Issue 16

RedCell Newsletter

KING'S HEALTH PARTNERS
Pioneering better health for all

HCC
South East London and South East

Hello and welcome to the latest edition of Red Cell News.

Despite the Covid-19 pandemic, we started 2021 excited about the year ahead. We have already completed various events and initiatives, with plans underway to continue with this across the region during the rest of the year. We have had two fantastic educational events for medical professionals - February 2021 titled 'Transfusion challenges in Haemoglobinopathy' and June 2021 'Therapies of the future' which were both very well attended with clinical team members joining us from across our network and the UK. We also hosted our first virtual Red Cell Day training day for Specialist Haematology Trainees in March 2021 which was presented virtually for the first time and was well received.

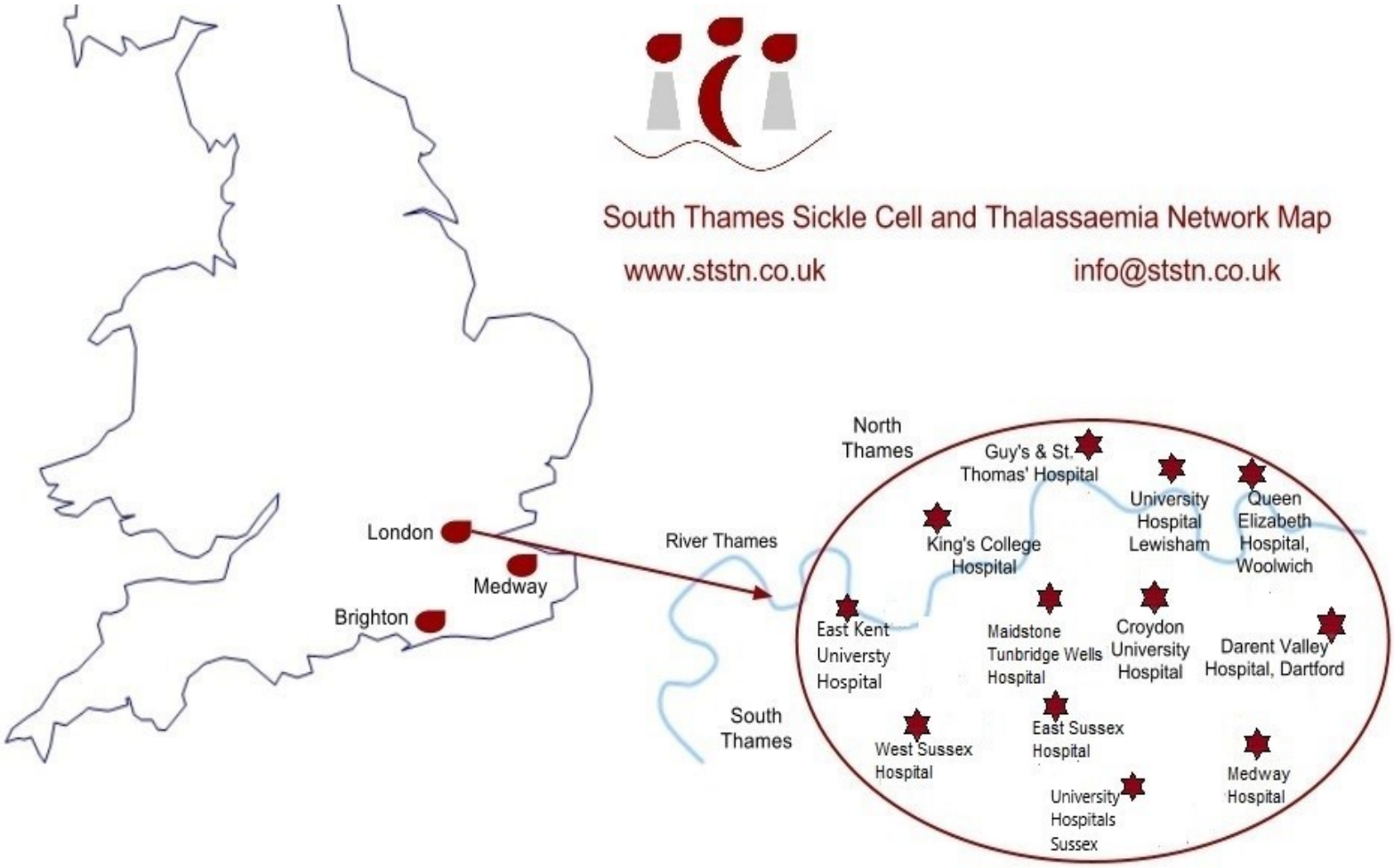
We have refreshed our website and continue to update our information for patients and clinicians, please take a look at www.ststn.co.uk. We're always looking at new ways to improve our overall service and how we can update the website to make it a helpful resource for professionals and patients alike. Currently we are making plans for a fun and friendly patient event (**Sickle Cell Awareness Day**) on the **14th July 2021** which will be held virtually via zoom. In addition, our patient support groups across the region continue to provide friendly, accessible sessions .

