PAINLESS

Special Edition

Magazine

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JUNE 19TH

WORLD SICKLE CELL DAY

Leadership Through Advocacy

The Voices Transforming The Sickle Cell Conversation

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Leadership Through Advocacy

The Voices Transforming the Sickle Cell Conversation

Leadership is often associated with positions, titles, achievements, and influence. Yet some of the most powerful forms of leadership do not come from privilege or authority — they are born through perseverance, courage, and the determination to keep moving forward when life presents its greatest challenges. As someone who has lived with Sickle Cell Disease, this Special Edition of Painless Magazine carries a deeply personal meaning for me.

Sickle Cell is not simply a medical condition; it is a lifelong journey that affects every part of your existence. It is learning to smile through moments of pain, finding strength during uncertainty, overcoming limitations placed upon you, and continuing to dream even when your body demands that you stop.

My personal experience has taught me that true leadership is not only demonstrated on stages or in boardrooms. Sometimes leadership happens quietly — in hospital rooms, during painful nights, in the decision to rise again after a crisis, in advocating for yourself, and in using your voice so others no longer feel invisible.

This edition is dedicated to those voices. It honours individuals who continue to move forward despite pain. Families who remain hopeful through uncertainty. Healthcare professionals who dedicate their lives to improving care.

Advocates who challenge stigma. Researchers driving innovation. Organisations creating awareness, support, and meaningful change. Across these pages, you will meet remarkable people whose stories redefine what leadership looks like.

Leadership is found within communities, advocacy campaigns, healthcare spaces, research centres, workplaces, and in the everyday resilience of people who refuse to allow a diagnosis to define their identity or limit their future.

This Special Sickle Cell Awareness Edition brings together voices from around the world — individuals living with Sickle Cell Disease, healthcare experts, public leaders, advocates, entrepreneurs, organisations, caregivers, and allies — all contributing to a growing global movement transforming how we understand, support, and respond to Sickle Cell.

For too long, many people living with Sickle Cell have suffered silently, facing not only physical pain but misunderstanding, stigma, and a lack of awareness. By sharing our experiences, we create visibility. By creating visibility, we create change.

These stories remind us that while Sickle Cell Disease presents undeniable challenges, it also reveals extraordinary strength, resilience, compassion, innovation, and leadership.

Throughout this issue, we go beyond healthcare alone. We explore advocacy, representation, emotional wellbeing, workplace inclusion, public policy, blood donation awareness, research, and the ongoing efforts needed to improve outcomes for individuals and families affected by Sickle Cell Disease.

At its heart, this edition is about transformation.

Transforming awareness into understanding.
Transforming understanding into action.
Transforming challenges into opportunities for change.
Transforming personal experiences into collective impact.

My own journey has shown me that our stories have power. Every conversation we start, every barrier we break, and every experience we share helps create a better future for the next generation living with Sickle Cell Disease.

As we mark another year of global awareness, we celebrate those who have chosen to raise their voices, challenge perceptions, advocate for progress, and lead conversations — often through circumstances they never chose.

To every individual living with Sickle Cell Disease, every parent, caregiver, advocate, healthcare professional, blood donor, organisation, researcher, and ally represented within these pages: thank you.

Your leadership matters.
Your voice matters.
Your journey matters.
Your story has the power to change lives.

Together, we are transforming the Sickle Cell conversation and creating a future where every person affected by this condition feels seen, supported, and empowered.

With gratitude,

Lady Anne Welsh
Chief Editor, Painless Magazine

Leading With Compassion: Advocacy, Healthcare Support & Hope Within The Sickle Cell Community

Ambassador Professor Olufolake Abdulrazaq

Your Excellency, what inspired your interest and involvement in supporting individuals and families affected by Sickle Cell Disease?

Thank you for having me. My interest and involvement in supporting individuals and families affected by Sickle Cell Disease was borne out of both compassion and awareness, which started over 30 years ago, then, a friend's child with sickle cell here in the United Kingdom had bone marrow transplant that eventually cured the child of the disease. With cutting edge technology available in the United Kingdom Health System then.

What also inspired me was the realization that, despite how common sickle cell disease is in Nigeria, there is still a need for greater awareness, early education, advocacy, and support systems, as many people still lack adequate information about genotype compatibility, early diagnosis, and the importance of preventive healthcare.

In my roles as First Lady of Kwara State, Founder Ajike People Support Center and Chairperson Nigeria Governors Spouses Forum, I believe leadership must also include advocacy for health conditions that significantly affect the wellbeing of our people, especially conditions that impact children and vulnerable families.

In this regard, my office and the Ajike People Support Center have led sensitization and awareness programs on sickle cell and engaged in partnerships with the Sickle Cell Foundation Nigeria and the United Kingdom Sickle Cell Society, among others, to support people living with the disease. We have also procured health insurance cover through the Kwara State Health Insurance Agency to support their care. Even as we speak, I continue to onboard new beneficiaries in to the scheme every year.

Through initiatives such as mentioned, we continue to support awareness campaigns, encourage health education, and advocate for stronger healthcare support systems for people living with sickle cell disease. My work on sickle cell is more than programs; it is about dignity, empathy, and ensuring that affected individuals know they are not alone.

It is also about encouraging society to move from sympathy to understanding and from awareness to action, as I believe that with increased education, early screening, stronger healthcare systems, and sustained support, we can reduce the burden of sickle cell disease and improve the quality of life for many families.

Going forward, it is our resolve to engage in more collaborations as we are open to support and partnerships both at home and in the diaspora for expanded interventions and amplified awareness and sensitization as well as routing for cutting edge technology to be brought to Nigeria.

Through your humanitarian work and initiatives, what realities have you observed about the challenges faced by people living with Sickle Cell, particularly within underserved communities?

Through my humanitarian engagements and interactions with families across communities, one of the most striking realities I have observed about people living with Sickle Cell Disease is that many of them are fighting battles far beyond the illness itself. In underserved communities, especially, the challenges are often multidimensional, medical, emotional, financial, and even social.

Another major reality is the financial burden on families. Managing sickle cell disease is not a one-time expense; it is continuous. From medications and hospital visits to emergency care and transportation, the costs can become overwhelming, especially for households already facing economic hardship. Despite these lived realities, at my office and the Ajike People Support Center, working with other NGOs we have continued to support awareness efforts, encourage genotype testing and counseling, and lead advocacy for stronger support systems for affected individuals and families.

I hold the belief that we must continue to strengthen awareness, support research and advocacy, and create policies that prioritize the well-being of people living with sickle cell disease. We are pleased to record that life expectancy for sufferers now almost is the same with the general population in the West and we are looking forward to that being the case in Nigeria also.

In your opinion, why is it important for public leaders, institutions, and governments to take a more active role in Sickle Cell awareness and healthcare advocacy?

In my opinion, it is really important for public leaders, institutions, and governments to take a more active role in Sickle Cell Disease awareness and healthcare advocacy because the impact of the condition extends far beyond individual families, it is a significant public health and social development concern.

Nigeria carries one of the highest burdens of sickle cell disease globally, which means that silence, limited awareness, or weak support systems can have serious consequences for countless children, young people, and families.

Public leadership, however, matters, as it helps shape priorities, influence public understanding, and mobilize action. When leaders speak openly about sickle cell disease, it helps reduce stigma, encourages early testing, promotes informed decision-making, and reassures affected families that they are seen and supported.

It may interest you to know that, I have worked with the erstwhile mayor of London Borough of Brent, Councilor Ernest Ezeajughi while in office. We produced awareness video on sickle cell disease and received books on awareness and management of sickle cell by Dr. Lola Oni, consultant and lecturer at the Brent sickle cell and Thalassemia for sensitization purposes.

We have also before now commissioned the Kwara State Arts and Culture performing troupe to produce an educative and entertaining drama for the viewing pleasure of audiences, so that the audience will be learning as they are being entertained.

This is why advocacy must go beyond awareness campaigns alone. It should include, greater access to genotype screening and counseling, Improved healthcare services and early intervention, Community education and preventive awareness, support for research and treatment and Policies that protect and support affected individuals and families

I also believe public leaders must help humanize the conversation as we are doing in my office and the Ajike People Support Center. Behind every medical statistic is a child trying to attend school, a parent trying to provide care, or a young person trying to live fully despite recurring health challenges. Advocacy helps ensure that these individuals are not forgotten.

Ultimately, governments and institutions have the capacity to create systems that move society from reaction to prevention, from stigma to understanding, and from isolation to support. And that is why sustained leadership and advocacy in this area are not optional but necessary.

The Ajike People Support Centre has continued to support vulnerable communities through impactful initiatives. How important is community-based intervention in improving the lives of individuals living with chronic health conditions such as Sickle Cell?

Thank you very much. Community-based intervention is extremely important in improving the lives of individuals living with chronic health conditions such as Sickle Cell Disease because healthcare challenges are often experienced first and most directly within the community. Conditions like sickle cell disease not only affect a person medically, they also affect families emotionally, socially, educationally, and economically. This is why support systems must go beyond hospitals alone and extend into communities where people live, learn, and work.

Through the Ajike People Support Centre, we have learned that community-based interventions create impact because they bring support closer to the people. They help bridge gaps in awareness, access, and understanding. For instance, awareness campaigns within communities help families understand the importance of genotype testing, early diagnosis, proper healthcare management, and preventive education. In many underserved areas, simple information can make a life-changing difference.

In this regard our interventions at the grassroots involves massive free genotype testing for members of rural communities coupled with the sensitization and awareness program that we conduct in these communities. Community-based initiatives also help reduce stigma. When conversations happen openly within schools, religious institutions, traditional settings, and local gatherings, people begin to replace fear and misinformation with empathy and understanding.

Through our work at the Ajike People Support Center, we have also seen how grassroots interventions can improve access to care through outreach programs, partnerships with healthcare providers, counseling services, and referral support. In many cases, these localized efforts help identify challenges early before they become more severe.

Most importantly, community-based intervention encourages shared responsibility. It shifts healthcare conversations from being seen solely as a government issue to becoming a collective social responsibility involving leaders, institutions, healthcare professionals, families, and citizens.

For chronic conditions like sickle cell disease, consistency of care and support is essential. And communities play a critical role in sustaining that support over time. You will agree with me that real progress happens when healthcare becomes people-centered, when awareness, compassion, and practical support exist not only in medical facilities but also within homes, schools, workplaces, and communities.

Ultimately, this is why I believe that community-based intervention remains one of the most effective tools for improving both the quality of life and long-term outcomes for individuals living with chronic health conditions.

Beyond medical care, many individuals living with Sickle Cell also face emotional, financial, and social challenges. How can society become more compassionate and supportive towards them and their families?

I believe one of the most important things society must understand is that people living with Sickle Cell Disease are not defined by their condition. They are individuals with dreams, talents, aspirations, and the desire to live full and meaningful lives. Compassion begins when we choose to see the person before the illness.

Beyond the medical concerns, many individuals and families affected by sickle cell disease carry emotional stress, financial pressure, and, in some cases, social stigma. This is why support must be holistic and not limited to treatment alone. Hence, society needs to become more informed. Awareness and education are essential. Many harmful attitudes come from misunderstanding or lack of knowledge. When communities understand what sickle cell disease truly is, they become more empathetic and supportive rather than judgmental.

Also, we must create environments of inclusion and sensitivity within schools, workplaces, religious institutions, and communities. Children living with sickle cell disease should not feel isolated because of frequent absences or health challenges. Employers and educators should also recognize that flexibility and understanding can make a significant difference.

Further to these, emotional and financial support systems are also critical. Managing sickle cell disease can place a heavy burden on families, especially in underserved communities. This is why stronger healthcare support, partnerships, and community-driven interventions remain necessary.

At the Ajike People Support Centre, we continue to advocate for awareness, support services, and community engagement aimed at improving the well-being of vulnerable individuals and families.
I also believe that public conversations matter. The more leaders, institutions, healthcare professionals, and advocates speak openly about sickle cell disease, the more we normalize understanding and reduce stigma.

Hence, compassion must move beyond sympathy into action that includes checking on affected families, supporting awareness efforts, encouraging genotype testing and counseling, creating inclusive policies and systems, and treating people living with sickle cell disease with dignity and respect.

At the heart of it all, society becomes more compassionate when we recognize that every individual deserves care, understanding, and the opportunity to live with hope and dignity.

What changes or improvements would you personally love to see in healthcare access, awareness, and support systems for individuals living with Sickle Cell in Nigeria and across Africa?

Thank you very. There are several changes I would sincerely love to see in healthcare access, awareness, and support systems for individuals living with Sickle Cell Disease across Nigeria and Africa, because the burden of the condition is significant and affects countless families.

