at all. There are two types of sickle-beta-thalassaemia, a version called plus which is seen a mild version and one called zero, which is severe because of the total lack of haemoglobin.

Thalassaemia Trait

Having the **thalassaemia trait or thalassaemia minor** offered an important advantage in malaria endemic countries. Thalassaemia is thus mainly found in people whose origins lie in countries located along the equatorial belt. These include countries in the Mediterranean, African, Asian and Middle Eastern regions. There is a difference in having thalassaemia which can be a very serious medical condition and carrying the thalassaemia trait or gene. Having the trait means you are healthy and it is typically asymptomatic. However, some people with trait can experience anaemia.

If you want to understand if you carry a thalassaemia gene or have the trait, you can ask to get a blood test from your doctor. In some countries, such as the United Kingdom, all babies have a blood spot test and you may also find out as a parent if your child carries the gene. Knowing your trait status is also important as if you carry the gene and you have a child with another person who is a carrier, you have a 1 in 4 chance, in each and every pregnancy with another person with the trait, of having a child with thalassaemia. A child with thalassaemia trait is perfectly healthy.

If you carry a gene for **alpha thalassaemia**, the situation is more complicated as there are 4 genes that make up the alpha globin chain. A child will have alpha thalassaemia if they inherit 3 or 4 copies of the gene but if they inherit 1 or 2 copies of the gene, they carry the gene or have the trait.

Good practice: People who had the thalassaemia trait in the United Kingdom said that they did not have a lot of education about what this entailed, where they could get tested nor how they could find out more information. This was in contrast to students from places like Greece who felt they were very well informed. Yet, all students appreciated getting impartial information which was not just medical in nature but also about the social aspects of having trait.

Higher Education and Inclusiveness

HE is becoming increasingly diverse and it has certain duties to ensure inclusion and diversity is respected. Colleges, vocational settings and universities also have duties to ensure non-discrimination, equality of opportunity and thus have to provide reasonable adjustments or accommodations, for instance, in ensuring exams are accessible for students with differing disabilities, chronic and medical conditions.

Good practice: People with thalassaemia may not go to universities of their choice because they prefer to be close to their families, and especially the hospitals where they receive their care. As well as checking on the colleges and universities of their choice, students and parents might want to contact the thalassaemia services in that city and ask to speak to a specialist nurse. They can also check with the **disability services (they are a part of equality and diversity services at a college or university)** to understand what support is available. Once accepted at a college or university, we would recommend **you ask your consultant to refer you to local team in the city** you will be attending. Even if you don't want to transfer all your care to the hospital near your institution, it is a good idea they meet you and aware you're living in the area. This is in case you require support whist in the city. It might be useful to ask your consultant to contact the consultant in that city, so they are aware of your medical history. The impact of commuting to colleges and universities was a significant cause of fatigue. Ask if you can visit accommodation to check it is accessible to your needs.

Universal Design for Learning

HE has an obligation to ensure **Universal Design for Learning (UDL**) which means that colleges and universities will engage in differing learning and teaching styles to engage a variety of learners in the classroom. They will also use digital methods and innovative technologies to allow inclusion and accessibility of learning. They will also ensure flexibility and have duties to **reasonable adjustments or accommodations** in the classroom, during practicals, placements or lab sessions and during assessments.

Good practice: Students with thalassaemia can push themselves to come into class when they are in pain, fatigued or at risk of infection. Parents of children with thalassaemia can also miss classes because they needed to attend hospital appointments for transfusions. With UDL and having all the learning materials available virtually, this issue has decreased and students can stay home or in hospital if needed and learn in their own time. Students said they appreciated when lecturers asked if they needed tutorials or made extra materials, like videos, available that they could follow in their own time to catch-up.

Decolonisation

As HE has become increasingly diverse, students and staff have begun to think about decolonisation and what this should look like in the classroom, during lectures and on campus. Students and staff have asked for more representation in the visual imagery, the texts and stories that we tell and a reappraisal of all our histories. That includes ensuring that thalassaemia is part of HE and all our educational learning as one of the major globally inherited blood conditions.

Good practice: Students felt it was hard to have to explain what thalassaemia was to their tutors, lecturers or fellow students. This necessitated disclosure and explaining a complicated medical condition. An inclusive atmosphere takes this burden away from students by ensuring everyone is informed and campuses are inclusive to all disabilities and medical conditions. Colleges and universities should teach about thalassaemia in medical and nursing degrees but also as part of our social and cultural history of diversity as global citizens. The voluntary sector can help with this.

Disability

People with thalassaemia may see themselves as having a chronic or medical condition and not view themselves as having a disability. How a person self-identifies is very personal but in order to get reasonable adjustments, rights to disability accommodations and ensure that a college or university is aware of their condition, they should get in touch with disability services, disability officer or learning support coordinator.

Disability services at colleges and universities can give you information about what support is available to you and also act as a liaison to your course and lecturers so they are aware. In the United Kingdom, if you are a citizen, you are entitled to a **Disability Student Allowance (DSA)** which helps students with medical conditions, learning difficulties or disabilities. Even if you are an international student, it is important to contact disability services, as they can also ensure assistance with practical issues, as well as give information about what to do in case of any emergency situation. They will also be aware of extra support, like **university financial support or hardship funds** which students can apply to for additional support, such as with heating, specialist diet or because they are unable to work. Specialist nurses or the voluntary sector will also be able to signpost to support available.

