



SICKLE  
CELL  
SOCIETY

**HCC**

South East London and South East

# REDCELL NEWSLETTER

Issue 19

## Topics of Discussion:

- Winter pressures and help available
- ED Changes and ED Nurse Interview
- Nursing Tips and advise
- Prescription support—PPC

Welcome to the latest edition of Red Cell News Issue 19

With the one year anniversary of the APPG report 'No One's Listening' approaching, we are sharing some of the changes we are implementing and working on within the Network.

The APPG report was an All-Party Parliamentary Group inquiry into avoidable deaths and failures of care for sickle cell disease (SCD) patients in secondary care. Since the report, there have been urgent discussions about the care provided to SCD patients to find solutions to improving services.

In September, patients and medical teams were filmed giving their views about SCD emergency care for a training film as part of an e-learning module to educate Emergency Department (ED) and ward staff about SCD. We hope to launch the module on the APPG report anniversary in November 2022. Teams across the network have been increasing their training of ED colleagues on the correct management of SCD patients.

One local initiative is the introduction of ED sickle nudge card at King's College Hospital. This is a ticket marked with the time and date of first pain relief, to empower our patients to gently remind ED staff to ensure that they are reviewed 30 minutes after their first pain relief, for a further check of observations and pain scores, offer of more pain relief if necessary, and ensure that there is access to the call bell, extra blankets and drinking water.

This winter will have extra pressures due to the energy crises. Our Welfare, Advisor Richard Conway, has compiled information about our schemes available to provide sickle cell and thalassemia patients with additional support, including website links.

Visit the Patient Zone on our website: [www.ststn.co.uk](http://www.ststn.co.uk) to find patient information, support group information and previous editions of the red cell newsletters. You can contact the team on email: [KCH-tr.SELSEHCC@nhs.net](mailto:KCH-tr.SELSEHCC@nhs.net) or suggest topics for us to discuss on our twitter page: [@STSTNetwork](https://twitter.com/STSTNetwork).

# Energy Crisis Advice Sheet 2022

**Richard Conway, Welfare Support Advisor**

**Guy's and St Thomas' NHS Trust Foundation Sickle Cell and Thalassemia Services**

In February 2022, the energy regulator Ofgem announced a 54% rise in energy price caps in the UK, leading to a predicted typical rise of around £700 per year to UK energy bills. In August, Ofgem announced the energy price cap will increase to £3,459, on average, for every UK household, from 1<sup>st</sup> October. Many people up and down the UK are beginning to worry about the rise in household energy expenses and the cost of living.

This advice sheet aims to help you understand what help is available towards the cost of energy bills, and what steps you can take to reducing your energy bills.

## Energy Bills Support Scheme

In October, the UK government offered every household in the UK £400 non-repayable discount over the winter period of 2022-23. You do not need to apply for the discount, and there is no need to contact your energy supplier to obtain the discount. The discount will be applied to your monthly household electricity bill over a 6-month period, starting in October 2022.

You should receive:

£66 in October and November

£67 in December, January, February and March

You should get the discount monthly, even if you pay for your energy quarterly or use a payment card.

Traditional prepayment meter users will get equivalent vouchers, either in paper form via Royal Mail post, or SMS texts. Check with your electricity supplier for further guidance on how they will provide you with the vouchers.

For more information and full details on the Energy Bills Support Scheme, you can follow this web link to the official UK government webpage:

<https://www.gov.uk/guidance/getting-the-energy-bills-support-scheme-discount#full-publication-update-history>

## Council Tax Rebate

As a further response to the rise of UK energy prices, the UK government has announced an additional £150 rebate to each household liable to pay Council Tax within bandings A-D.

If you live in a property banded A-D, either the Local Authority will pay the £150 rebate directly into your account (direct debit accounts), or they will contact you in writing to give you further details as to how you will receive the £150.

This rebate is to help off-set the rise in energy costs. Council Tax bandings are used to determine which household are eligible for the rebate. This £150 rebate does not need to be repaid. You do not need to contact the Local Authority to receive the rebate.

For more information on the Council Tax Rebate, you can follow this web link to the official UK government factsheet:

<https://www.gov.uk/guidance/council-tax-rebate-factsheet>

## UK Wide

You can find out what schemes and funds your local council has set up for local residents in need of support by following this web link to the Gov.UK webpage:

<https://www.gov.uk/find-local-council>

Enter your postcode into the search bar and you will be taken straight to your Local authority webpage. When in the council web page, enter 'Local Welfare Provision' into the search bar and you should find further information on emergency schemes available, eligibility and how to claim.

