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HCC
South East London and South East

Red Cell Newsletter

We hope you have had a good start to 2023!

This newsletter includes exciting developments across our South East London and South East Network.

We are looking for ways to develop our educational events, including new topics and help for staff to upskill. We are exploring ways to increase patient engagement, and new ways to communicate with patients, families, friends, and communities.

This edition includes information about nutrition for those with sickle cell disease; links to our Patient Experience Survey; a young person's experience of transitioning to adult services and accessing emergency care while away at university; and details of planned building work at King's to accommodate a new haematology outpatient area, sickle and thalassemia support unit, and expanded red cell exchange services.

We are also delighted to include an updated press release from the Sickle Cell Society regarding last year's APPG 'No one's listening' report, and some planned improvements in services across England prompted by the report.

If you want to get involved with your newsletter please email: KCH-tr.SELSEHCC@nhs.net

Inside this issue

One year on from 'No One's Listening' – the Sickle & Thalassemia APPG report into UK healthcare for sickle cell disorders — The Sickle Cell Society press release.

On 15th November 2021 the Sickle Cell and Thalassemia All Party Parliamentary Group released a parliamentary report seeking to capture the reality of Sickle Cell and Thalassemia healthcare in the UK.

The report revealed many heart-breaking realities faced by individuals with sickle cell and thalassemia. The findings of the report highlighted a low awareness of sickle cell disorders among healthcare professionals across the UK. This led to traumatic experiences in hospitals , with some people with Sickle Cell being left to wait for hours in excruciating pain, often being deeply misunderstood, or not receiving timely and effective treatment for their condition.

Basic understanding of the condition covers an awareness of the need to keep those with sickle cell disorders well hydrated, warm , and administer

effective pain relief within 30 minutes of presentation, in accordance with NICE guidelines.

Those presenting acutely unwell and in pain require regular monitoring to detect and treat complications.

As the fastest growing genetic blood condition, sickle cell disorders affect about 15,000 people in the UK. The condition changes the shape of red blood cells leading to debilitating episodes of extreme pain. Sickle cell disorders can also impact almost any organ in the body, including shoulder and hip joints, eyes, kidneys, liver, and lungs. There is a high risk of stroke.

Sickle cell can affect every aspect of a person's life, from their ability to participate normally in work and education as well as having an impact on mental health, including dealing with sustained pain and fatigue.

The report highlighted that the troubling health care inequalities faced by Sickle Cell patients were unavoidably linked to racism as the condition predominantly affects those from African and Caribbean backgrounds. The report references the negative attitudes and stereotypes that Sickle Cell patients face when visiting hospital.

The report called for nationwide improvements in care across the country. The report was triggered by the tragic and avoidable death of Evan Smith who sadly passed away after calling 999 from his hospital bed. The investigation into his death highlighted a lack of understanding of his sickle cell disease as a contributing factor to his death. There have been other potentially preventable deaths in those with sickle cell disease since Evan's passing.

Since the launch of the report in November 2021, a Westminster Hall debate on Sickle Cell took place, alongside a commitment from the then Secretary of State, Sajid Javid MP, that there would be a government national action plan to address the healthcare inequalities faced by those with Sickle Cell and other red cell disorders.

In the year since the report, the NHS Royal Health Observatory have begun research on sickle cell, disorders with a focus on race. The NHS have also launched the 'Can You Tell It's Sickle Cell' campaign to raise awareness of the condition among the public and healthcare professionals,. There is a commitment to review healthcare pathways for those with sickle cell disorders.

However, until all individuals with sickle cell disorders have their trust restored in the healthcare system and can feel confident that they will be treated with empathy and the requisite knowledge of their condition – there remains work to be done.

On the anniversary of the report, the Sickle Cell Society, the Sickle Cell and Thalassemia APPG alongside the many voices of Sickle Cell patients, their families and carers, national charities and campaign groups cannot emphasise enough the lifesaving importance of a UK Sickle Cell healthcare review, to ensure that avoidable deaths of those with sickle cell disorders, and harrowing traumatic hospitalisations are no longer the norm for this section of our society.

Janet Daby MP, Chair of the Sickle Cell & Thalassemia APPG said, "For too long people with Sickle Cell have been let down when they are at their most vulnerable. As Chair of the APPG, it is my ambition to ensure all the recommendations from this report are implemented in full. If this happens, patient experiences in healthcare settings will improve dramatically. It is time for Sickle Cell to be taken seriously."