We hope you enjoy this issue!

In This Issue:

* Making decisions about covid-19 vaccine
* Semen storage prior to hydroxycarbamide
* Focus on local support groups
* UKTS patient conference & AGM
* Patient zone & stories

Mission Statement: "to improve patient experience by offering better treatment outcomes for people with sickle call and thalassaemia"



Making Decisions about the COVID –19 Vaccine

Written by: Dr Abbie Wickham, Clinical Psychologist, Guy's & St Thomas hospital

It's normal to feel conflicted about important decisions about your health. Some people with sickle cell have found deciding whether or not to have the COVID-19 vaccination challenging. If you are struggling to make this decision yourself, you may find following these steps useful in helping you to come to a decision that is right for you.

1) Manage difficult emotions

It's normal to feel fear, confusion, anger or sadness when making a difficult decision about our health. Strong emotions can make it harder for our brains to make sense of things and think things through. Try some relaxation and mindfulness exercises before thinking things through. Some can be found on headspace (via the app).

2) List all of the options available to you

You might find it helpful to write these down to keep track and easily compare them.

3) Gather information about your options

What do you already know? Did you use reliable sources? Is it fact or opinion? Information on the internet and social media is often unchecked and it is unclear where it came from. Do you have any unanswered questions? Look for the answers from reliable sources such as your Haematology Team, NHS or gov.uk websites. Some information videos can also be found on the STSTN youtube channel and the Sickle Cell Society website.

4) What are the risks and benefits?

What are the positives and downsides/dangers of each option?

5) Weigh up risks and benefits

Compare your lists of risks and benefits for each option. Are there any options with more risks than benefits? Some risks/benefits matter more to us than others – try scoring each one based on it's importance to you personally. Which option scores high on benefits and low on risks?

Remember

Making decisions alone can be difficult. Who could help you? Who do you trust?

Uncertainty exists in everything. **There is no such thing as a risk free choice**. Inaction is action – it is still a choice.

The best decision for you still may feel uncomfortable – this is normal.

Others may have strong view on what is right for you. It does not mean you have to follow their advice

This is **your** choice about **your** health.

Semen storage prior to hydroxycarbamide use

Written by: Dr Sara Stuart-Smith Haematology Consultant, Kings College

Why store sperm?

Some men on treatment with hydroxycarbamide will have a reduction in their sperm count. This will not affect your sexual function, ability to have sex or an erection or to orgasm, and in many cases it will not affect your ability to conceive a baby. Hydroxycarbamide can result in a reduced number of mobile sperm in your ejaculate and in some cases it can impair your ability to become a father in the future. By storing sperm samples before you start treatment, your fertility can be ensured.

How many times do I need to come in to provide a sperm sample?

Usually once, but occasionally it may be necessary to produce and freeze more than one semen sample to allow sufficient sperm to be stored for future use.

How will the sperm be used?

Many men will not need to use their stored sperm as they are able to stop hydroxycarbamide treatment for 3 months to allow their sperm count to normalise, before trying to start a family.
Those unable to conceive naturally, will need to use their stored semen for assisted conception treatment (intra-uterine insemination [IUI], in vitro fertilisation [IVF] or intracytoplasmic sperm injection [ICSI]).

Why do I need to have a blood test for HIV and hepatitis?

Viruses are potentially carried in semen and can contaminate other samples. You will have to have a blood test for HIV, hepatitis B and C at the time you store your sperm. Your sperm cannot be stored without these results.

How long will my sperm be stored for?

Under the provisions of the Human Fertilisation and Embryology Act your semen samples may remain in storage for up to 10 years, or until you reach the age of 55 years, whichever is the longer.

How do you store sperm?