I would like to see greater emphasis on prevention through education and early awareness. Many people still lack adequate understanding of genotype compatibility, genetic counseling, and early screening. I believe awareness should begin early, in schools, communities, religious institutions, and healthcare settings, so that young people are empowered to make informed decisions.

I would love to see improved access to quality and affordable healthcare, especially in underserved and rural communities in Africa. Too many families still struggle to access specialized care, routine medications, diagnostic services, and emergency support, as healthcare should not depend on geography or financial capacity.

Also, we need stronger support systems for families and caregivers. Living with sickle cell disease affects entire households emotionally, financially, and socially; hence, counseling services, psychosocial support, and community-based assistance should become more accessible and integrated into healthcare delivery.

Further to these, I would also like to see more investment in research, innovation, and healthcare infrastructure related to sickle cell disease across Africa. Given the prevalence of the condition on the continent, Africa must continue to strengthen its capacity for research, treatment advancements, and data-driven interventions. Importantly, I would love to see more collaboration between governments, healthcare institutions, development partners, civil society organizations, researchers, and communities. As addressing sickle cell disease effectively requires a coordinated and sustained approach.

But beyond systems and policies, what I hope for most is a future where individuals living with sickle cell disease can live with dignity, hope, and opportunity, where they are supported not only medically, but emotionally and socially as well. Because ultimately, healthcare is not only about treating illness; it is about protecting human dignity and improving quality of life.

Finally, what message of encouragement and hope would Your Excellency like to share with individuals living with Sickle Cell and the families supporting them?

To every individual living with Sickle Cell Disease, and to every parent, caregiver, and family member supporting them, my message today is one of hope, strength, and encouragement. I want you to know that you are not alone.

I understand that living with sickle cell disease can be physically painful, emotionally exhausting, and at times deeply challenging, not only for those directly affected, but also for the families who walk that journey alongside them. There are moments of uncertainty, moments of fear, and moments when the burden may feel overwhelming. But even in those difficult moments, please remember that your life has value, your story matters, and your future remains full of possibilities.

While we must continue to replace stigma with understanding, silence with awareness, and isolation with support as a society, I enjoin everyone to continue seeking knowledge, prioritizing healthcare, supporting one another, and speaking openly about the realities of sickle cell disease. Awareness saves lives, and compassion strengthens communities.


AJIKE PEOPLE SUPPORT CENTRE
... we rise by lifting others

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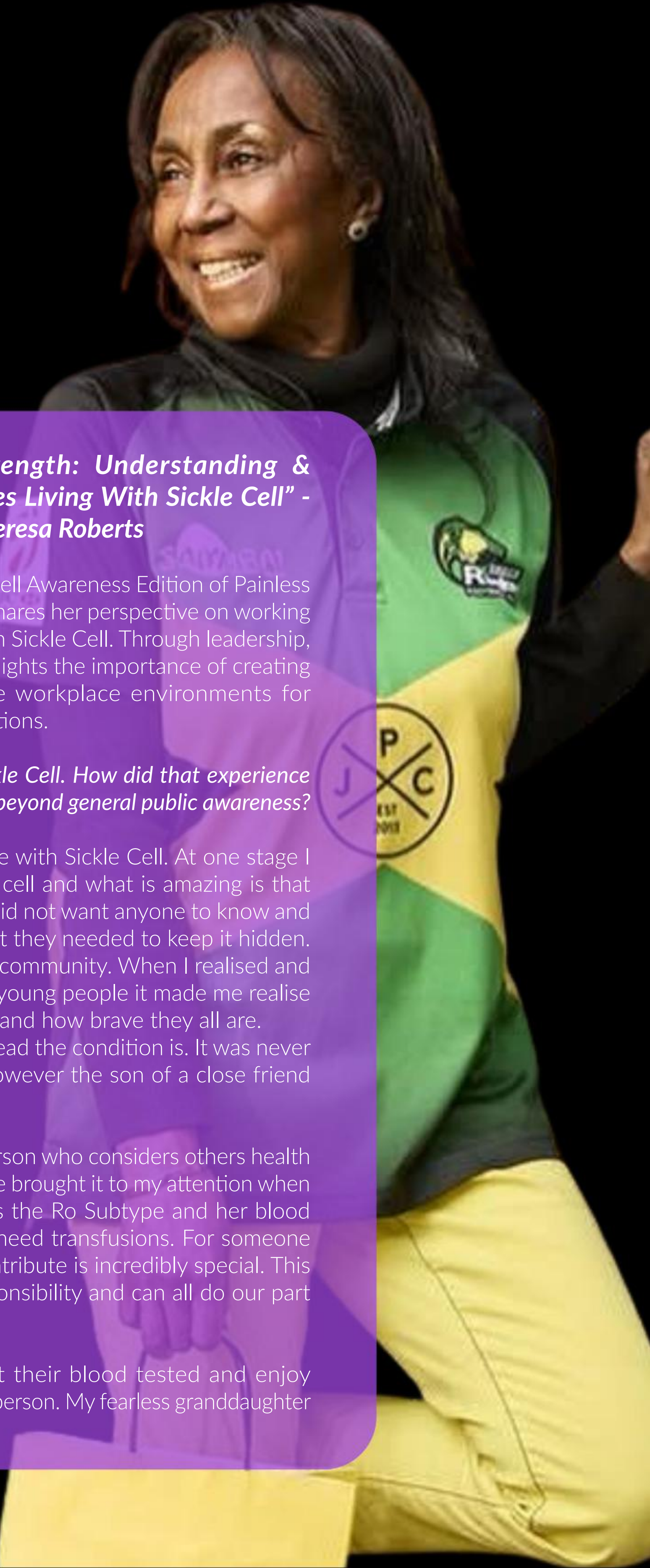


"Working With Strength: Understanding & Supporting Employees Living With Sickle Cell" - With Ambassador Theresa Roberts

In this special conversation for the Sickle Cell Awareness Edition of Painless Magazine, Ambassador Theresa Roberts shares her perspective on working with and supporting employees living with Sickle Cell. Through leadership, empathy, and real-life experience, she highlights the importance of creating more understanding and compassionate workplace environments for individuals navigating chronic health conditions.

As an employer of someone living with Sickle Cell. How did that experience deepen your understanding of the condition beyond general public awareness?

I have had a number of employees who live with Sickle Cell. At one stage I realised three of my employees had sickle cell and what is amazing is that none of them told me this, I suppose they did not want anyone to know and that in itself is very sad that maybe they felt they needed to keep it hidden. I had not realised it was so rife in the black community. When I realised and I could see the pain and suffering of these young people it made me realise how painful it was to live with this disease and how brave they all are.
I had not realised prior to this how widespread the condition is. It was never something that affected my own family, however the son of a close friend lost his life to sickle cell.

My granddaughter, a selfless and special person who considers others health and how they feel wanted to do her part. She brought it to my attention when she told me that as a blood donor she has the Ro Subtype and her blood donations help those with sickle cell who need transfusions. For someone so young to think this way and actively contribute is incredibly special. This brings home to me that we all have a responsibility and can all do our part in helping others.

For someone to be brave enough to get their blood tested and enjoy contributing to someone's health is a special person. My fearless granddaughter

> *“When I realised and I could see the pain and suffering of these young people it made me realise how painful it was to live with this disease and how brave they all are.”*

has opened my eyes about how important it is for more young people to contribute and she inspires me to do more. It’s brave, special and kind to want to help people in the world who are suffering.

From your perspective as a leader and employer, what are some of the biggest misconceptions workplaces may have about individuals living with Sickle Cell?

Lack of awareness about sickle cell will of course lead to misconceptions. It’s inevitable that this will lead to discrimination but if you offer support and accommodation you will have a capable and productive employee.

The reality is that sickle cell often causes extreme tiredness and therefore employers may think there will be high absenteeism or that they can’t cope with demanding jobs. The correct approach is to openly communicate and focus on abilities. If you are an educated employer you can make effective adjustments.

What have you learned about the importance of empathy, flexibility, and communication when supporting employees navigating chronic health conditions?

Empathy is crucial as without it, employees may hide their condition and therefore not receive the support they need. Education and dialogue can help change attitudes and remove harmful stereotypes. Communication is key. Employers that are willing to learn can become better advocates for inclusion as a whole.

In your experience, how can workplaces create environments where employees living with Sickle Cell feel understood, respected, and supported rather than judged or limited?

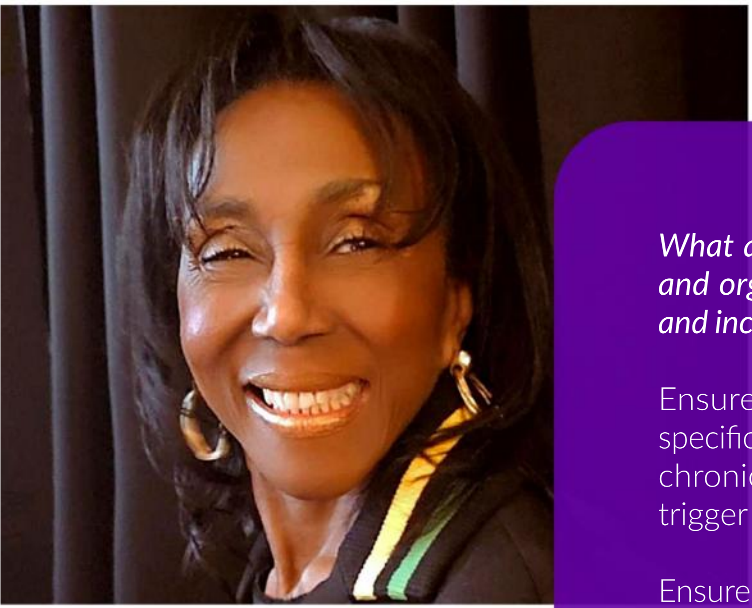
Accommodation such as scheduled breaks, keeping hydrated and flexibility are all no cost and benefit everyone. These things are simple and with flexible policies and understanding, people with sickle cell can succeed in many roles. We need to recognise that people with sickle cell are often highly resilient and create an environment in which they feel valued.

Many individuals living with invisible illnesses often struggle silently in professional spaces. Why do you think conversations around workplace wellbeing and chronic illness are still not happening enough?

Unfortunately many may feel there is a stigma attached or they will be seen as unreliable and do not wish to open up. There is a worry that disclosure will result in being labelled as 'difficult' and could harm career prospects.

Because symptoms are not always visible some employers may find it difficult to understand the severity of certain conditions and of course a general lack of awareness from an employer is going to lead to unfair assumptions about absence and performance.

Openness is crucial mainly because you don't want employees having to mask symptoms. Silence comes at a cost because if an employee hides their condition then an employer will never be able to build an understanding of it.



What advice would you give to employers, managers, and organisations on becoming more compassionate and inclusive towards employees living with Sickle Cell?

Ensure management and Human Resources have specific training that covers sickle cell's invisible nature, chronic fatigue and unpredictability and what can trigger these.

Ensure employees feel safe to disclose their condition and know that they are supported and can discuss their needs without fear of stigma.

For individuals living with Sickle Cell who may sometimes feel misunderstood or unsupported professionally, what words of encouragement or reassurance would you like to leave with them?

You are a survivor and your strength can help you find a supportive professional space. If you feel undervalued do not let that restrict your potential.

Change can happen with honest conversation, but if you find yourself deciding that you deserve better there are many organisations who will see your value.

Choosing Purpose Through Pain

Resilience, Healing & Personal Growth in the Sickle Cell

Mbasiti Jesse is a Purpose Alignment Coach, media entrepreneur, and founder of The Life Pathfinder Int'l, where she helps individuals discover and live in alignment with their purpose through transformative content, coaching, and community.