To read more please go to the Sickle Cell Society website:
www.sicklecellsociety.org

Nutrition for Sickle Cell Disease

My name is Maeve O'Shea. I'm a senior specialist haematology dietitian at King's College Hospital. During sickle cell crises, energy intake can be poor and people often have unintentional weight loss. We know good nutrition is essential to aid recovery and keep the body working well.

Is there a recommended way to eat for weight gain?
To gain weight, you need to take in more energy than you expend. The best technique to gain weight is to follow a high energy, high protein diet. I'd recommend eating three portions of high protein foods every day. Sources of high protein include meat, fish, eggs, nuts, beans, pulses, soya, tofu or other meat-free sources. Aim for two to three portions of milk or foods made from milk every day e.g. cheese, milk and yoghurt or non-dairy alternatives like soya milk. Have a serving of starchy food at each meal (e.g. bread, cereals, potatoes, yam, plantain, pasta, chapatti or rice). Eat some fruit and vegetables every day.
If you have a poor appetite, try to eat little and often, with regular snacks. Good snacks to choose include things like cheese and crackers, yogurts, nuts, eggs etc. To increase the nutrient density of your food, try fortifying your food by adding extra cheese, cream, yogurt, oil, nut butters etc.

Are there some foods that can lead to increase in crises?
There are no foods that are known to increase the risk of pain crises.

Are there some food that can reduce the risk of a crises?
Some studies have suggested that fish oils containing the omega-3 fatty acids, eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA), prevent the blockage of blood flow which could help in alleviating some of the problems associated with sickle cell disease. However, more studies need to be conducted before this can be recommended as a supplement. If you enjoy fish, have two portions a week of oily fish such as mackerel, salmon, herring, trout, pilchards or sardines. These are rich in these omega-3 fatty acids.

One sometimes gets told that there are traces of protein in the urine. What diet will be good for protein replacement?
Protein in urine should be investigated by your doctor. The question is not how to replace the protein you are passing in your urine but why are you passing protein via urine.

What constitutes as a high-protein diet?

Your body needs protein to perform a wide range of functions, such as building and repairing muscles and other body tissues. We need extra protein (as well as extra energy) when we are ill, injured or stressed, to repair any damage.

If you are a healthy weight and have no kidney issues, I'd recommend 1.0-1.5g protein per kg body weight per day.

To meet your protein requirements, aim to include a source of protein in each meal e.g. eggs, dairy, meat, fish, pulses, nuts, soya, tofu, mycoprotein (Quorn). If you are snacking during the day, choose snacks containing protein e.g. yogurts, crackers and cheese, nuts.

A portion of protein is a palm-sized piece of meat or fish, two eggs is considered to be a portion, and four tablespoons of tofu, pulses or mycoprotein.

Is there a recommended view on supplements i.e. protein powders, vitamin D etc.?

Overall, there is no nutritional supplement that can have the same benefits as a healthy balanced diet.

Sunshine, not food, is where most of your vitamin D comes from. So even a healthy, well balanced diet, that provides all the other vitamins and goodness you need, is unlikely to provide enough vitamin D. We are all recommended to take 10 micrograms of vitamin D per day in the winter months or year round if you don't have much sun exposure. Check with your GP or Sickle Team before taking supplements.

Deficiencies of some micronutrients, vitamins, and minerals have been shown to be prevalent in patients with sickle cell disorders so if you are concerned you might be lacking in certain nutrients ask your team to check this for you and/or refer you to a registered dietitian.

Supplements may have interactions with some medication and some are unsafe if you suffer from certain medical conditions. This is why it is important to talk to your doctor before taking any supplements.

Protein powders can be a useful way of meeting your protein requirements if you struggle to meet these through diet alone. However, the fitness supplement industry is poorly regulated and these products may have high levels of vitamins/minerals that are not recommended, or differing levels of protein than reported on the label. These products can also be expensive and it is possible to meet your protein requirements through diet alone. If you do want to use protein powders ensure you purchase them from a reputable store.

If you are struggling to gain weight or are losing weight, ask your GP to refer you to a registered dietitian who can provide you with specialist advice.

Conversation with Richard about his Transition experience.