If you are exempt from paying Council Tax– e.g. students (Class N), under 18 (Class S), Severely Mentally Impaired (Class U) etc. you will still be eligible for the rebate.

## Local Welfare Provision

The UK government has added a further £144million to discretionary funds available to Local Authorities. This is to help those on low incomes receive further help towards energy bills, and other crisis'. This further help is commonly referred to as the Local Welfare Provision. Lambeth, Lewisham, and Southwark Local Authorities call this provision by different names:

### Lambeth – Household Support Scheme

This local welfare provision is aimed at Lambeth residents facing crisis, emergency, or disaster. This includes help towards fuel payments.

To find out more about this local welfare provision, whether you are eligible, and even to make an application, follow this web link to the Lambeth Local Authority webpage: <https://beta.lambeth.gov.uk/benefits-financial-support/extra-support-people-crisis/household-support-scheme>

### **Lewisham – Household Fund**

This fund can help Lewisham residents with money towards food, rent and utility bills. To find out more about the Household Fund, whether you are eligible and how to apply, follow this web link to Lewisham Local Authority webpage: <https://lewisham.gov.uk/myservices/benefits/the-household-fund>

### **Southwark – Hardship Fund**

This scheme is designed to help people in debt with household bills including gas, electric and water bills. To find out more about the Hardship Fund, whether you are eligible and how to apply, follow this web link to Southwark Local Authority webpage: <https://www.southwark.gov.uk/benefits-and-support/hardship-fund>

### **Warm Homes Discount**

Under this scheme, you could receive up to £140 per year towards your electricity bill. To be eligible for this discount you will need to contact your energy supplier to see if they are part of the scheme. If they are, you need to ask them if you qualify. To qualify, you will need to show your energy supplier that you are on a low-income by providing a letter proving you receive an income-based welfare benefit.

This could be a letter from:

- Employment Support Allowance
- Income Support
- Housing Benefit
- Universal Credit
- Pension Credit Guarantee

If you receive both gas and electricity from the same supplier, you may be able to ask the supplier to award the discount on your gas supply instead of electricity.

For further information on the Warm Homes Discount, whether you might be eligible, and how to apply, you can follow this web link:

<https://www.gov.uk/the-warm-home-discount-scheme>

## Winter Fuel Payment

If you were born on or before 26<sup>th</sup> September 1955, you could be eligible to receive between £100 and £300 per year towards your winter fuel bills.

The amount you can receive each winter varies according to your personal circumstances. Your age or other people living with you who are also eligible can also affect the amount you receive.

The payment is made to you automatically each year, either in November or December, but if you are applying for the first time, you should receive your first payment before the next Christmas.

For further information on the Winter Fuel Payment and how to make a claim, you can follow this web link:

<https://www.gov.uk/winter-fuel-payment>

## Cold Weather Payment

If the average temperature in your area is, or is forecasted to be, below zero degrees Celsius for over 7 consecutive days, you will receive £25 for every 7-day period that this happens. Each year the scheme runs from the 1<sup>st</sup> November to the 31<sup>st</sup> March the next year.

To find out more about the Cold Weather Payment, if you might be eligible, and how to make a claim, you can follow this web link to the Gov.UK webpage:

<https://www.gov.uk/cold-weather-payment>

## Cost of Living Payment

If you are on a low income, receiving an income-related Legacy benefit, Working Tax Credits, or Universal Credit, Pension Credit or disability benefit, you may be eligible for a Cost of Living payment to help combat the rise in energy and cost of living.

The Cost of Living payment will consist of £650, split into 2 separate payments:

First payment - £326

Second payment - £324

## List of benefits and payment times:

### Universal Credit

To get the first Cost of Living Payment of £326, you must have been entitled to a payment (or later found to be entitled to a payment) of Universal Credit for an assessment period that ended in the period 26 April 2022 to 25 May 2022.

If you received a 'nil award' for UC during this period, you will not be eligible for the Cost of Living payment. The DWP will update this guidance when the government has announced the qualifying dates to get the second payment of £324. The payment will be made separately from your UC monthly payment.

**Income-based benefits: Jobseekers Allowance (JSA), Employment and Support Allowance (ESA), Income Support (IS), Pension Credit (PC).**

To receive the first Cost of Living Payment of £326, you must have been entitled to a payment (or later found to be entitled to a payment) of income-based JSA, income related ESA, Income Support or Pension Credit for any day in the period 26 April 2022 to 25 May 2022. The DWP will update its guidance when the government has announced the qualifying dates to get the second payment of £324.