Good practice: Disability services can be useful to ensure that students do not have to disclose personally but there is an awareness in their lecturers and personal tutor of their condition while protecting their privacy to other students. If there is an issue with anaemia or iron overload, for example before a transfusion, reasonable adjustments can be put in place such as giving a student time to work from home so they can rest.

Higher Education and Reasonable Adjustments

Symptoms of Thalassaemia

People with thalassaemia mostly look fine which is why having thalassaemia is sometimes described as an **invisible disability**. There are mild and severe versions of thalassaemia and it affects every person differently. People can have a range of symptoms which they learn how to cope with, such as anaemia, jaundice, fatigue and even a range of pain. However, there can also be more serious issues like iron-overload or reactions to transfusions. People with thalassaemia might also need to go the hospital or clinic on a regular basis, for example, for blood transfusions.

Good practice: If you are a personal tutor with a student with thalassaemia, ensure you give face-to-face or virtual meetings as required by the student. Ask students about their needs for adjustments or accommodations to attend class or follow lectures. Assure them that their privacy will be kept but the team is aware of their condition and any needs to attend hospital appointments. As well as academic life, ask them about joining societies and social life. Students are not their medical conditions and often want to experience life as a student.

How can the symptoms of thalassaemia be prevented?

Certain factors have been identified as more likely to precipitate anaemia and fatigue. These include infections, dehydration, strenuous exertion, stress, alcohol, caffeine, drugs and smoking. Advice to people living with thalassaemia includes living a healthy life with moderate exercise and healthy diet. People on iron chelation have to regularly take their medicines. We also know people with thalassaemia can become more physically and mentally tired closer to their transfusions. It is good practice to engage in moderate exercise and there is no reason why people with thalassaemia cannot join a gym or engage in university sports at a high-level.

Good practice: There will be times when students with thalassaemia might need support due to absences. They should be able to catch up with the work in their own time. Lecturers usually allow for that by ensuring lectures are recorded and also available online or in paper format. Additional virtual or face to face tutorials can also be organized to allow students who have missed sessions to catch-up. Students can also struggle to write when experiencing fatigue and may need a note-taker, equipment to record a lecture or speech to text software.

Fatigue: The person with thalassaemia may experience anaemia. This may mean they feel tired, have fatigue, are lethargic and unable to concentrate. They may feel tired to the point where they feel they need to sleep. Climbing numerous flights of stairs several times per day to get to and from the lecture, taking public transport or walking to campus can be physically demanding for students and cause fatigue. They might also be drowsy due to pain medication or because they are due a blood transfusion. Students with thalassaemia are also increasingly working as well as studying during a cost-of-living crisis, affecting fatigue and energy levels.

Good practice: Try to ensure that classrooms are timetabled close to each other for students with thalassaemia. Ensure that students are housed in accommodation within walking distance to campus or that they have parking available to them. If needed, make it possible for students with thalassaemia to stay in university accommodation on campus reducing their commute. Colleges should also be aware of the impact of commuting and working on their students. Be aware jobs requiring heavy manual labour or evening shifts might take a toll on a student's health and should be discouraged.

Mental Health: Living with a serious medical condition can cause a lot of stress. It is important that a strong network of support is built up around a person with thalassemia. They have also related that before a transfusion their mental health can be affected and they can feel low. Additionally, some people with thalassaemia have described experiences of discrimination and racism affecting their mental health. They can also suffer from depression and anxiety due to the demands of medical treatments and hospital admissions. This is also the case for parents of children of children with thalassaemia and it's important to ask how they are looking after themselves and if they have enough support.

Good practice: Be aware of any changes in your students and make them aware of any physical or mental health differences that you see. Ensure that you signpost where they can get support with academic and other issues on campus. We know students are living in very difficult times with financial and other pressures that can cause immense stress. They should be aware where they can get private and confidential mental health support or counselling. In some cultures, it may not be the norm to talk about feelings or mental health and students may prefer prayer and faith-counselling.

Life away from home: HE is often the first time that a student lives away from home and their support networks. This can be a challenging but also a very rewarding time in a person's life and it's good to prepare for that transition. We have developed the following HE plan below to allow you to begin to prepare and to put into practice some of the advice contained in this guide.

Consultant/Haematology team:

-Can they make contact on your behalf with the team in the city you are going to or send your or your child's medical records there?
-Is there a thalassaemia centre or transfusion clinic?
-Have they got access to medicines they need?
-Is there a support group or voluntary group you can join?

Disability Services:

-What educational reasonable adjustments do you need? In the classroom? During assignments?
-What information do they need about your condition?
-Do you have any additional learning needs?

Accommodation:

-If you are living at home or on campus, have you tested the commute?
-Do you need any support?

Personal Tutor:

-Do you need to let them know about any personal or academic issues?
-Any reasonable accommodations that need to be put in place?

Family, guardians and friends:

-Have you got a text ready in your phone that you can press in case you need anything?
-Have you discussed who will check-up on you and when?
-Who is going to be part of your support network? What are their jobs?

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