Richard transitioned in to Adult Services a year before starting University. While Richard was in University he experienced one crises episode. He reports that this was an intense and exhausting experience. When trying to ring for an ambulance he was asked for his postcode, but as he hadn't memorised his new postcode he wasn't able to give this information. The 999 responder searched for his University and helped identify the campus.

Once the postcode issue had been resolved, it took over an hour for the ambulance team to arrive and then a further hour and half to get to the local hospital. He arrived and was admitted but did not receive pain relief until two hours later. He noticed that there was a lack of knowledge and understanding about sickle cell disease, and as this was not his local hospital they did not have his care plan so he called his parents to help. His parents took him to his usual hospital, where he was able to complete treatment for his crises.

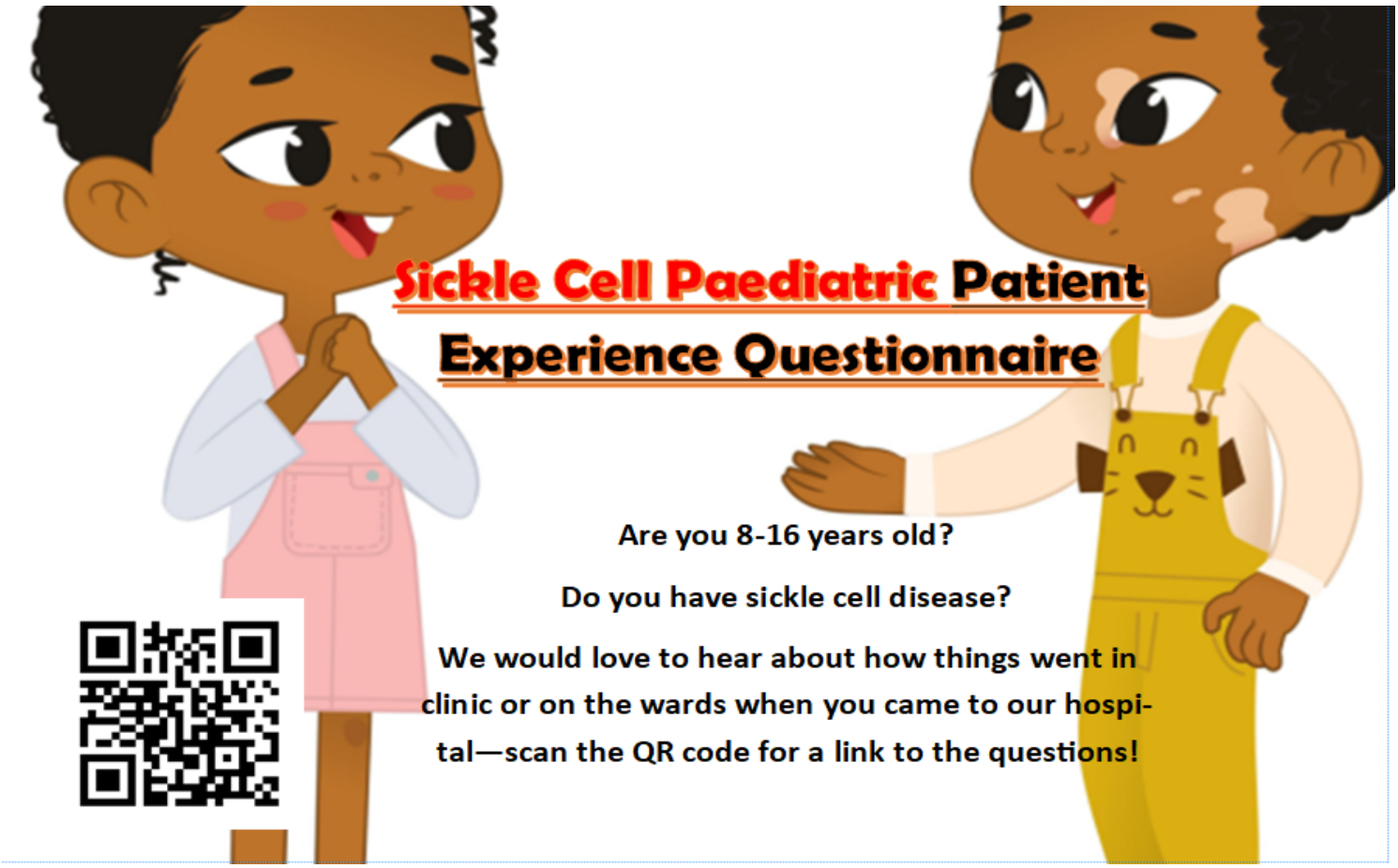
Richard explained that during his time in University he tried his best to eat well, including fruits and vegetables, tried to stay hydrated and joined a gym to keep active. He advises people that want to go to the gym to get advice and start gently. Speak with a personal trainer and/or your doctor so that they can guide you. Richard goes to the gym with his mates but trainers who offer him support and guidance as well. He believes that he is well supported by his friends and can speak openly with them about his sickle cell disease.