## **Tax credits**

To receive the first Cost of Living Payment of £326, you must have been entitled (or later found to be entitled) for any day in the period 26 April 2022 to 25 May 2022

to:

- a payment of tax credits
- an annual award of at least £26 of tax credits

If you get both Child Tax Credit and Working Tax Credit, you will receive a Cost of Living Payment for Child Tax Credit only.

If you get Tax Credits from HMRC and a low income benefit from DWP, you will get a Cost of Living Payment from DWP only.

## **Disability Cost of Living Payment**

You may get a lump sum payment of £150 if you are receiving any of the following disability benefits:

Attendance Allowance (AA)	Constant Attendance Allowance (CAA)
Disability Living Allowance (DLA) for adults	Disability Living Allowance (DLA) for children
Personal Independence Payment (PIP)	Adult Disability Payment (ADP) (in Scotland)
Child Disability Payment (CDP) (in Scotland)	Armed Forces Independence Payment (AFIP)
War Pension Mobility Supplement	

To be eligible, you must have received a payment (or later receive a payment) of one of these qualifying benefits for 25 May 2022 to get the payment.

If you receive a Disability Cost of Living Payment, but later find that you were not eligible for it, you may have to pay it back.

You will be paid the £150 Disability Cost of Living Payment automatically from 20 September 2022. Most people will receive their payment by the beginning of October 2022. To find out more about the Cost of Living payment, if you might be eligible, to find out the timetable for payments, or to report a missing payment, you can follow this web link to the Gov.UK webpage:

<https://www.gov.uk/guidance/cost-of-living-payment>



## Further Resources

Below are some further resources you may wish to consider if faced with a fuel poverty crisis:

**Fuel Bank Foundation:** <https://www.fuelbankfoundation.org>

**Fuel Bank £40 voucher:** <https://cvha.org.uk/data/>

**Fuel Bank Voucher Leaflet 2021 10 12 21 51 15.pdf**

**End Fuel Poverty:** <https://www.endfuelpoverty.org.uk/resources/>

**Turn2Us:** <https://www.turn2us.org.uk/Benefit-guides/Fuel-Poverty/Useful-resources#guide-content>

**National Energy Action:** <https://www.nea.org.uk/>

**Citizen's Advice:** <https://www.citizensadvice.org.uk/consumer/energy/energy-supply/get-help-paying-your-bills/grants-and-benefits-to-help-you-pay-your-energy-bills/>

## Emergency Department (ED) Changes and Patient Nudge Card

There have been some local changes to EDs across the network.

King's ED have posters ensuring that those with specific conditions, including sickle cell disease, bypass the triage queues and go directly to reception to register.

A new 'Nudge card' is being tried out to empower patients to prompt staff to check on them 30 minutes after their first dose of analgesia, offer more pain relief and other medications, repeat the pain score and essential observations, contact the Haematology team for an early review, and make sure they are as comfortable as possible.

### **KCH Emergency Department Sickle 'Nudge' Card**

This card is hopefully useful for both you and us.

We want to give you the best care in your time of crisis. A&E is obviously very busy. It will feel like time moves slow for you and moves fast for us. This card can be used to 'nudge' us after your first treatment.

We will check your Sickle Care Plan document. We aim to deliver your pain relief within 30 minutes.

*The ED nurse can circle as appropriate*

**Name of analgesia:** oxycodone/morphine/other:.....

**Dose of analgesia:** 5mg/7.5mg/10mg/12.5mg/15mg/other:.....

**Time administered:** .....am/pm

**Please 'nudge' our team in 30 minutes to:**

1. Reassess your pain score (1-10)
2. Repeat your vital signs (blood pressure, temperature, blood oxygen levels, pulse rate)
3. Offer you more pain relief if required. You don't need to wait 2 hours before another dose.
4. Offer anti-sickness, oral pain medications, extra blanket and drinking water.
5. Escalate to on-call haematology doctors if there are concerns (e.g. high temperature)

## Interview with Zara Asare-Evans ED Nurse

Hello, my name is Zara. I have been a senior sister in the emergency department (ED) at King's College Hospital for five years. Working in ED is a challenging but rewarding job. My role includes being the ED sickle link nurse.

The most difficult part of my role is managing a shift which is short staffed with a high influx of patients. The priority is to maintain patient safety. It is also important to ensure that all staff on shift are okay.