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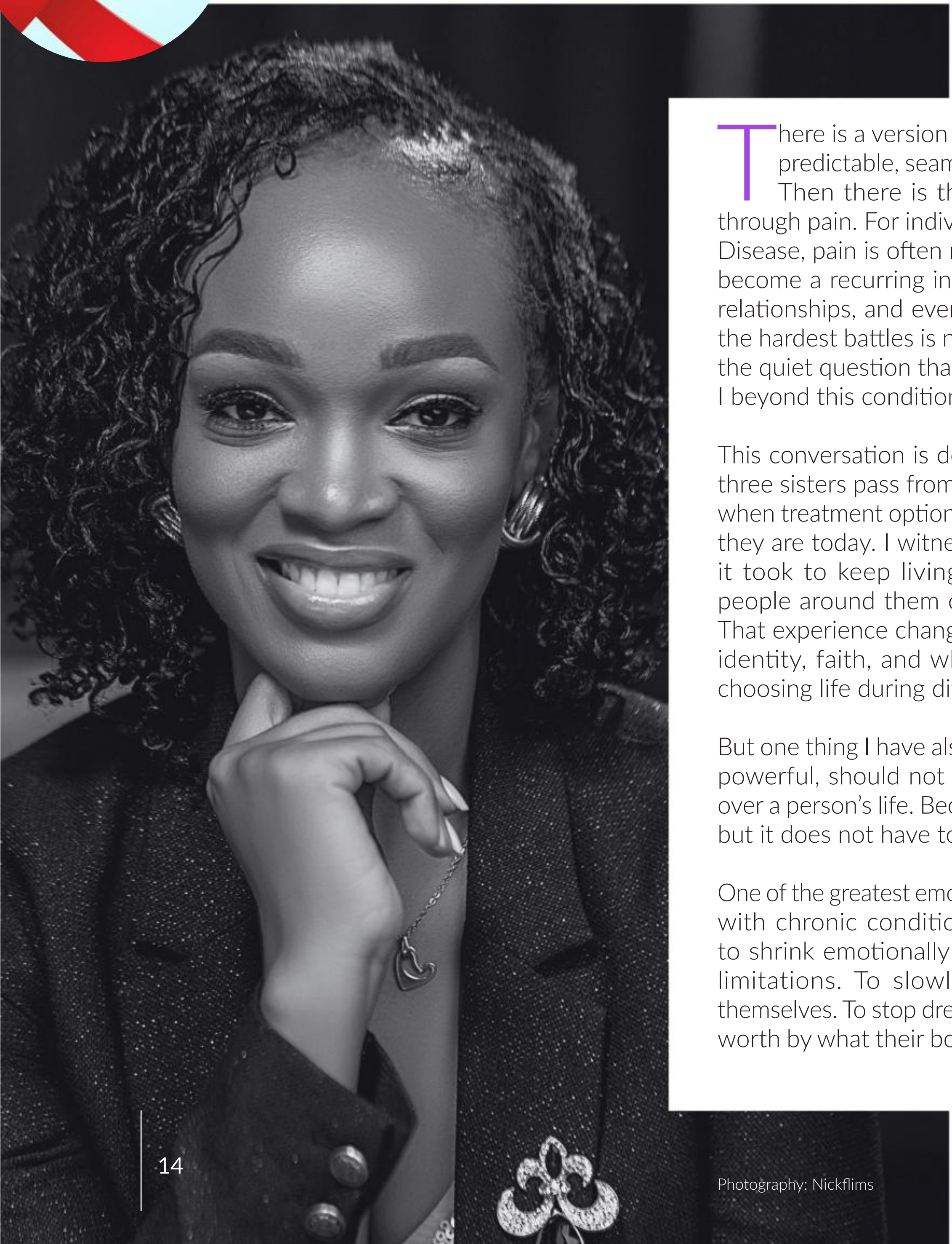

There is a version of life many of us imagine—predictable, seamless, and within our control. Then there is the version of life we meet through pain. For individuals living with Sickle Cell Disease, pain is often more than a moment. It can become a recurring interruption to plans, energy, relationships, and even identity itself. And one of the hardest battles is not always physical pain, but the quiet question that can come with it: Who am I beyond this condition?

This conversation is deeply personal to me. I had three sisters pass from sickle cell anemia at a time when treatment options were far more limited than they are today. I witnessed firsthand the strength it took to keep living through pain that many people around them could not fully understand. That experience changed the way I see resilience, identity, faith, and what it truly means to keep choosing life during difficult seasons.

But one thing I have also learned is this: pain, while powerful, should not become the final authority over a person's life. Because pain changes people—but it does not have to erase them.

One of the greatest emotional struggles many people with chronic conditions face is the temptation to shrink emotionally and mentally around their limitations. To slowly lower expectations for themselves. To stop dreaming fully. To measure their worth by what their body currently allows. Society

Photography: Nickflims

Photography: Brookmatrix

can unintentionally reinforce this through pity, misunderstanding, or reduced expectations. But human identity is bigger than physical limitation. You are still creative. Still capable. Still worthy of impact, love, joy, and meaningful living.

Purpose is not always found in perfect conditions. Sometimes it is revealed in the decision to keep showing up for life even when life feels heavy. And that does not mean pretending difficult days do not exist. There will be moments of exhaustion, frustration, uncertainty, and even grief. Healing is not always the absence of pain. Sometimes healing begins when a person stops seeing themselves only through the lens of suffering and starts reconnecting with their humanity again. Because strength is not denying reality. Strength is refusing to let pain become the complete definition of your existence.

In my work as a Purpose Alignment Coach and through platforms like The Life Pathfinder, I have seen how easy it is for people to lose themselves in difficult seasons. But I have also seen how powerful it becomes when people begin reclaiming identity, hope, and intentional living again—even in imperfect circumstances. Purpose does not always remove pain, but it can give pain context. It can remind a person that life is still happening now—not only after everything becomes easier. Joy is still possible. Growth is still possible. Impact is still possible. Sometimes purpose looks less like grand achievement and more like refusing to surrender your humanity to hardship.

It looks like:

- ***pursuing your dreams at your own pace,***
- ***allowing yourself to be supported,***
- ***finding meaning in everyday moments,***
- ***choosing to live fully instead of only surviving.***

To anyone navigating life with sickle cell: your journey may require a different rhythm, but it is not a lesser life. You are not behind. You are not disqualified from purpose. And you are not defined solely by the hardest thing you carry.

Your story is still unfolding. And even in difficult seasons, there is still purpose waiting to be lived.

Photography: Brookmatrix

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Thriving Beyond the Diagnosis

Mindset, Lifestyle & Emotional Strength in the Sickle Cell Journey

Dr Lewis Thomas

I was 12 years old when I first thought I was going to die.

The pain was relentless, unlike anything I'd felt before. Lying in a hospital bed, I realised for the first time that life was going to be different for me. Sickle cell was like an atomic bomb inside me that I was somehow going to have to build a life around.

20 years later I'm a doctor, a coach, and the founder of The Sickleverse - a digital education platform helping people with sickle cell disease access clear, trustworthy information to live fully. But the journey to get here wasn't straightforward.

I was diagnosed with sickle cell SC genotype at birth. My parents could have let the negative narratives about sickle cell define how they raised me. Instead, they made a vow to raise 'the healthiest child with sickle cell ever'. They told me, consistently and with conviction, that I could do anything I wanted in life as long as I put my mind to it. And I believed them. That belief became the foundation everything else was built on – including, at times, a stubbornness that got me into trouble.

Growing up, I wasn't prepared to sit on the sidelines. The pain of missing out felt almost as bad as the pain of a sickle cell crisis. I wanted to play basketball, drink alcohol and do all the things my peers were. But the fun and games came with painful consequences time after time.

The difficulty was that I had no one around me who also had sickle cell. The invisibility of my illness made it hard to understand and there was loneliness in that. I often felt an unfair restriction was placed on my life in comparison to other kids. It took maturity to understand that it was okay to say no to crisis triggers.

Becoming a doctor felt like the natural destination. From my first inpatient admission, I was drawn to medicine – partly to understand my own illness, partly because I wanted to spare other people the pain I'd experienced. I worked extremely hard academically. I was fortunate that my sickle cell didn't limit me in this area. Qualifying was a huge personal victory for me. But throughout medical training and practice, I hid my diagnosis from almost everyone.

Only my closest friends knew, and even then, only when a hospital admission made it impossible to hide. I was afraid of being perceived as weak. I didn't want to be misrepresented by people who knew nothing about sickle cell. I thought they wouldn't understand the strength of character it takes to live with it.

When I started practicing as a junior doctor, things changed. Whether it was the stress of the job or simply the natural progression of the sickle cell, my threshold for crises lowered. I was ending up in hospital more often than before, which forced me to look honestly at the environment I was working in.

It made me feel like a robot on a conveyor belt. I was just ticking boxes and signing things, there was no time for the human connection I was naturally seeking. There were too few resources and not enough time to actually help people in the way I'd always imagined. Having experienced being a patient myself, the moral weight of that inadequacy was hard to carry.

Between physical illness and growing existential dread I realised I seriously needed to reconsider my future career path and what I wanted do with my one life. The moment of clarity actually came unexpectedly whilst sitting on a beach in Crete. My mind drifted back to work and I just decided then and there to change my life.

Changing meant walking away from clinical practice, something I'd worked so hard to achieve. It was like giving up my fight against sickle cell and to me that felt like the ultimate failure. That was the emotional investment that I had to let go on top of everything else, finances, training, etc.

But eventually I understood that it wasn't failure. Failure would have been continuing on a path I knew was leading no-where good – and doing more harm to myself in the long run. Even though I knew this deep down it took a while for me to connect to it strongly enough to overcome societal judgement.

I'd grown so much since I was 12. I still had to navigate my life around sickle cell. But now I had 11 years medical practice behind me. Now I'd matured to a place where I didn't need to fit into the norm. I realised this was the moment my true purpose was calling. I decided to stop trying to navigate around sickle cell and navigate towards it – in a way that would help millions of people living with it globally and allow me to truly thrive.

What I Know Now

Living with sickle cell has taught me things I couldn't have learned any other way.

First, don't pray for an easy life. Pray for the strength to handle hardship – because life will challenge you regardless, whether through sickle cell or something else entirely. And when you find or create the right environment for yourself, everything you've been through will pay off.

Second, vulnerability is strength disguised as weakness. True strength is being able to face your emotions, not burying them deep inside yourself. Learning to open up and own your story is one of the most freeing things you can do for yourself. The only restrictions that truly matter are the ones you place on yourself.

And to anyone newly diagnosed reading this: You will be okay. Don't fight it, don't deny it. Give yourself time to learn and adapt. The fear will pass, and you will find your way to joy again. I promise you that.

Dr Lewis Thomas lives with sickle cell disease in Manchester, UK. He practiced as a medical doctor for 12 years before stepping back from his role as a General Practitioner in 2025. Since then he has become an established creator of relatable and trustworthy sickle cell education online.

Drawing on his medical training and lived experience with sickle cell disease, he empowers others living with the condition to understand their bodies, advocate for themselves, and stay healthy. He is also an accredited personal development coach.

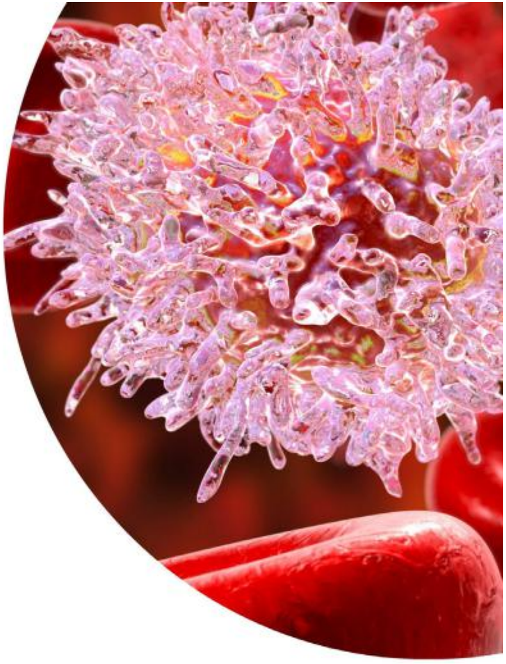
In December 2025, Dr Thomas founded The Sickleverse – an online community and patient education platform that encapsulates all of his educational services. It continues to address the unmet needs raised by his growing social media following, combining accessible content with genuine lived insight.

To complement this work, Dr Thomas serves on the board of the Sickle Cell Knowledge and Information Network (SCKIN). As Director for User Experience, he ensures patients are able to engage with AI in a meaningful way to improve their health.

Expertise: Sickle cell patient education, lived experience (HbSC), medical education
Background: Retired NHS GP · 12 years clinical practice · Accredited Life Coach

www.sickleverse.com

Available for: Podcast interviews, speaking engagements, content collaborations



THE RESPONSIBILITY OF CREATORS AND PLATFORMS IN SHAPING NARRATIVES AROUND SICKLE CELL

Written by Glory Beyi

Many people still do not understand what sickle cell is. Content creators frequently use sickle cell as the target of jokes under the excuse of “dark humour”, allowing ignorance surrounding the disease to become embedded within culture.

As algorithms continue to reward shock value regardless of the subject, genuine awareness of the disease does not reach the same corners of the internet as harmful jokes. As a result, the reality of living with sickle cell gets overlooked and drowned out by “yellow eye” jokes, despite yellowing of the eyes being a symptom of haemolysis.