You will be provided with a sterile pot & plastic bag

Using a marker pen, write your name & date of birth on the pot

Following production, ensure the pot is at the Fertility Unit within an hour and keep the sample at body temperature

When you arrive at the clinic, ensure the pot is handed to the embryology team

On arrival you will be provided with a sterile pot & plastic bag

Using a marker pen, write your name & date of birth on the pot

We will guide you to a private room for approx. 20-30 minutes

Support Group

Across our network the patient support groups play a vital part in delivering care/support for people living with sickle cell and their families. Patients and family members get a chance to discuss whatever it is they are feeling in order for us as a service to provide the best possible care.

King's College Hospital Adult Sickle Support Group

Author: Dr Sara Stuart-Smith, Haematologist, Kings College London

The King's Adult Sickle Support Group meets by Zoom every month on the second Thursday of the month from 5:30-7pm, and is an interactive supportive group of individuals facilitated by our psychologist, a senior Clinical Nurse Specialist and a member of the medical team.

Prior to COVID19 we met monthly face to face with tea, coffee and snacks in the Boardroom on the ground floor near the main entrance at King's.

We welcome anyone over the age of 16 to our group, including friends and family members/ carers of those with sickle cell disease.

There is usually an educational session at the beginning of the meeting, including COVID19, vaccinations, travel, relationships, research medications, or any other topic which has been requested by members of the group.

Contact: Giselle Padmore-Payne, Clinical nurse specialist, 02032991424 for more info.

GSTT Sickle Cell Support Group

Author: Dr Ji Park, Clinical Psychologist, Guys & St Thomas Hospital

The GSTT sickle cell support group is a weekly space for our adult patients with sickle cell disease who attend GSTT and their relatives. It is a space to hear from each other about living with sickle cell, explore ideas, and focus on finding or offering solutions for challenges. The group is facilitated by psychologists.

Previously, people were able to attend the group face to face but since the outbreak of Covid-19, virtual support groups were offered to reduce the risk of infections. People, who signed up to the support group reminders, were sent weekly emails about the group with instructions on how to join. Over the past year, there has been an increase in the number of attendees to the virtual group. Typically, 17 to 30 people attend the group each week. Attendees provided feedback that the practical convenience of joining virtual groups made it easier to attend over face to face groups, which had posed challenges with travelling to the hospital site, for example, due to sickle pain and cold weather.

In addition to the groups providing a reflective space for people to hear from each other, the group continued to offer a monthly space for people to hear about particular topics from different health professionals. At the start of the year, we provided talks from a consultant in infectious diseases and consultants in haematology, who shared information about the Covid vaccine. This provided a space to ask questions about the vaccine so that people could be supported to make informed decisions. There have been other talks on clinical trials in sickle cell and health implications of getting older with sickle cell, which allowed people to hear new information and maintain some familiarity and connection with the sickle cell team.

As the Covid situation changes, we look forward to adapting the support group to meet people's needs and perhaps offering a combinations of virtual and face to face groups. If you are a GSTT patient who is interested in finding out more, please email us at hps@gstt.nhs.uk.

Support Group

Croydon Sickle Cell & Thalassaemia Support Group
Author: Sonia Meikle, Chair of Croydon Sickle Cell & Thalassaemia Support Group

CSC&TSG was founded by a group of specialist nurses passionate about raising awareness of the conditions and improving support in the community. Thirty years on and the group is co-located with the specialist clinical nurses and continues to provide help, support and advice to people living with the conditions, their family members and carers.

2020/2021 was an unusual year for everyone. Our members were advised to shield very early on as the pandemic unfolded. The group had to adjust to new ways of working whilst continuing to provide our services. We delivered food hampers, welfare rights advice and a listening ear for those impacted by self isolation.

We run monthly virtual support group meetings and have a running agenda item on reviewing medication and treatment. Over the past four meetings we have discussed hydroxycarbamide, penicillin, co-ordinate my care and infection risk.

We also have a spotlight on benefits and welfare reform and its impact for people living with long term health conditions and on housing.

The group run a number of projects in partnership with other local charities including tuition support and online training from Croydon Supplementary Education Project and weekly food hamper drops with Croydon African Caribbean Family Organisation

CSC&TSG run featured campaigns on our website and the current campaign is called Robert's story – good day bad day. Member involvement is at the heart of what we do and we encourage and consult with them every step of the way. The specialist clinical nurses refer patients to us but we provide an accessible service so that members can reach us at anytime because sometimes, 'a helping hand is all that's needed'.