I chose a career in Accident and Emergency because I liked the diversity of patients and cases. I enjoy learning new things and knowing that every day will be different. A typical day when I am the nurse in charge of the shift includes allocating staff to work in specific areas, then receiving handover. I walk around the department to make sure staff are okay working in their allocated areas. I receive those who have been brought to the resuscitation area by 'blue light' ambulance and visit the psychiatric liaison nurse's office to discuss all mental health patients in the department.



I have several goals towards improving current sickle care. One of my first goals when I started at King's was to improve the time to first analgesia dose for patients presenting in crisis. Since starting at King's, I have seen this improve drastically. Another goal is to improve staff knowledge about sickle cell disease. In the emergency department there is a high staff turnover, and some staff have worked in hospitals where they saw little or no sickle cell cases. I aim to teach healthcare professionals in the department how to promptly treat those in sickle cell crisis and what symptoms to look for which may indicate that the patient has additional complications.

The advice I would give to young people going through the transition process to adult services is to trust the process. I understand that it can be daunting and scary, but there has been such improvement in the management of sickle cell, especially in ED that most patients will not find the transition as bad as they anticipated. I encourage all young people to ask as many questions as possible when transitioning to adult services. The team in the emergency department are approachable, friendly, honest and transparent and we will always be happy to answer your questions.

The advice I would give to adults in crisis in ED is to be vocal about the pain you are experiencing. The staff in ED are efficient in delivering prompt analgesia to those in crisis. However, due to high numbers of patients in the department and capacity issues, finding a suitable place to assess patients can sometimes prove challenging. I would also advise adults to remind nurses and doctors about pain relief medications. Although the staff are good at administering first line pain relief, we have many patients to see and treat we may need a gentle reminder at times!



## NHS Prescription Prepayment Certificates (PPCs)

A PPC could save you money if you pay for your NHS prescriptions. The certificate covers all your NHS prescriptions for a set price. You will save money if you need more than 3 items in 3 months, or 11 items in 12 months.

The prescription charge in England is £9.35 per item, a PPC costs:

- £30.25 for 3 months
- £108.10 for 12 months

Before buying a PPC, you can check if you are entitled to free NHS prescriptions and other help with health costs using this link:

<https://www.nhsbsa.nhs.uk/check-if-youre-eligible-help>

### How much can you save?

Number of prescribed medicines you need each month	Saving with a 12 month PPC	Saving with a 3 month PPC
2	More than £116 a year	More than £25 in 3 months
3	More than £228 a year	More than £53 in 3 months
4	More than £340 a year	More than £81 in 3 months

### How can you buy a PPC?

- Online
- With a registered Pharmacy

To get a digital PPC via email, contact the team and on **0300 330 1341** or you can follow this link for the website and online form;

<https://nhsbsa.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificates-ppcs>

## Patient Story—Fatima Malik

Fatima is a sickle cell patient who has birthed two beautiful children and is currently on her third pregnancy. She has kindly answered some questions to explain how she has been coping with pregnancy. Fatima is 34-weeks pregnant and has been under the care of St Thomas's Hospital. She has had several hospital admissions over the past month.

### **How are you finding pregnancy?**

A blessing – not everyone has the opportunity to have a baby. Having a pregnancy while having SCD is challenging, but ultimately incredibly rewarding. Sometimes you feel like you can't do it, but you find the strength to make it through.

### **Did you have any complications?**

I have had multiple hospital admission in this year – at least twice a month. I have had low haemoglobin, swollen ankles, high blood pressure, difficulty breathing, and a major sickle crisis.

### **How was your experience with the midwives?**

This is my third pregnancy and I have felt massively supported by the midwives. They made me feel like super woman. When you have people who actually listen, and understand, it makes it easier to open up. They do their utmost to make you feel safe and you never feel alone.

### **Did your treatment plan need to be reviewed once you found out you were pregnant?**

Yes and No. They changed certain medications, adding clexane and aspirin and stopping Ibuprofen, but my emergency pain relief remained the same. They made sure that I got the correct care and medication for me and my unborn baby. This made me feel reassured.

### **Did your unborn child have any genetic testing during pregnancy?**

No, I was meant to go for genetic testing, but due to multiple hospital admissions I was unable to take up that opportunity. I am aware that my child has a 1 in 2 chance of inheriting a sickle disorder, as my partner has sickle trait (HbSA), and I have HbS $\beta$  thalassaemia.