The blood disease predominantly affects those of African and Caribbean descent, and 18,500 people in the UK alone, according to the Sickle Cell Society. Day to day, we pass many people with the condition without always realising what they are going through. The only visible indicator associated with sickle cell is yellowing of the eyes, which has become the entry point for jokes that circulate across the internet. With over 2.4 billion users on social media daily, spending an average of 2 hours 28 minutes online, we are all aware of the speed at which content is pushed into the cycle of ‘likes and reposts’ displayed on our “For You” pages. We have also seen how repeated jokes can quickly become trends among content creators and familiar faces on our mobile screens.

Many digital platforms and creators often prioritise virality over recognising the weight that each word in their content can hold. In this absence of responsibility, people living with sickle cell are left dealing with pain crises, blood transfusions and frequent hospital visits, while being isolated and ignored at the expense of cheap social media laughs.

Awareness of the blood disorder is present, especially in multicultural areas of the UK such as London however, the online representation of sickle cell has been reduced to one-liners that continue to spread across social media. Conversations around sickle cell often become loudest when humour is involved, yet much quieter when discussions turn towards education, blood donation and support for those living with the condition. In online spaces where attention has become currency, entertainment is often prioritised. This has created an environment where many people become familiar with the jokes attached to sickle cell without ever learning the daily reality of living with it.

> ***“Content creators frequently use sickle cell as the target of jokes under the excuse of “dark humour”, allowing ignorance surrounding the disease to become embedded within culture.***

For some people, sickle cell only exists as a passing jest seen online. For others, it exists in hospital wards, family homes and everyday routines shaped around medication, fatigue and constant symptoms. The disconnect between online humour and real life experience becomes even more concerning when those making the jokes may never have witnessed the seriousness of the disease beyond a viral clip or comment section.

The internet rarely stays online. When serious illnesses are constantly reduced to punchlines, it becomes harder for people living with them to be taken seriously in real life. For some young people with sickle cell, repeatedly seeing their condition mocked online can create embarrassment and emotional exhaustion during stages in life where confidence and identity are still being formed. What begins as “just jokes” online can slowly shape attitudes offline. If creators profit from influence, it is fair to say they also shape the perception of their audiences and wider online communities.

The same system applies to society’s attitude towards sickle cell. If people living with the condition are constantly reduced to mockery, then how can communities be encouraged to come together and donate blood for the transfusions needed to strengthen and support the lives of those with sickle cell?

The issue is not simply one insensitive joke or one creator making a careless comment. It is the normalisation that follows when the same remarks are repeated so often that they become part of online culture. Influence comes with awareness. Raising awareness of blood donation centres, encouraging conversations about testing for the trait and correcting misinformation on their platforms would hold far more value than degrading remarks made for entertainment.

> *“Raising awareness of blood donation centres, encouraging conversations about testing for the trait and correcting misinformation on their platforms would hold far more value than degrading remarks made for entertainment.”*

Widening the discussion around what sickle cell is, how people can find out if they carry the trait and what can be done to help holds importance beyond the internet. Not only can it challenge the stigma surrounding the disease among peers in school playgrounds and workplaces, but it can also remove the shame that some young people may feel about living with sickle cell.

Creators and major platforms online help shape what society laughs at, ignores and chooses to understand. Sickle cell deserves to exist as more than a punchline or a passing comment packaged as a joke.

Glory is a dynamic presenter and live host, currently hosting the early weekend breakfast show on Capital Xtra. Known for her infectious energy and deep connection to music & culture, she brings a strong, engaging presence across radio, television, digital platforms, and live events.

Her experience spans major stages and cultural moments, including BRITs Week, the BAFTAs, UK Black Pride, Comedy Central, Camp Bestival, and the Music Industry Awards, where she has confidently hosted audiences of over 10,000 people. Alongside her work across broadcast, TV, and live events, Glory has built a strong and growing digital audience rooted in relatable, unapologetic commentary on music, culture, and her world view, further showcasing her connection with audiences across platforms.

Glory is a versatile talent with a proven ability to connect with both live and broadcast audiences, consistently bringing charisma, confidence, and presence to every platform she steps onto.

More Than Blood

Why the Growing Call for Black Blood Donors Matters

By Painless Universal

For many people living with Sickle Cell Disease, blood is more than medicine. It is survival. It is relief after unbearable pain. It is another chance to keep going.

Across the UK, the demand for specialised blood used to treat people living with Sickle Cell Disease has risen significantly over the last decade, leading to urgent calls for more Black blood donors to come forward. According to recent reports, requests for haemoglobin S-negative blood, the type most commonly needed for Sickle Cell transfusions have increased dramatically as more patients require ongoing treatment and support.

But behind the statistics are real people and real lives. Children trying to stay in school despite painful crises. Young adults balancing careers while navigating hospital visits and chronic fatigue. Parents carrying the emotional and financial weight of long-term care. Families learning to live around uncertainty while still holding on to hope.

Because Sickle Cell Disease mainly affects individuals of African and Caribbean heritage, ethnically matched blood is often essential for safer and more effective treatment. Many patients develop antibodies over time, making compatible blood increasingly difficult to find unless donors come from similar ethnic backgrounds. And yet, despite the growing need, Black donors remain underrepresented within donor systems.

This reality has sparked important conversations around healthcare awareness, representation, trust, and community responsibility.

> *"One blood donation can directly impact and potentially save the life of someone living with Sickle Cell Disease."*

For some individuals living with Sickle Cell, blood transfusions are not occasional procedures. They are part of everyday life. They help reduce complications, improve oxygen flow, manage severe symptoms, and in some cases prevent life-threatening emergencies.

Without access to properly matched blood, treatment becomes far more difficult. But beyond medicine, this conversation is also deeply human.

Many within the Sickle Cell community have long spoken about feeling overlooked within wider healthcare conversations, despite the condition affecting thousands of individuals and families across the UK and globally. The growing call for Black blood donors therefore represents something much bigger than a medical appeal. It is also a call for visibility, solidarity, and support.

Advocacy organisations and healthcare groups continue to encourage more conversations around blood donation within Black communities while working to address misinformation, fear, and mistrust surrounding healthcare systems. Their message remains simple but powerful: one blood donation can directly impact and potentially save the life of someone living with Sickle Cell Disease.

There is something incredibly powerful about knowing that a stranger's decision to donate blood could help another person live more fully, recover more quickly, or simply make it through another difficult week. Sometimes, healing begins with community.

And perhaps that is the heart of this conversation: reminding individuals living with Sickle Cell that they are not alone. As awareness around Sickle Cell Disease continues to grow globally, one thing remains clear — awareness matters, but action matters too. Because for many people living with Sickle Cell Disease, access to the right blood is not optional.

It is life.

How to Give Blood in the UK

Donating blood in the UK is free, safe and takes about one hour. NHS Blood and Transplant urgently needs donors of Black heritage to help treat Sickle Cell patients.

To be eligible, you must be aged 17–65, weigh at least 50kg, and be in good general health. Men can donate every three months; women every four months.

To register and book:
- Visit www.blood.co.uk or download the NHS Give Blood app
- Find your nearest of 27 donor centres or a local community donation session

If you live outside England.

One hour. One decision. One life changed.

A Familiar Foreigner Holding Onto Normalcy

by Maite Rodriguez

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Luilli Photography (IG: @LuilliPhotography)

"It was a grief so present and consuming, yet constantly pushed aside because our reality did not allow us the luxury of stopping long enough to fully confront it."

Almost a decade ago, I ran into a friend I hadn't seen in a few months, and we took some time to catch up on each other's lives. He was about fifteen years older than me, had been married for over twenty years, was raising three teenage children, and was highly respected in his career. I admired what I considered his very "adult" life and all that he had built.

During our conversation, he asked me a question that caught me completely off guard: "Maite, how is your health, and your family's health?" At 23 years old, the question felt oddly out of place — even amusing. I was young, healthy, and surrounded by people who seemed healthy too. What could he possibly mean by that?

Unfortunately, but also gratefully, I came to understand the weight of that question very soon after. Within six months, my grandmother became terminally ill and passed away. Nine months after her death, my mother experienced a multiple sclerosis flare that left her hospitalized for two weeks and with limited mobility. This happened while I was seven months pregnant with my first child, whom I would later learn had sickle cell anemia (HbSS).

I often think my naivety that day existed for a reason. I don't believe my friend remembers that conversation, but his question has stayed with me ever since — a constant reminder that there was a path unfolding before me long before I could recognize it.

At the time of my daughter's birth, she seemed as perfect as any newborn does in the eyes of their parents. My husband and I were terrified to suddenly be responsible for a life beyond our own, yet overjoyed to begin this new chapter. In the blur of those first few weeks, we received our daughter's diagnosis, and the news came as a profound shock.

We did not fully understand what it meant at the time, so we turned to the internet in search of answers. It felt impossible to comprehend that our perfect child had inherited this terrifying disease from us. There was guilt, sadness, and above all, fear — fear of the unknown, accompanied by a quiet but persistent sense of hopelessness that never fully left us.

As she grew, so did our worries. The medications, specialist appointments, hospital admissions, and the careful planning required every time we left the house gradually became our new normal. What once felt overwhelming slowly transformed into the accepted rhythm of parenthood.

And with that, grief entered our lives. It was a grief so present and consuming, yet constantly pushed aside because our reality did not allow us the luxury of stopping long enough to fully confront it. Deep down, we both understood what we were mourning, even if we were too afraid to say it aloud. We grieved the childhood our daughter deserved — one free from pain, hospital stays, and constant health scares.

We mourned the experiences and opportunities we knew this disease would continue to take from her. And beneath all of it lived our greatest fear: that one day we might be forced to do the unimaginable and grieve the loss of our perfect child.

So, we made what was both the hardest and the most effortless decision of our lives: we chose to invite hope back into the picture and fight to save her life. We embarked on a three-year journey that ultimately led to our eldest daughter undergoing a stem cell transplant to cure her sickle cell disease. She received her baby sister's perfectly matched stem cells — a gift that ultimately freed her from the disease.

Luilli Photography (IG: @LuilliPhotography)

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Throughout this deeply transformative process, we came to realize that it was not only Alessia who was being healed. In many ways, we were being transformed alongside her. Her journey toward healing slowly became our own, allowing us to begin moving forward after years of fear and grief, now carrying something we had not allowed ourselves to hold onto for a very long time: renewed hope.

And although the journey was neither pain-free nor easy, it was worth it. Although healing is far from over, we are finally living through life rather than merely surviving it. Although we lost so much of ourselves to this disease, we also discovered the beauty hidden within normalcy. I have become a familiar foreigner to the woman I used to be.

The person I am now — gentler, more honest, and more grounded — still carries the same longing that once lived within me: the desire to become, and to help others become.

Luilli Photography (IG: @LuilliPhotography)

This foreigner feels familiar because the girl I once was still recognizes her and beams with pride. She understands that although the journey that led us here was not the one we had envisioned, it was the one necessary for us to discover the true beauty of normalcy — and to learn how to find it, hold onto it, and preserve it without losing ourselves in the process.

This transformation did not emerge from nowhere. It was born from pain and grief.

It was the pain of helplessness and powerlessness. The raw suffering that comes from watching your child suffer over and over again. A pain that could not always understand reason, yet clung to it desperately because without it, there would have only been more pain, more fear, and more uncertainty.

> *“Throughout this deeply transformative process, we came to realize that it was not only Alessia who was being healed. In many ways, we were being transformed alongside her.”*

But the journey was never about becoming someone entirely new. It was about returning to myself with greater understanding, softer edges, and the courage to exist authentically even after the storm. Somewhere between who I was and who I am becoming, I found peace in understanding that healing does not erase us; it introduces us to ourselves again.

And now, almost a decade later, I finally understand the true meaning behind the question my friend asked me that day: “How is your health?” Because, in the end, our health is often intertwined with the well-being of those we love, becoming the fragile foundation upon which our sense of normalcy is built.

Maite Rodriguez is a mom, social worker, educator, author, and advocate supporting children and individuals living with chronic illnesses and disabilities. Originally from Santo Domingo, Dominican Republic, she draws on personal and professional experiences—including her daughter’s journey with sickle cell disease—to create empowering stories and advance patient, caregiver, and bone marrow transplant advocacy, while serving as a board member of Sickle Cell Prodigy.

Her debut book, inspired by her daughter’s journey with sickle cell disease, honors the strength of children and families. She lives in Long Island, New York, with her family and enjoys tending to her flower and vegetable garden.

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Cure, Hope and a New Chapter

REDEFINING LIFE BEYOND SICKLE CELL ANAEMIA

By Simone Bruna

I was born with Sickle Cell Disease in a very small town, at a time when almost nobody knew about the condition. I grew up surrounded by a lack of information, misunderstanding and invisibility. Barriers that can be just as painful as the condition itself. Sickle Cell Disease is already a severe, degenerative and chronic illness, but the absence of information intensifies the suffering of patients and their families even further.