We have a number events organised over the coming months:

World Sickle Cell Day	19.6.2021
AGM	10.7.2021
Sponsored Walk	21.8.2021

Contact us for more information

www.cscatsg.org

cscatsg@outlook.com

07305 953422

Support Group

Lewisham & Greenwich Patient Support Group

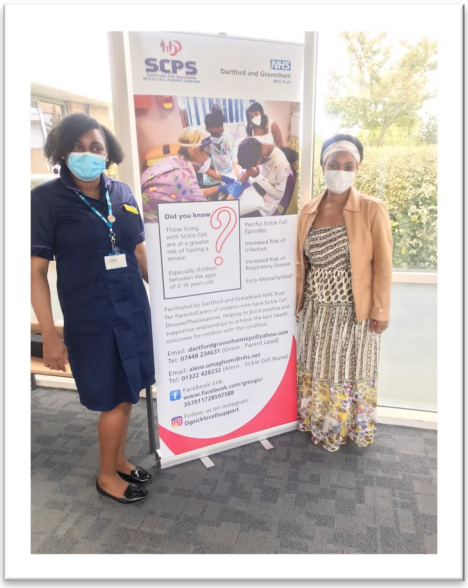
Our colleagues at Lewisham and Greenwich NHS Trust (Lewisham and Queen Elizabeth Hospitals) are currently re-establishing their patient group. We will update our website with future details.

In the meantime, patients are welcome to join our other groups and events at King's Adult Sickle Group and our regional event our Sickle Cell Awareness Day 14th July 2021

Dartford & Gravesham Sickle Cell Parent Support Group

Author: Alero Omaghomi, Paediatric Haematology CNS, Darren Valley Hospital

Dartford and Gravesham Sickle Cell Parent Support Group is a nurse led support group funded by Valley Hospital Charity. This has been developed to provide support for parents and caregivers of children and young people living with sickle cell disease & thalassaemia through education and advocacy. The group is based in Darent Valley Hospital and led by Alero Omaghomi (CNS) with the support of Mrs Grace Bolaji (Parent Support Leader). The group offers a community of like-minded individuals with shared experiences who provide friendship, support and understanding for one another to help promote well-being and improve quality of life



Community Centre Update

Author: Nkechi Anyanwu, Community Matron, Wooden Spoon House

The South East London Sickle Cell & Thalassaemia team ran our first webinar for Parents & Children support group on 12th April 2021, it was well attended and going forward we will meet monthly to discuss on going issues / topics regarding pain management, coping strategies and the overall care and management of children , adolescent and young adults living with SCT in our local community.

Please see the email address below for more information.

gst-tr.woodenspoonsupportgroup@nhs.net

UKTS Patient Conference & AGM

Author: Romaine Maharaj, Executive Director, UKTS

UKTS is the national charity for thalassaemia in the UK with over 43 years of experience in supporting patients, their families and the network of medical and educational professionals involved in their care. As the first port of call for all things thalassaemia, our over-riding aim is to improve the lives of all those living with the condition.

Press release 05 / 2021:

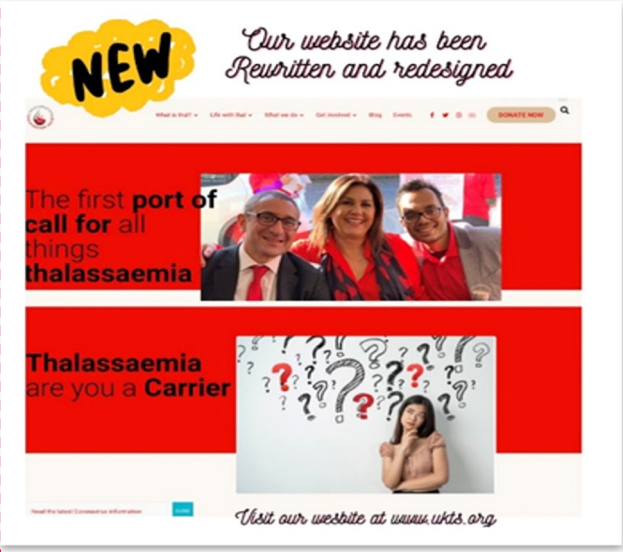
On Sunday 16th May 2021, UKTS held a patient conference and AGM and took the opportunity to launch their new website and logo.

262 members (UK, Italy, Greece, Brazil, India Pakistan and Trinidad and Tobago) registered for the virtual event this year. The event included presentations from Professor John Porter, Professor Josu De La Fuente, Professor Baba Inusa, Dr Farrukh Shah, Dr Julian Waung and Dr Chinea Eziefula.