**Did you experience any crises whilst pregnant?**

Yes. I have had multiple admissions due to sickle crises this year – on average twice a month. I am on an blood exchange transfusion programme, so have to attend hospital every 4-6 weeks.

**What advice would you give to other pregnant women with sickle cell disease?**

I would advise them to always be true to themselves, to stay strong, and never give up. There are brighter days ahead. Look forward to meeting your beautiful child. It's ok not to be ok—allow yourself to let it all out.

**What aftercare did you receive after your previous pregnancies?**

I continued to receive aftercare from Safer Homes Team, which was absolutely amazing – the lady came every week. She was very supportive and personalised her care. There is no book that teaches you how to become a parent, but having the support of the aftercare team helped massively.

## Patient Story—Amuche Iroegbulem

Initially I was very anxious about being getting pregnant and what problems I would face going into this phase of my life. Having spent half of my 20's thinking I wouldn't be able to carry children through fear of the complications that would come with it, I was very pleased to learn that this wasn't the case through an appointment with one of the haematology consultants, Dr Sara Stuart-Smith. She ran me through the possible complications for myself and baby (none of which were as extreme as I had thought), what treatments can be offered throughout the pregnancy and also reassured me on any worries I had regarding being pregnant with Sickle Cell Disease. Fast forward 5 years from this initial conversation and I now have two beautiful, healthy babies.

I found both pregnancies easy to manage. I was on hydroxycarbamide prior to being pregnant as a way to manage my Sickle Cell. When you want to get pregnant you are advised to come off hydroxycarbamide at least 3 months before you start trying to conceive. I worried that coming off this medication would subject me to more crises, but I was wrong. It was as if my body knew it had to be strong for the next 9 months and with both pregnancies, I had 2 crisis that resulted in hospital admission, one in the first trimester and one a couple of weeks before I gave birth. Apart from those crises I frequently felt very short of breath and fatigued, to a level I'm familiar with when my haemoglobin is low, usually during a crisis. In both pregnancies I was approached about joining a clinical trial which would see if having red cell exchange transfusions every 6-10 weeks would improve pregnancy outcomes or women with Sickle Cell.

Sadly, I did not get the intervention arm of the trial for my first pregnancy so my anaemia symptoms were managed by having top up blood transfusions when needed, about every 6-8 weeks. I believe this helped prevent crises during the pregnancy.

In my second pregnancy, amazingly I got the intervention arm of the trial and with regular exchange transfusions, I did not experience severe anaemia. I was put on Penicillin, Folic Acid, Vitamin D and Aspirin.

Both pregnancies were overseen by the joint clinic with Dr Jemma Johns and Dr Sara Stuart-Smith but due to where I lived at the time of my first pregnancy, I was under non-specialised midwives who were not at a different hospital. I found this to be quite a struggle as when I had questions or worries, I was always told I should email my consultants and so there was not much immediate reassurance. This changed with my second pregnancy as I was under specialist midwives at King's who were on hand to answer any questions. I also felt safe in their care as I knew they were familiar with looking after pregnant women with sickle cell disorders.

The medical staff at King's were on hand to offer advice and support if I needed it. Often my biggest worries were shortness of breath, as sometimes even when I'd have a transfusion it would still persist. I was advised by both the doctors and the midwives to take it easy during this time. For example, my midwives let me know that sick notes can be provided for work if needed. Living with a chronic illness you get used to the mentality that you have to push through and be strong to avoid being seen as 'weak' or a 'burden', I had to be reminded that my body was going through some big changes and for my baby to grow healthily I needed to remain well. This meant lowering my work load, resting a lot more than usual and relying on friends and family when I needed help and support.





The biggest piece of advice I would give to other pregnant women with sickle cell is that information is power. Ask all your questions and making sure you're being informed every step of the way. You will have so many questions and worries throughout the 9 months and you should know that no question is silly and all your worries are valid. Your doctors and midwives are easy to reach, so you don't need to wait until your next appointment to speak to them if you have concerns.



Lastly, I would stress the importance of a good support network. This will be one of the biggest shifts of your life, not only because you're growing a human but you're doing this while managing your illness. Be sure to always ask for help, including help getting to your appointments and making antenatal classes. I'm so grateful for my husband, family and friends because as well as my doctors and midwives, they truly contributed towards my smooth pregnancies.

As a whole, I felt very safe delivering both my babies at King's and thank all those involved in my care for helping me bring my two miracles in to the world.