My childhood was extremely difficult. Doctors told my family that I would probably not live very long, perhaps not beyond the ages of seven or fifteen. I was deeply jaundiced, a common characteristic of Sickle Cell Disease, but one that frequently provoked fear and prejudice. From an early age, I had to cope not only with physical pain, but also with the burden of judgement and social exclusion.

The vaso-occlusive crises were always torturous with excruciating pain that is impossible to fully describe. The suffering became even greater when it became clear that many healthcare professionals did not know how to properly manage those crises, and in some cases were not even familiar with Sickle Cell Disease itself. Racism was also present from some of my earliest memories of medical treatment. Hearing advice that I “should not marry a Black man in order not to have children with Sickle Cell Disease” was profoundly cruel, a mindset that turned genetics into an instrument of prejudice.

> *“My childhood was extremely difficult. Doctors told my family that I would probably not live very long, perhaps not beyond the ages of seven or fifteen.”*

Even in the face of all this, I continued growing and surviving. It was only in 2007, at the age of 21, that I met another person living with Sickle Cell Disease. Until then, I had felt completely alone in the world. That was when I found support within the patient advocacy movement, and my life began to change. Through symposiums, conferences and national events, I gained access to knowledge that literally transformed my life.

I had the privilege of meeting the unforgettable Kwaku Ohene-Frempong, a world-renowned specialist in Sickle Cell Disease. During an important event in Brazil, he spoke to us about hydroxyurea and explained that, at that moment, it was our best therapeutic option.

Until then, I had feared the medication because healthcare professionals often spoke about its risks without explaining its benefits. Accurate information freed me from fear, and my quality of life improved significantly. But although hydroxyurea represented a major advancement, it was not a cure.

Even with treatment, I faced severe complications, including sickle cell retinopathy, nephropathy and osteonecrosis of the hip. Osteonecrosis stole my mobility, my lightness and my independence. And alongside the pain came a sense of hopelessness.

Bone marrow transplantation, the only concrete possibility of a cure, was considered accessible only to patients who had fully matched siblings. I am an only child. So I grew up believing that a cure was not meant for me.

But I never completely lost hope. I followed the development of gene therapy with great anticipation, and watched as medicine advanced in another transformative direction: haploidentical transplantation. With this approach, the donor no longer needs to be a perfect match, around 50% genetic compatibility is sufficient.

This dramatically expanded the possibilities of a cure for people who previously had none. After a long struggle to find a willing medical team and a compatible donor, my cousin generously agreed to donate his bone marrow, giving me the opportunity to have a new life free from Sickle Cell Disease.

After living with Sickle Cell Disease for 38 years, I underwent a haploidentical bone marrow transplant and was given the opportunity to be reborn without the disease. And this is precisely where the hardest part to explain begins: redefining life beyond Sickle Cell Anaemia.

For the first time, I can look towards the horizon without seeing only limits, pain or fear. Throughout my life, I lived in a constant state of alertness, a continual acceleration of anxiety because, deep down, I felt that at any moment my time could come to an end. My dreams were shaped around survival. Now, for the first time, I am learning to slow down. Learning that perhaps I can finally look ahead with more peace, and reclaim projects I once did not even dare to imagine.

“Throughout my life, I lived in a constant state of alertness, a continual acceleration of anxiety because, deep down, I felt that at any moment my time could come to an end.”

Of course, the scars remain. The osteonecrosis continues to be a deeply painful legacy, and there are emotional scars that may never fully disappear. After all, surviving for so many years with such a severe condition profoundly changes the way we see the world, our bodies and life itself. And yet, today, the future seems hopeful.

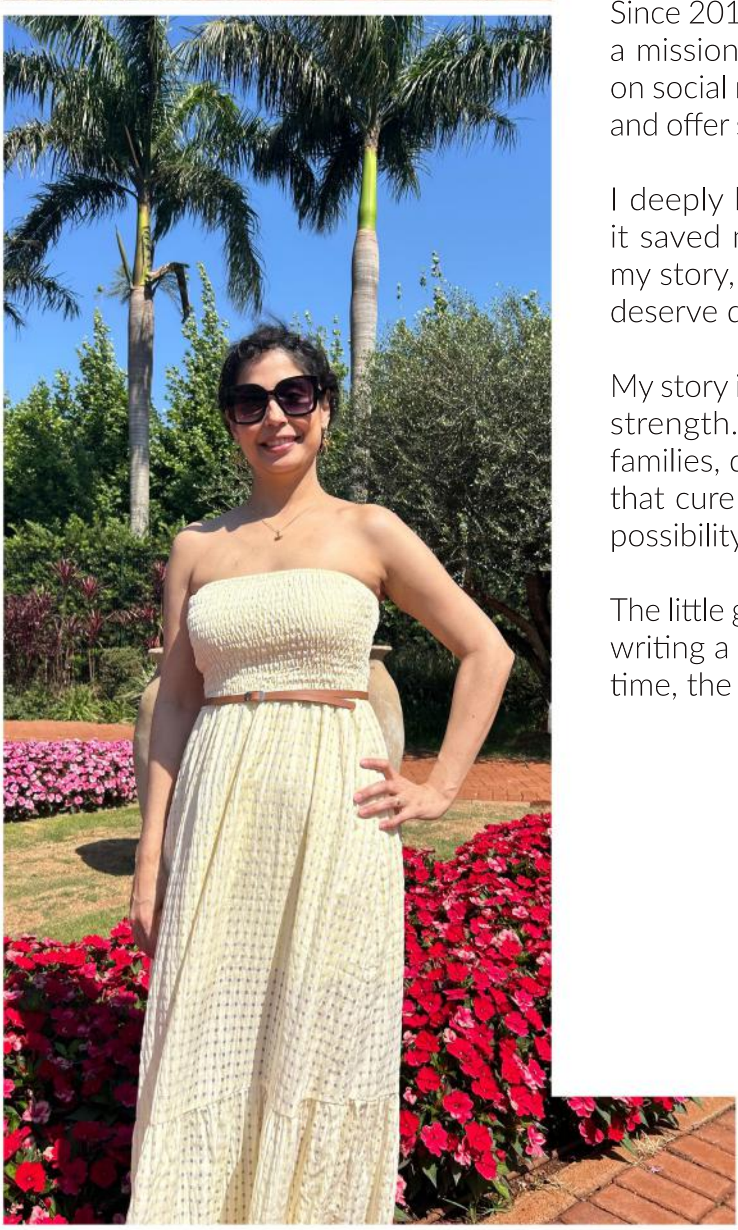
Since 2016, I have transformed my lived experience into a mission through digital content, sharing my journey on social media to provide information, raise awareness and offer support across Portuguese-speaking countries.

I deeply believe that information saves lives just as it saved mine. Today, I use my voice not only to tell my story, but also to help others understand that they deserve dignity, access to healthcare and hope.

My story is about resilience, faith, science and collective strength. It is about doctors, researchers, activists, families, donors and patients who continue fighting so that cure ceases to be a privilege and becomes a real possibility for all.

The little girl who was told she would not live long is now writing a new chapter of her own life. And for the first time, the word guiding my future is no longer survival.

It is hope.



Turning Pain into Purpose

By Judith Ojonugwa Matthew

My name is Judith Ojonugwa Matthew and my story is about endurance, grit and courage. Diagnosed with avascular necrosis at age 24, a condition that damaged my hip joints, I have endured countless sickle cell crisis until my hip implant became my only path to mobility

At six months old, life took a turn that defined my journey: I was diagnosed with sickle cell, Thirty one years later, i have survived the battles that came with it but this battles have transformed my pain into purpose.

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“Living with sickle cell isn't easy, it takes grit, purpose, and the courage to turn pain into purpose.

Today, I am an advocate, the founder of Judith Ojonugwa Sickle Cell Foundation **@JOSCEFOUNDATION**, and a voice that insists sickle cell warriors deserve both empathy and inclusion.

I was diagnosed at 6 months and trust me living with this condition from 6 months till now that I’m 31 isn’t cheesecake. It takes grit, it takes a purposeful person.

It takes one who is tenacious. It takes one who is daring to live with sickle cell because Nigeria also has the highest burden of this disease and having sickle cell in a country like Nigeria, with the state of inflation here and there, and you are a warrior and now a woman Is so tough.

So what this meant for me was that I needed to double up on the things that brings money.

TOUGHEST PART OF MY JOURNEY WITH SICKLE CELL, AND HOW I FOUND STRENGTH TO KEEP PUSHING

“The toughest part of my journey with sickle cell is recurring crisis, fatigue, pleural effusion, ovarian cyst, temporary amnesia, having an enlarged heart, and battling with this lifelong AVN, What has kept me going is the ability to push through and turn my pain into purpose.”

“Living with sickle cell has sharpened my life in the area of dealing with low self-esteem, depression, and causing me to be anxious due to the frequent pain, opioids and NSAIDs I have taken from hospital visits. In the area of career choices, this has caused me to lose out on 9-5 jobs, thereby making me take up freelance jobs, on relationships, this has made finding a partner difficult. Several complaints rise from the fact that it is expensive to manage.

“It takes one who is tenacious. It takes one who is daring to live with sickle cell.”

AWARENESS AND ADVOCACY

“I am using my platform as an advocate to change narrative by dispelling several myths, that sickle cell warriors are lazy and unfit, the myth that they won’t live past the age of 10 (1 mean, I am 31 years old), the myth that they are unintelligent. I’m dispelling these myths and spreading facts.

I’ve also built a safe space for warriors, connecting them and reducing the feeling of loneliness and isolation. I’ve also shared stories of success and resilience to inspire younger warriors living with sickle cell.


TMC PHOTOS


TMC PHOTOS

WHAT AM I PROUD OF?

I’m proud of founding the Judith Ojonugwa Sickle Cell Foundation **(JOSCEFOUNDATION)** an NGO that caters to the needs of warriors.

I’m also proud of my personal growth and achievements despite everything sickle cell has thrown at me,

I am grateful that I am playing a huge part in advocating for this cause because the future looks promising. Awareness is growing, rescarch is advancing, and advocacy is gaining momentum.

Organizations like JOSCEFOUNDATION and the Sickle Cell Foundation in Lagos, are leading the change, For me , I will continue advocating for more awareness, better education. policy changes. and improved access to healthcare for warriors across the country.

United Voices Unfinished Work

The Richard Coker Foundation on Collaboration, Hope and the Future of Sickle Cell

For more than two decades, The Richard Coker Foundation (www.therichardcokerfoundation.com) has worked tirelessly to raise awareness, support families and champion hope for those living with sickle cell and other rare blood diseases across the United Kingdom, Africa and beyond. Founded in 2004 in memory of Filmmaker Richard Coker (Enahoro) by his dear mother Dame Julie Coker, friend Baba-Jallah Epega and other family members; following his courageous battle with complications arising from sickle cell condition, our mission has always been rooted in dignity, compassion, education and action.

Today, we stand at a pivotal moment in the global sickle cell journey.
Scientific breakthroughs, emerging gene therapies, improved clinical understanding and stronger advocacy movements are creating unprecedented opportunities to transform lives. Yet despite this progress, millions across Africa and the diaspora still face barriers to diagnosis, treatment, education and long-term support. Too many families continue to navigate this journey in silence, isolation and inequality.

“The future of sickle cell progress cannot be built in silos.”

At The Richard Coker Foundation, we believe the future of sickle cell progress cannot be built in silos.

No single organisation, institution, researcher or advocate can solve these challenges alone. Working within the Sickle Cell Alliance with the National Institute of Healthcare & Research, Imperial College Healthcare NHS Trust and the Global Action Network for Sickle Cell Disorder & other Inherent Blood Disorders Africa: the time has come for greater collaboration between patient groups, healthcare providers, researchers, policymakers, charities, community leaders and responsible corporate partners. Through our collective work and our growing network of clinicians, advocates, patients and international stakeholders, we are committed to helping build bridges between research, care and community.

Our global vision is bold but necessary: a future where every child born with sickle cell has access to early diagnosis, quality healthcare, culturally relevant education, nutritional support, empowered communities and the dignity of opportunity. A future where African-led research, diaspora collaboration and international partnerships work hand in hand to reduce suffering and accelerate innovation.

Through initiatives such as Voices of Resilience - World Sickle Cell Day 19 June 2026, we aim to convene clinicians, researchers, patient advocates and policymakers to reshape the narrative of sickle cell worldwide and strengthen UK–Africa healthcare collaboration.

Shaftesbury School Wandsworth

RCF, The Venus Bushfires Pidgin Opera & Gibraltar Orchestra Recital on Stage 2019 Sickle Cell Awareness.