This programme was the first of its kind as it was focused on topics not previously discussed. Members also had the opportunity to share concerns as well as to provide feedback on the rearrangement of the service and how it affected them based on location. Apart from the speakers, over 20 consultants and health care professionals, despite their extremely hectic workload, signed on to support this event and some have since mentioned that they intend to arrange similar meetings in their areas on a regular basis.

Video recordings of some of the presentations will be made available on the UKTS YOUTUBE platform shortly (https://www.youtube.com/c/UnitedKingdomThalassaemiaSociety)

Please visit our website for more details: **www.ukts.org**



Patient Zone

Living with Sickle Cell

Author: Bola Jibodu, Patient

My name is Bola, I'm married with two children and I have sickle cell. I volunteer for the Sickle Cell Society, a national charity supporting people with sickle cell disease. As a volunteer, I raise awareness about blood donation and the need for more people from black-heritage backgrounds to give blood. I recently took part in a short film to raise awareness of sickle cell and of the innovative treatment of Automated Exchanged Blood Transfusion that has greatly improved my life. My parents found out I had sickle cell when I was 10 months old. They told me that as a baby I would cry non-stop for days. I had swollen joints which made them take me to the hospital where they did a genotype test and found out that I have SCD Hb SS. This is the most common and severe type of sickle cell disease.

Although I was diagnosed early in life, as I grew up, and, as early as the age of 5 years, the experiences of having sickle cell disorder (SCD) became surreal for me. **I was always sick!** It was very hard being a child with sickle cell growing up. It was difficult for my parents to watch their baby in pain and not be able to help.

SCD has had a lifelong impact on me both as a child and as an adult. There was a constant uncertainty in the background about whether I would live or how long for. Every hospital trip drained my parents financially and emotionally. I could not enjoy my childhood or a have proper education as I was always sick. As I got older, the crisis pain increased because of exhaustion and wanting to do more for myself. I always wanted to do more for my family, children, and those around me, but doing too much led to another episode of crisis and my children would ask, '**Mummy why are you always sick?'**

With SCD, there are specific activities I must avoid. Any strenuous activity can bring on a crisis, even getting too excited or being stressed can bring on a crisis episode. Other triggers to a crisis include infection, dehydration, exhaustion, or a change in weather conditions. Anything can trigger a crisis. I used to have crisis every single month and I would spend weeks in the hospital recovering. Those without SCD cannot comprehend what it feels like to have crisis. Doctors and scientists struggle to classify it, sometimes describing it as 'severe, excruciating pain'. For me, the pain experienced in my joints and my chest are the most severe. It feels like a very heavy metal is pressing on my bones. As my body tries to cope with this pain, I often run out of oxygen and my whole-body system starts to shut down.

When Covid happened in 2020, it was especially scary for me because of my health. I was concerned about getting infections which is a predominate cause of a sickle cell crisis. More so, many people that suffer from SCD usually have issues with their lungs and oxygen saturation already, therefore there was a real threat to me should I have caught Covid. There was also the threat of a shortage of blood for treatment of people with sickle cell as people were not donating blood as much due to the pandemic. People with SCD were classed 'Extremely Clinically Vulnerable' so I had to shield at home for many months which was not very easy at all. My husband had to stay off work to minimise the risk of bringing the virus home to me.

Having been stuck at home for a long time due to shielding, I am very excited that I can go back to some sort of normality with work and especially now that I have had my two doses of vaccine. Nevertheless, I still get really worried as having sickle cell means I am highly prone to infection. This year I am also looking forward to continuing my volunteer role at Sickle Cell Society on its Give Blood, Spread Love, England project. We need more black people to start giving blood to ensure that there is enough ethnically matched blood available to meet the needs of people like me who have regular blood transfusions. If you are of black heritage and do not give blood, please consider signing up as a donor here: http://bit.ly/scsgiveblood Donated blood is essential in keeping me alive and well.

Patient Zone

Completing my training and surviving Lockdown with sickle cell

Author: Munirah McCloud, Patient

I started my counselling studies part time in 2011. When my mother became ill, I became her carer. I found myself challenged sometimes juggling between my needs and hers, many times I had to leave my class with a phone call to be at her side.

When mum passed away I found her death really hard to bear. I started to struggle on my course, I found it difficult to hold on to anything. I kept crying everywhere, knowing, and not knowing why. I couldn't focus on academic work. I took a year off in 2015/16, I spoke to Marlene who referred me to the psychologist. I found Gary (the psychologist) understanding and compassionate. He taught me some CBT and mindfulness skills. I also discovered mindfulness complimented both my faith and my psychodynamic counselling training which helped me in focusing to engage with the Uni work, take breaks and sleep. With his support I was able to do my repeat assignment to go back on my course in 2019.

