

## Sickle Cell Disease: Chronic Complications (Chronic Pain)

Profile	
<b>Version:</b>	V1.0
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<b>Executive/Divisional sponsor:</b>	<i>Dr Lisa Pickering, Divisional Chair DGB February 2019</i>
<b>Applies to:</b>	<i>All staff involved in the care of patients with Sickle Cell Disease</i>
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Approval	
<b>Approval person/Committee:</b>	<i>MedCard Divisional Governance Board</i>
<b>Date:</b>	<i>14<sup>th</sup> February 2019</i>

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## Policy Gateway

Please complete the checklist and tables below to provide assurance around the policy review process.

- I have involved everyone who should be consulted about this policy/guidance
- I have identified the target audience for this policy/guidance
- I have completed the correct template fully and properly
- I have identified the correct approval route for this policy/guidance
- I have saved a word version of this policy/guidance for future reviews and reference

Please set out what makes you an appropriate person to conduct this review:

Lead for Red Cell Pain Management Service

Please set out the legislation, guidance and best practice you consulted for this review:

- West Midlands Review Service – Quality Standards: Health Services for People with Haemoglobin Disorders (2018/19)
- Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK 2018 (Sickle Cell Society) <https://www.sicklecellsociety.org/wp-content/uploads/2018/04/Web-version-FINAL-SCS-Standards-GSM-6.4.18.pdf>

Please identify the key people you involved in reviewing this policy why, and when:

*Dr Elizabeth Rhodes, Consultant Haematologist*  
*Dr Julia Sikorska, Consultant Haematologist*

Summarise the key changes you have made and why:

Updates in line with the UK standards of care for SCD  
 Updated contact details

## **Executive Summary**

The management of chronic pain in Sickle Cell Disease (SCD) is an important part of the holistic care of patients with SCD. It is important not only to be able to identify patients who are suffering from chronic pain but to be able to offer care and support to help manage it in a multidisciplinary setting.

## 1. Introduction

Chronic pain (pain lasting longer than 3-6 months) can be common in SCD, although the exact prevalence is not known. It is a difficult to manage consequence for some patients with SCD and it is important that it is asked about and addressed.

## 2. Status and Purpose

This document is part of the Haematology Department's guidelines on the management of patients with SCD and is applicable to all staff involved in the care of these patients.

## 3. Definitions

Sickle Cell Disease – inherited lifelong condition due to abnormal haemoglobin variant.

## 4. Scope

This guideline is relevant to the care of patients with SCD who are suffering from chronic pain or every day pain at home.

## 5. Roles and Responsibilities

**5.1 Haemoglobinopathy team (Consultant haematologists, Clinical Nurse Specialist and Clinical Health Psychologist)** – Responsible for the care of these patients, developing and updating guidelines to be reflective of good practice and to deliver the training to ensure good safe care.

**5.2 Medical staff involved in the care of patients with SCD.** Responsible with the oversight of the haemoglobinopathy team to deliver the care to these patients in line with guidelines where possible.

**5.3 Nursing staff and allied health professionals involved in the care of patients with SCD on wards, day unit and other areas of St George's** responsible with the oversight of the haemoglobinopathy team to deliver the care of these patients in line with guidelines where possible.

## 6.0 Content

Chronic pain (pain lasting longer than 3-6 months) can be common in SCD, although the exact prevalence is not known. It is a difficult to manage consequence for some patients with SCD and it is important that it is asked about and addressed.

### **At St George's Hospital, we observe the following standards:**

- Patients should be asked whether they suffer from chronic pain (which they may describe as 'every day' pain, 'background' pain or 'on-going' pain) as part of their annual review. If they describe chronic pain, they should be asked about frequency, site, duration, triggers and impact of pain on functioning.
- An underlying cause of chronic pain (including avascular necrosis of a joint) should be sought and treated if appropriate.
- Patients should be helped to understand the differences between acute and chronic pain, that chronic pain is not necessarily an indication of tissue injury or damage, and that different management approaches may be necessary and more helpful than those used for acute crisis pain.
- Patients with chronic pain, especially if the pain is impacting on mood or function, should be referred to the Red Cell Pain Management Service (RCPMS), a multidisciplinary chronic pain team, with experience of SCD, offering both pharmacological and non-pharmacological interventions.
- Onward referral to an Orthopaedic Consultant and/or Consultant in Pain Medicine is considered for patients presenting with persistent pain who may benefit from further investigation, consideration of interventions including joint surgery, or review of pain medication.