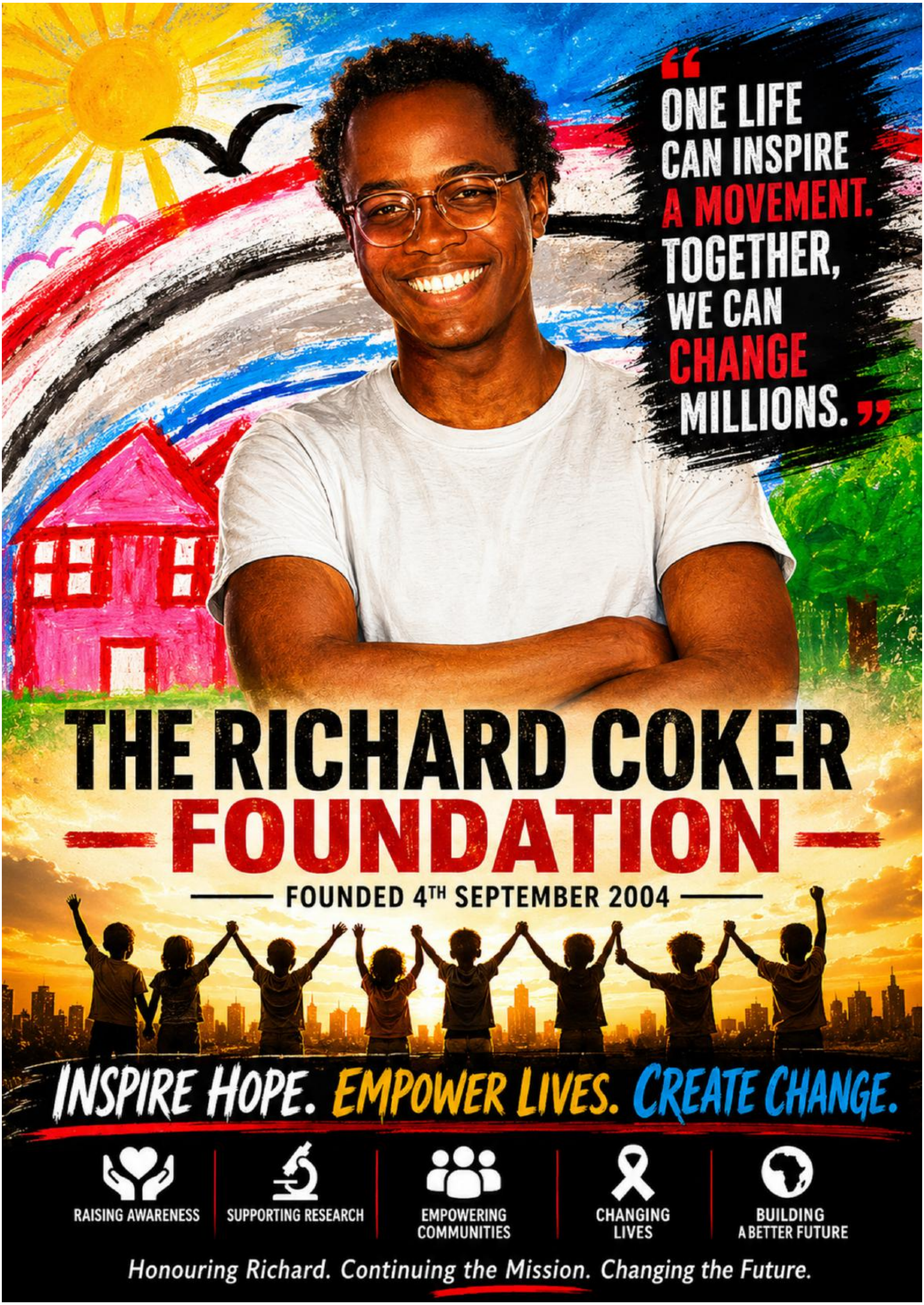
Uncle Mike Enahoro, Aunty Julie Coker & Richard Coker Enahoro at Richard's Baptism

RCF SC July 22 Ayo

We invite all organisations and individuals working within the sickle cell field to join us, not in competition, but in collective purpose.

Together, we can amplify awareness, inspire resilience, support research, empower communities and help ensure that people living with sickle cell are not merely surviving, but truly living well.

“The future will not be built by isolated voices. It will be built by united ones.”



THE RICHARD COKER

FOUNDATION

FOUNDED 4TH SEPTEMBER 2004

INSPIRE HOPE. EMPOWER LIVES. CREATE CHANGE.

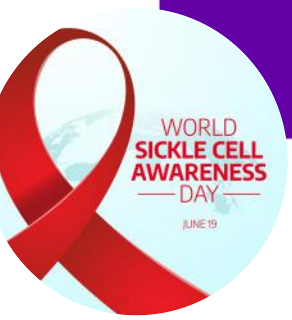
- RAISING AWARENESS
- SUPPORTING RESEARCH
- EMPOWERING COMMUNITIES
- CHANGING LIVES
- BUILDING A BETTER FUTURE

Honouring Richard. Continuing the Mission. Changing the Future.

Beyond Awareness... My Story Through Pain

By Dr. Manahil Mansoor

Living with sickle cell disease has never been just a medical condition to me. It has been a lifelong journey that shaped the way I see life, strength, and even myself. Since childhood, pain was always present in some form. Pain crises, exhaustion, hospital visits, and days where simply getting through the day felt like an achievement. Over the years, I learned how to smile through discomfort, how to continue despite fatigue, and how to appear “fine” even when my body was struggling in silence.



I thought I understood my illness.
I thought I had adapted to it.
Then one day, I heard a new diagnosis:

Moyamoya Disease

A rare condition that affects the arteries of the brain, causing them to narrow and restrict blood flow. To compensate, the body forms tiny fragile vessels that, on scans, resemble a cloud of smoke — which is why it is called “Moyamoya.”

And honestly, that was exactly how life began to feel:
blurred vision, difficulty speaking, intense headaches, fear, confusion, and moments of deep uncertainty.

“The condition I had lived with all my life had quietly placed stress on my blood vessels for years, eventually opening the door to neurological complications I never imagined I would face.”

What affected me most was discovering the connection between Moyamoya and sickle cell disease. The condition I had lived with all my life had quietly placed stress on my blood vessels for years, eventually opening the door to neurological complications I never imagined I would face.
That realization changed me.

I knew I could no longer live on survival mode alone. I needed to rebuild my life differently — with more awareness, more balance, and more compassion toward myself.

I began redefining what wellness meant to me.
Rest was no longer something I felt guilty for needing.
Mental health became part of my healing.
Listening to my body became essential, not optional.

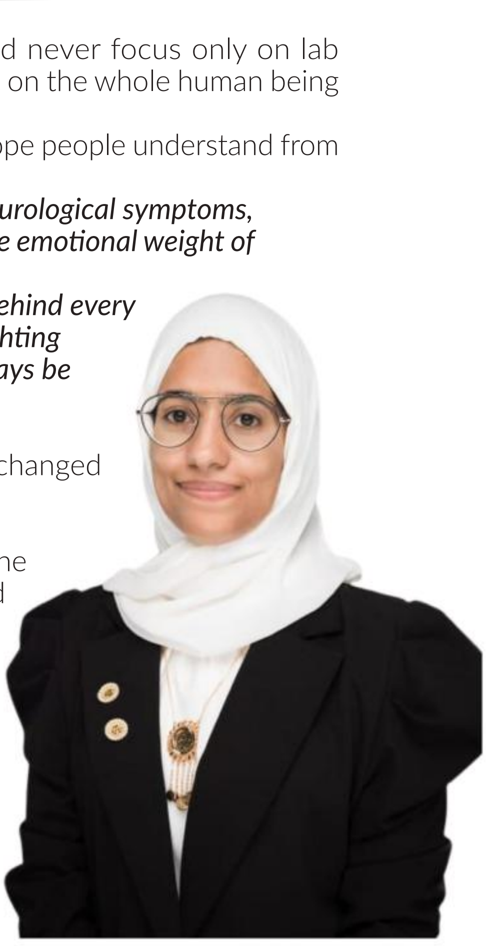
For the first time, I stopped trying to simply “push through” everything. Instead, I started living more consciously.

This experience taught me that chronic illness is never only physical. It affects the mind, emotions, relationships, and every detail of daily life. And that is why real care should never focus only on lab results or numbers, but on the whole human being behind the diagnosis.
If there is one thing I hope people understand from my story, it is this:
Never ignore sudden neurological symptoms,
Never underestimate the emotional weight of chronic illness,
And never forget that behind every diagnosis is a person fighting battles that cannot always be seen.

What I went through changed me deeply.

But somewhere after the fear, exhaustion, and uncertainty...

I found a new version of myself — one that lives with greater awareness, softness, and strength.



From Lived Experience to Self-Expression

Beauty, Identity & Strength Beyond Sickle Cell

With Aziliz

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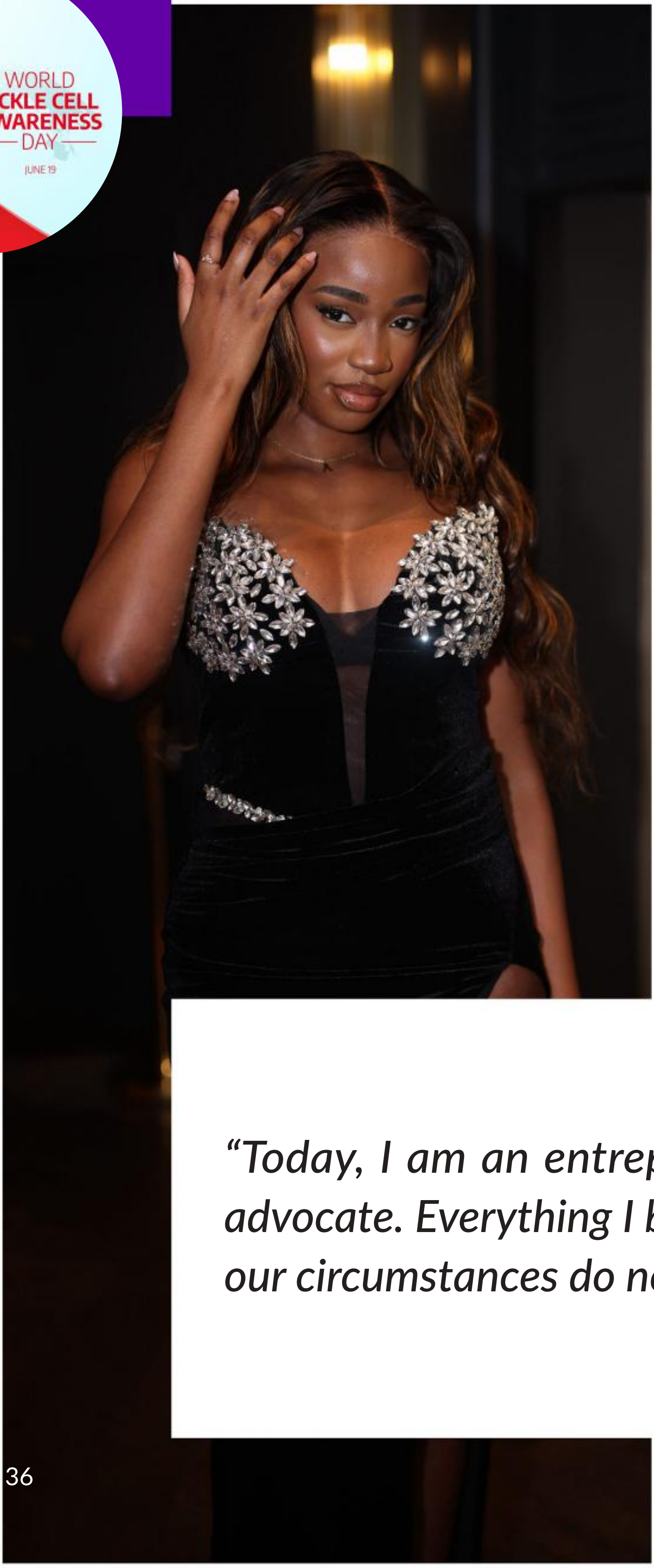


In this inspiring feature for the Sickle Cell Awareness Edition of Painless Magazine, Aziliz shares her journey of navigating life, confidence, and self-expression while living with Sickle Cell.

Through conversations around beauty, identity, resilience, and emotional wellbeing, she reflects on what it means to embrace strength beyond the diagnosis and redefine self-worth on her own terms.

Growing up with Sickle Cell can shape many aspects of a person's life and identity. Looking back, how would you describe your journey from childhood to becoming the woman and entrepreneur you are today?

My journey has been one of resilience, transformation, and purpose. I was born with Sickle Cell Disease, and although my childhood was relatively stable, my teenage years brought severe complications that completely changed my life. I experienced unbearable pain crises, suffered a stroke, and even fell into a coma. At 18, doctors told me that a bone marrow transplant was my best chance of survival.