I was challenged at times in the 2nd year in 2019. A new set of students and I was the only Black student. The politics was difficult, like hearing from my fellow classmates that I was expected to fail, as black student don't make it, even with all the learning support at MSc level. I reflected on why my academic success was important and I really knew I couldn't afford to fail. My daughter, my mum and friends were all rooting for me. I used chanting and the mindfulness exercises to get back on track with my studies, and was supported by my friend Grace, and all the sickle cell team, Daniel, Dr Sara, Dr Moji, Giselle, Fester, Virginia and Gary. It is a requirement to have therapy on my course, monies were tight, so I found a low-cost black woman of colour who made it possible to talk about living with sickle cells, which helped build my self-esteem and confidence as a black student.

I felt vulnerable showing myself in crisis, not being able to hold a pen or the mouse on screen. My Dr Moji said I may had caught the covid-19 and this was affecting my sickle cells, I had more crisis at home throughout the year than ever.

In terms of academic supported in the end the university, seemed to acknowledge my sickle cell disability and other health needs fully. I was given access to software and support persons, which facilitated my needs. It was important having the universities support, ultimately it made it possible to challenge low expectations about being good enough as a black disabled student at this level of study. It felt amazing when my tutor sent me an email saying I had passed all my assignments.

Thanks everyone, I found support gave me the courage in the lockdown, to persevere and graduate this spring with a MSC in Adult Psychodynamic counselling and Psychotherapy. I felt so proud. I hired the gown, and a friend took pictures and I told everyone I knew to watch, though it was only virtual on YouTube. Coming through the challenging times with so much good friends by my side somehow made my journey with the loss of my mum more bearable.

I would like to leave you with some Buddhist encouragement if I may.

Courage: "The important thing is to take that first step. Bravely overcoming one small fear gives you the courage to take on the next". (D. Ikeda), Nam- Myoho- Renge -Kyo.

Patient Zone

Author: Rashidat Bodunrin

The Reason The Pen Fell - Poem

It's complicated, if this beginning weightless in retrospect had announced to fate it's promise.
The days mockery of this dream July usher my delusions,
That an emptiness so warm blankets it's seclusion.
Innocent rape of mind,
Remind not this at your mercy to rewind,
Rhyming distortion of time,
Subsequent to repetitious demise,
In that July winter; clothed in a glove,
My hands lost it's grip of a pen,
Because a defiled trusting commits no years to such beginnings.

This poem was written during my hip replacement surgery admission

A-Z - Poem

Dark scars on wooden grass,
Faint pen, a begging read,
Sweat and tears on pursed lips,
A-Z reads between,
Painted tissues in the bin,
As these meanings dilate my iris to see.

Adrenaline clothes the sun,
Wind - neurone tempered,
Heartfelt fingertips,
Letters spelt out on the tip of a captive tongue,
Poem my heart to sing.
Rhythm on a rolling stone,
Pen redeem yourself!
Purge me to read,
A-Z

Patient Zone

Local Patient Support Group Info:

* Kings College Hospital - Every second Thursday of each month, 17:30 to 19:00 via zoom (Any patient welcome from any trust)
* Guy's & St Thomas Hospital - Thursdays, 13:00 to 14:00, via online platform bluejeans or zoom
* South East London Sickle Cell and Thalassaemia Centre - Last Friday of every month 10:00 to 12:00 at the centre: Mary Sheridan Centre, Wooden Spoon House, 5 Dugard Way, London, SE11 4TH
* Lewisham & Greenwhich - Awaiting details. However in the meantime patients are more than welcome to join Kings College Hospital support group sessions
* Croydon Sickle Cell & Thalassemia Centre - Monday to Friday, 9:00 to 17:00, 316 Whitehorse Road, CRO 2LE by appointment only, Contact: 07305953422 or email: cscatsg@outlook.com
* Dartford & Gravesham Sickle cell support group - Last Wednesday of every month, at 17:30 via zoom. Parents of children with Sickle cell can attend.

Visit **patient zone** on our website: **www.ststn.co.uk** to find patient information, clinic times, support group information and previous editions of the red cell newsletters.

South Thames Sickle Cell & Thalassaemia Network

Do you have a story to tell:

Email **info@ststn.co.uk** if you'd like to share your experiences or would like to contribute to red cell news in any way.