### **Standards for pain medication:**

- Use of opioids should be regularly reviewed at clinic visits, including at annual review. Patients should be provided with an individualised medication plan and have the opportunity to discuss any questions or concerns about medication.
- Referral to the CNS should be considered for patients who require additional support managing medicines or developing an individualised medication plan.
- Referral to the Consultant in Pain Medicine should be considered for patients where there are concerns regarding medication, including patients who are regularly taking opioids at home.

### **Notes regarding medication for persistent pain in SCD**

Currently there is a lack of specific guidelines relating to management of chronic pain in SCD and so good practice guidelines can be derived from evidence for prescribing in non-cancer chronic pain (Chou *et al.*, 2009; Franklin, 2014). Atypical analgesics (e.g. gabapentin, amitriptyline, pregabalin, duloxetine) are useful for the management of neuropathic pain.

There is increasing awareness and concern about prescription opioids in the management of chronic pain. At doses of more than 120 mg oral morphine equivalent a day there is increased risk of harm, with no increased benefit and the likelihood that opioid-based medication is not working (BMA board of science, 2017). The prescriber must be aware of these cautions, while also recognising the difference between physical dependence (which is to be expected and should not automatically raise concerns) and addiction (which is more problematic) (Savage *et al.*, 2003). Understanding the balance between giving sufficient pain relief and the risk of side effects is important, particularly since for many patients the levels of pain experienced will be difficult for them to manage.

All health care professionals involved in caring for the patient, including primary care, should be aware of prescribing plans for opioids and who the key prescriber is.

**Flow chart for managing chronic pain at St George's Hospital**

Patient asked about pain (both acute/crisis and chronic/persistent/everyday) at each clinic visit.

If patient describes chronic pain, ask about severity, frequency and impact on life. Consider referral to RCPMS, if patient in agreement.



Referral made to red cell pain management service. Triaged into:



Pain clinic with consultant anaesthetist and specialist physiotherapist.

May lead to:  
Medication changes  
Injection procedures  
Referral on for joint assessment



Joint assessment with clinical psychology and specialist physiotherapy.

May lead to:  
Pain workshop  
Exercise group ('circulate')  
Individual pain management sessions  
Group pain management programme ('breaking the cycle')  
Referral to pain clinic



## **7. Dissemination and implementation**

### **7.1 Dissemination:**

Guidelines will be available on the departmental intranet page and available in paper form in the junior doctor office in haematology.

### **7.2. Implementation**

Guidelines will be promoted by the haemoglobinopathy team.

## **8. Consequences of Breaching the Policy**

Failing to follow this policy could lead to action under the Trust's disciplinary policy.

## **9. Monitoring compliance**

The table below outlines the process for monitoring compliance with this document.



**Monitoring compliance and effectiveness table**

<b>Element/ Activity being monitored</b>	<b>Lead/role</b>	<b>Methodology to be used for monitoring</b>	<b>Frequency of monitoring and Reporting arrangements</b>	<b>Acting on recommendations and Leads</b>	<b>Change in practice and lessons to be shared</b>
<i>WMQRS peer review quality standards</i>	<i>Consultant haematologist</i>	<i>As required (every 2-3 year)</i>	<i>The lead or committee is expected to read and interrogate the report to identify deficiencies in the system and act upon them. Consider stating this responsibility in committee terms of reference.</i>	<i>Required actions will be identified and completed in a specified timeframe. Consider stating this responsibility in committee terms of reference.  These will be discussed at Divisional governance board</i>	<i>Required changes to practice will be identified and actioned within a specific timeframe. A lead member of the team will be identified to take each change forward where appropriate. Lessons will be shared with all the relevant stakeholders.</i>

## 10. Associated documentation

## 11. References

- West Midlands Review Service – Quality Standards: Health Services for People with Haemoglobin Disorders (2018/19)
- Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK 2018 (Sickle Cell Society) <https://www.sicklecellsociety.org/wp-content/uploads/2018/04/Web-version-FINAL-SCS-Standards-GSM-6.4.18.pdf>