> *"Today, I am an entrepreneur, content creator, and advocate. Everything I build is rooted in the belief that our circumstances do not define our future."*

At 20 years old, I underwent that transplant, which ultimately cured me. Going through such life-altering experiences at a young age forced me to mature quickly and develop a level of determination that still guides me today.

Today, I am an entrepreneur, content creator, and advocate. Everything I build is rooted in the belief that our circumstances do not define our future. My journey taught me that even after the darkest moments, it is possible to reinvent yourself, dream bigger, and create a life that once felt impossible.

In what ways has living with Sickle Cell influenced your relationship with confidence, beauty, and self-image over the years?

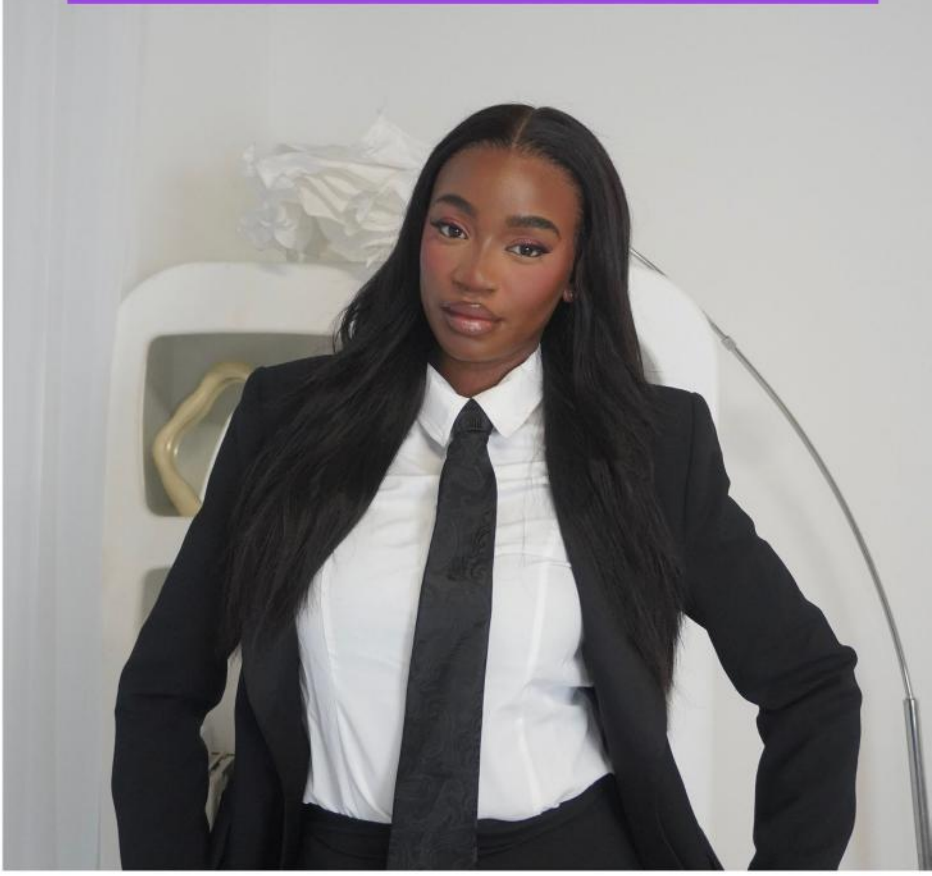
Sickle Cell Disease deeply impacted my confidence at different stages of my life. There were moments when I felt disconnected from my body because of hospitalizations, treatments, and the physical changes that came with them. After my transplant, I lost my hair and had to rebuild my confidence from the ground up. I had to learn that beauty was not defined by how healthy, perfect, or strong I appeared to others. True confidence came from accepting my story rather than hiding it.

Today, beauty means authenticity. It is about embracing every chapter of my journey. The scars, the challenges, and the victories. The experiences that once made me feel insecure are now part of what makes me unique.

Beauty and skincare are often seen as external, but for many people they can also become deeply emotional and healing experiences. What does self-care personally mean to you?

For me, self-care goes far beyond skincare routines or beauty treatments. Self-care is listening to my body, respecting my limits, and allowing myself moments of peace without guilt.

After spending so much of my life in medical environments, I learned that caring for myself is also about celebrating life. Whether it is taking care of my skin, traveling, exercising, creating content, or simply spending time with loved ones, these moments remind me that I am more than a patient or a diagnosis. Self-care is an act of gratitude toward the body that carried me through everything.



Were there moments during your journey where you struggled with feeling "different" or misunderstood because of your condition? How did you navigate those experiences emotionally?

Absolutely. One of the hardest parts of living with an invisible illness is that people often do not understand what you are experiencing. There were times when I looked fine on the outside while dealing with intense pain internally.

As a teenager, I sometimes felt isolated because my reality was different from that of my friends. While others were focused on typical teenage experiences, I was attending medical appointments and worrying about my health.

What helped me navigate those emotions was finding purpose in my experience. Over time, I realized that my story could inspire and educate others. Speaking openly about my journey transformed something that once felt isolating into a source of connection.

Your platform and brand reflect elegance, confidence, and self-expression. How intentional was it for you to build a brand that reflects strength beyond your diagnosis?

It was very intentional. While Sickle Cell Disease is an important part of my story, I never wanted it to be the only thing people saw when they looked at me. I am also a woman who loves fashion, beauty, travel, entrepreneurship, and creativity.

Building my brand was my way of showing that people living with chronic illnesses can be multidimensional. We can be ambitious, glamorous, successful, vulnerable, and powerful all at the same time.

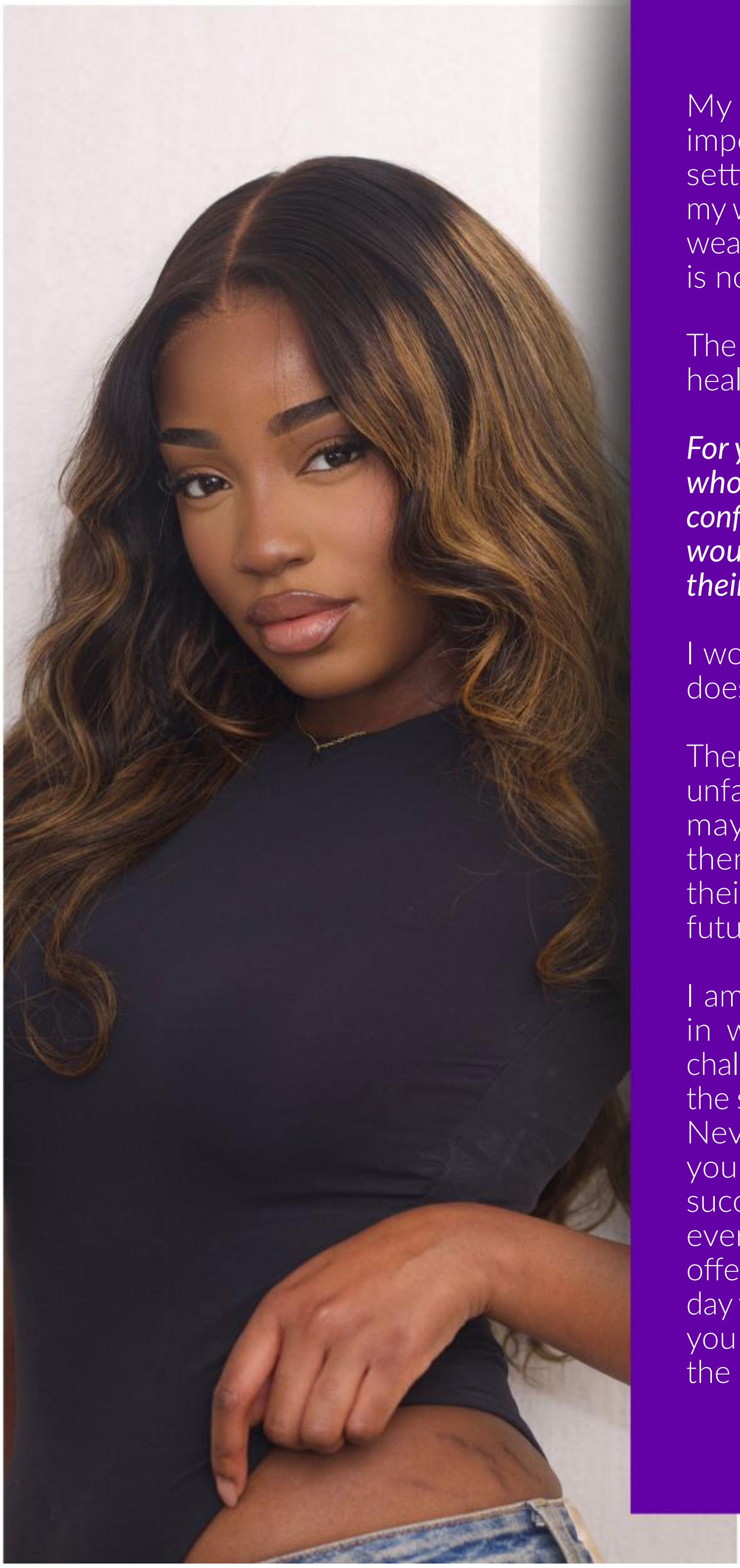
I want my platform to challenge stereotypes and remind people that a diagnosis should never limit how big they allow themselves to dream.

Many people living with chronic conditions often feel pressure to constantly appear "strong." What have you learned about vulnerability, rest, and protecting your emotional wellbeing?

I have learned that strength is not about pretending everything is okay.

For a long time, I believed I had to be strong all the time because that was what people expected from me. But real strength is knowing when to ask for help, when to rest, and when to acknowledge that something is difficult.

“I have learned that strength is not about pretending everything is okay.”



My health journey taught me the importance of protecting my peace, setting boundaries, and prioritizing my wellbeing without guilt. Rest is not weakness it is necessary. Vulnerability is not failure it is honesty.

The more I embraced those truths, the healthier and happier I became.

For young people living with Sickle Cell who may currently be struggling with confidence, identity, or self-worth, what would you want them to know about their future and their potential?

I would tell them that their diagnosis does not determine their destiny.

There may be moments when life feels unfair, exhausting, or uncertain. There may be days when they question themselves or feel left behind. But their dreams remain valid, and their future is still full of possibilities.

I am living proof that life can change in ways you cannot imagine. The challenges you face today can become the source of your strength tomorrow. Never allow your illness to define your worth. You are worthy of love, success, happiness, confidence, and every opportunity this world has to offer. Your story is powerful, and one day you may realize that the very thing you thought would limit you became the reason you inspired others.

Beyond the Surface of Wellness

By Dannielle McNish

In the world of modern healthcare, the word "wellness" and "fullness" are often used as a vague buzzword. However, as a Registered Nutritionist and the founder of Most High Foods ltd, I view wellness through a much more precise lens; which is the biological results of intentional, cellular nourishment. For those living with Sickle Cell like me, nutrition is not a luxury or a secondary hobby; it is a foundational pillar of the management of this blood disorder.

Sickle Cell is a condition characterised by its high physiological demand because, the body is constantly working to produce new red blood cells, manage oxidative stress, and navigate inflammatory responses. To support a body under this level of pressure, we cannot rely on a standard, passive diet, we must transition to a proactive, bioavailable nutritional strategy that respects the complexity of the human body.

The Science of Nourishment: Supporting the "Sickle Cell Warriors" Body.

The term "Sickle Cell Warrior" is fitting because the body is in a constant state of internal defence. From a nutritional perspective this means the body's "burn rate" for certain nutrients is much higher than average. Therefore; nourishment for the Sickle Cell community must focus on three primary goals: erythropoiesis (the production of red blood cells), inflammation reduction, and energy optimisation.

When we prioritise nutrient-dense wholefoods, we aren't just "eating healthy" we are providing the raw materials for the blood's optimum health. This means focusing on natural sources of folate, Vitamin B12, and plant-based iron, which are essential for haemoglobin synthesis. However, it is not just about what you eat; it's about what you absorb! This is where the holistic approach of Most High Foods becomes a game-changer!