He also mentioned that it is important not shy away from talking up about having sickle cell to your teachers and University staff, as he knows that once they are aware of what is going on they can offer you the best help and support.

Tips for a smoother journey:

1. **Save your new address, postcode and care plan and on your phone**
2. **Tell your Sickle Team before you leave for University so they can liaise with your new services and plan a clinic appointment at the beginning of term**
3. **Pack enough medications, including pain relief**
4. **Pack a thermometer and emergency antibiotics**
5. **Eat healthily, rest and sleep sensibly, keep hydrated, and pace yourself**

Patient Experience Survey's — PREMS



Currently the SELSE HCC is collecting data about patients' experiences of visiting our network hospitals for outpatient appointments and accessing emergency care, including hospital admission.

We want to hear directly from service users about the changes or improvements they would like to see in our services.

Please scan the QR code to go to the questionnaire. We want to hear from as many services users as possible.

If you also want to be included in our email distribution list, please email us KCH-tr.SELSEHCC@nhs.net.

Adult Sickle Cell

Patient Experience Feedback

Do you have sickle cell disease?

Are you age 16 or over?

Let us know about your experience of receiving care in hospital

Hearing from your experience will help us improve our service

Please scan the QR code below and this will take you through to the questionnaire.

We undertook a survey in 2018 that has helped us put in changes to our sickle cell service based on your experience of care.

We would like you to let us know if things have improved since then.

Sickle Cell Disease

Parent Experience Questionnaire

If you have a child age 0-16 with sickle cell disease, we would like to hear form you!

Scan the QR code in the poster for the questionnaire. Learning about your experience in hospital will help us design your service better

We undertook a survey in 2018 that has helped us put in changes to our sickle cell service based on your experience of care. We would like you to let us know if things have improved since then by completing the survey again.

Planned Building Work at King's College Hospital

The proposed building work at King's College Hospital will provide new facilities, including a Haematology Outpatient Department, a larger apheresis unit, a dedicated Sickle Cell Support Unit, Ambulatory and Supportive Therapy Unit, and expanded laboratory space

Ground floor facilities will include:

- Entrance lobby
- Patient welfare and information
- Café
- Haematology Outpatients
  - Waiting and reception areas
  - Assessment rooms
  - Consultation rooms
  - Counselling/interview rooms
  - Phlebotomy

Apheresis Improvements

Many patients with sickle cell disease across our network already benefit from being on a regular automated red cell exchange transfusion programme to optimise their health by replacing their red cells with healthy donor red cells every four to ten weeks.

Unfortunately, some patients who would benefit from this treatment, are currently not able to access apheresis because of a lack of capacity.

Our SELSE HCC network have been given the opportunity to expand local apheresis (red cell exchange) services and have applied for extra funding to support development and growth within this service. This will include new machines and additional staff across our network, including at Lewisham and Greenwich, King's, Guy's and St Thomas', Evelina Children's Hospital, and Croydon University Hospital.

Farewells

Richard Conway

We thank Richard, our former Welfare Advisor, for his dedication and hard work.

We wish him all the best in his new role and future ventures.

Yvonne Owusu-Sekyere
Community CNS

We say thank you and farewell to Yvonne, who was our Community CNS for many years.

We thank her for her hard work and dedication and wish her a long, happy and fulfilling retirement.

Welcome

Chifundo Stubbs
SELSE HCC network
Practice Development Nurse

We welcome Chifundo Stubbs, our new SELSE HCC network Practice Development Nurse.

Chifundo will support our network by developing and sharing training materials and supporting the nurses throughout our network by providing education and training.