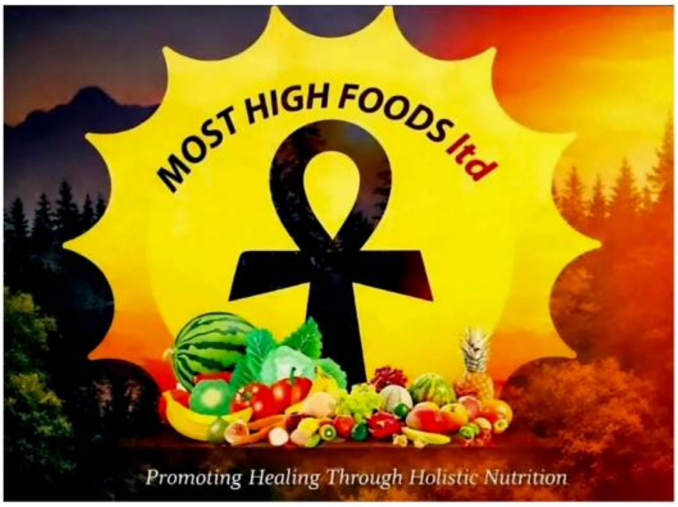
The Mineral Connection: Why Sea Moss is Essential.

One of the most frequent questions I receive at Most High Foods is about the role of sea moss. In the context of holistic wellness, sea moss is far more than a trend; it is a nutritional powerhouse specifically suited for those requiring mineral stability. The human body requires 102 essential minerals to function at its peak; from conducting electrical impulses in the brain to regulating heart rhythm and muscle contraction.

Sea moss provides 92 of these 102 minerals in a bioavailable form. For a Sickle Cell warrior, minerals like magnesium are critical for muscle relaxation and reducing the intensity of vascular constriction. Potassium and sodium balance is essential for maintaining cellular hydration, ensuring that the blood remains as fluid as possible to prevent viscous blood flow or "sticking" that leads to a pain crisis. Incorporating sea moss essentially is "re-mineralising" a system that is often depleted by the stress of the condition.

Combatting Fatigue and Stress Naturally.

Fatigue is one of the most debilitating aspects of the Sickle Cell journey. Fatigue is not just a result of low oxygen, but of "mitochondrial



sluggishness” which is the energy centres of your cells that aren’t getting the micronutrients they need to produce ATP (energy) effectively in the mitochondria.

To support the body during periods of high stress:

1. ***High-Antioxidant Foods: Berries, dark leafy greens, and cruciferous vegetables. These act as “clean-up crews” for the oxidative stress that damages cell membranes.***
2. ***Anti-Inflammatory Fats: Incorporating seeds like blackseed, hemp and flax seeds, which provide the Omega-3 fatty acids necessary to keep cell walls flexible.***
3. ***The “Energy-Dense” foods : While the body maintains a strict blood pH, eating “Energy-dense” foods (mostly plants) reduces the metabolic load on the kidneys and liver, allowing the body to focus its energy on repair rather than processing acidity and toxins.***

Nutrition as a Tool, Not a Temporary Fix.

The most important message I share with my clients is that nutrition is a long-term lifestyle tool. We have been conditioned to look for “cures” and “quick fixes,” but the body does not work in 21-day cycles; It works in years and decades; and by using nutrition as a “fix” leads to a cycle of frustration!

When you view it as a lifestyle tool, you empower yourself, you stop being a victim of symptoms and start becoming a steward of your health. This shift in perspective is what changes the trajectory of a wellness journey, moving you from a state of survival where you are only reacting to pain to a state of maintenance and vitality.

Bridging the Gap: Education and Transformation.

Understanding the science of nutrition is one thing but implementing it into a busy, modern life is another. This is the gap I bridge through my Holistic Nutrition Courses. I realised early in my career that a meal plan isn’t enough, and people need to understand the why and the how.

My courses are designed to take the guesswork out of your health journey transition. covering everything from mineral density to how to restructure your pantry to support an “Energy dense food” healthy lifestyle. For the Sickle Cell community, this education is a form of advocacy. When you know how to fuel your body specifically for its needs, you gain a level of autonomy that is often lost in the medical system. My mission is to ensure that everyone has the tools to change their diet for the better, permanently.

The path to Healing is not a destination; it is a daily practice. For Lady Anne Welsh, her Team and the entire community served by Painless Magazine, I want to offer a message of encouragement:

“Your body is incredibly resilient. When you provide it with the right mineral environment and intentional nourishment, you are not just surviving, you are thriving and honouring the temple you live in”.

By embracing a holistic, mineral-rich lifestyle, we can support our energy, protect our immunity, and walk a path of natural wellness that lasts a lifetime.

Dannielle McNish, MSc, ANutr, a Registered Nutritionist with the Association for Nutrition (AfN) and the founder of Most High Foods Ltd. With a Master of Science in Food Safety & Quality Management and Nutrition and health. Dannielle merges clinical expertise with holistic principles to champion the healing power of mineral-dense, whole foods. Through her Holistic Nutrition Courses and her work with sea moss, empowers individuals to transform their health outcomes by moving toward an intentional, plant-centred lifestyle.

What to eat and avoid to manage Sickle Cell naturally

By Leigh

Sickle Cell Disease is often viewed purely as a blood disorder, but the deeper issue is that sickle cell creates chronic inflammation, oxidative stress and reduced oxygen delivery throughout the body.

One of the biggest overlooked factors is how much nutrition impacts inflammation, circulation, energy production and recovery. The body is constantly working harder in sickle cell, meaning nutrient demands are often significantly higher than average.

This is why many symptoms are linked not only to blood flow, but also to chronic oxidative stress and mineral depletion:

- Fatigue and low energy
- Pain crises and inflammation
- Poor circulation
- Frequent infections
- Brain fog and weakness
- Delayed recovery
- Shortness of breath
- Nutritional deficiencies

Within this framework, the goal is not simply symptom management, it is to:

- Reduce inflammation and oxidative stress
- Support healthy circulation
- Improve oxygen delivery
- Protect blood vessels
- Support immune resilience
- Restore depleted nutrients and minerals

We put together this comprehensive list of supportive foods and herbs as well as things to avoid to help your journey.

Recommended Foods

Dark leafy greens
Rich in folate, magnesium and antioxidants which support red blood cell production and nervous system function.

Beetroot
Contains nitrates that may help support circulation and oxygen delivery throughout the body.

Berries
Blueberries, blackberries and cherries provide powerful antioxidants that help protect cells from oxidative stress.

Omega-3 rich foods
Wild salmon, sardines, flaxseed and walnuts help calm inflammation and support blood vessel health.

Hydrating fruits
Watermelon, cucumber and oranges help maintain hydration, which is extremely important in sickle cell to support blood flow and reduce crisis risk.

Iron-supportive foods
Lentils, pumpkin seeds and spirulina contain nutrients involved in healthy blood production.

Mineral-rich foods
Seamoss, coconut water and leafy greens provide potassium, magnesium and trace minerals which support hydration and muscle function.

High-quality protein
Fish, avocado, legumes and organic poultry support tissue repair and recovery.

Herbal Support

Full Spectrum Seamoss (1 tbsp daily)
Provides a broad spectrum of minerals that support hydration, energy production and overall cellular function.

Cold Pressed Black Seed Oil (1 tsp daily)
Helps regulate inflammation and oxidative stress while supporting immune health.

Raw Spirulina (1 tsp daily)
Rich in chlorophyll, antioxidants and nutrients that support energy and blood health.

Raw Moringa Seeds (2 seeds)
Contains iron, antioxidants and anti-inflammatory compounds that may support fatigue and nutrient replenishment.

Things to Avoid

Dehydration
One of the biggest triggers for pain crises as thicker blood increases the likelihood of sickling.

Ultra-processed foods
Often increase inflammation, oxidative stress and vascular strain.

Excess sugar
Can worsen inflammation and energy instability.

Excess alcohol
May contribute to dehydration and increased stress on the body.

Smoking
Reduces oxygen availability and places further strain on circulation and blood vessels.

Highly inflammatory oils
Frequent consumption of heavily processed vegetable oils and fried foods may aggravate inflammation.

Extreme temperatures
Very cold weather or overheating can sometimes trigger circulation changes and sickle cell crises.

Overexertion
Pushing beyond physical limits without adequate hydration and recovery may increase the risk of fatigue and pain episodes.

Sickle Cell Disease requires far more than simply managing pain episodes, it requires supporting the entire body through nourishment, hydration, circulation support and inflammation reduction.

While nutrition and herbs are not a replacement for medical care, they may play an important supportive role in helping individuals improve resilience, energy, recovery and overall quality of life.

Greater awareness around the role of lifestyle, nutrition and holistic support can help empower families and individuals living with sickle cell to better support the body every single day, not just during a crisis

Leigh is a qualified naturopath and master herbalist and founder of MagicTree Superfoods, voted IE100 Herbal Supplement Company of the year 2026. Leigh is dedicated to helping people to reverse chronic health issues with natural and holistic methods.

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MYTHS VS FACTS

Common Misconceptions About Sickle Cell Disease

By Painless Universal

Separating Dangerous Myths from Scientific Truth — and Why It Matters

Sickle cell disease affects more than 300,000 newborns every year worldwide, making it one of the most common severe genetic disorders on the planet. Despite this, it remains one of the most misunderstood — surrounded by myths that shape how patients are treated in hospitals, schools, workplaces, and communities. These misconceptions do not merely cause offence. They cause harm. Correcting them is a matter of clinical urgency and basic human dignity.

MYTH: Sickle cell disease only affects Black people.
FACT: Sickle cell disease affects people across multiple ethnicities and geographic regions.
The sickle cell mutation arose independently in sub-Saharan Africa, the Mediterranean, the Middle East, and India — regions historically affected by malaria, against which the carrier (trait) form offered partial protection. Today, the condition is found in people of Greek, Italian, Turkish, Arab, South Asian, and Hispanic descent, among others. Diagnosing on the basis of skin colour rather than ancestry and family history puts patients at serious risk of being missed entirely.

MYTH: People with sickle cell disease do not live past childhood.
FACT: With appropriate medical care, people with sickle cell disease routinely live into adulthood and beyond.
Where newborn screening, prophylactic penicillin, hydroxyurea therapy, and access to blood transfusions are available, survival has improved dramatically — many patients now live into their fifth and sixth decades. Where these interventions are absent, mortality remains high. The problem is inequity of access, not biological inevitability. When patients internalise the myth of early death, it diminishes ambition, discourages treatment-seeking, and compounds psychological harm.

MYTH: Sickle cell pain crises are exaggerated, and patients seek opioids for non-medical reasons.
FACT: Vaso-occlusive crises produce some of the most severe acute pain documented in clinical medicine.
During a crisis, sickled red blood cells block small blood vessels, cutting off oxygen to tissues and generating ischaemic pain that patients consistently rate at levels comparable to acute myocardial infarction. Research has extensively documented the under-treatment of pain in sickle cell disease, driven by bias and stigma — disproportionately affecting Black patients. Undertreated pain prolongs crises, increases hospitalisation, and causes lasting psychological trauma. Adequate, timely analgesia is not permissiveness. It is standard medical care.

MYTH: Sickle cell disease impairs intelligence.
FACT: Sickle cell disease does not inherently affect intellectual capacity.
Some patients who have experienced stroke or silent cerebral infarction may develop specific cognitive difficulties with attention or processing speed. These are targeted, addressable neurological complications — not a measure of general intelligence, and not universal. Many apparent learning difficulties in sickle cell patients are compounded by external factors: interrupted schooling, chronic pain, stigma, and inadequate educational support. The distinction between specific neurological challenge and generalised incapacity must not be collapsed.

MYTH: If both parents carry sickle cell trait, all their children will have the disease.
FACT: Each pregnancy carries a 25% chance of the disease, 50% chance of trait, and 25% chance of neither.
This is fundamental Mendelian inheritance. Each pregnancy is an independent event — previous outcomes do not alter the probabilities for subsequent ones. Poor genetic literacy drives fear-based reproductive decisions and reinforces stigma. Accurate genetic counselling empowers families to make informed choices without the distortion of myth.

These are not rare misunderstandings held by the uninformed. They circulate in clinical settings, educational institutions, and public discourse with remarkable persistence. The consequences are measurable: delayed diagnoses, undertreated pain, diminished life expectations, and patients who have been failed by the very systems meant to support them.

Scientific progress in sickle cell disease — including gene therapy approvals, expanded transplant options, and new disease-modifying agents — is accelerating. But that progress reaches its full potential only when the cultural and clinical environment surrounding patients is as accurate as the medicine being offered to them. Getting the facts right is not a preliminary step. It is part of the treatment.

Disclaimer:
The information contained in this article is intended for general educational and awareness purposes only. It does not constitute medical advice, diagnosis, or treatment. While every effort has been made to ensure the accuracy of the information presented, medical knowledge is continually evolving and individual circumstances vary. Readers are strongly encouraged to consult a qualified healthcare professional regarding any questions or concerns they may have about sickle cell disease or any other medical condition. The views and information expressed in this article are based on established scientific literature and clinical research available at the time of publication. Neither Painless Magazine nor its contributors accept liability for any loss or damage arising from reliance on the content of this article.

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