Sickle Cell and Wellbeing in NHS Services

A Guide for Policy, Practice and Patients on Wellbeing and Sickle Cell Disorder (SCD)

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Wellbeing and Sickle Cell Patients

This guide is based on research examining the shielding experiences of people with sickle cell disorders (SCD) and parents of children with the condition during the COVID-19 pandemic. The aim was to improve NHS services for this population group. Services have duties under the **Equality Act 2010** to ensure equity and tackle health inequalities. Since SCD disproportionately affects Black, Asian and Minority Ethnic (BAME) communities, there are also duties not to engage in direct or indirect racist discrimination, nor in harassment or victimization. It is important that anti-racist and anti-bias training is offered in all NHS services and cultural competency encouraged amongst all staff. Additionally, that conditions affecting the BAME population, like SCD, become a mandatory part of all nursing and medical educational and NHS training programmes.

What is Sickle Cell Disease/Sickle Cell Disorder (SCD)?

Sickle cell disease/disorder (SCD) is a collective name for a set of inherited chronic conditions. SCD covers a spectrum, from milder to severe forms of SCD, but with support people with SCD can have a good quality of life. SCD is associated with episodes of severe pain called sickle cell painful crises. A complex combination of factors can cause the red blood cells to become blocked in the blood vessels, causing acute pain. Premature destruction of red blood cells also leaves the person with SCD severely anaemic and chronically fatigued. Many systems of the body can be affected: different key organs can be damaged over time and multiple symptoms can occur in different parts of the body. Main types of SCD are sickle cell anaemia, haemoglobin SC disease and sickle beta-thalassaemia.

Is SCD a disability in law?

The Equality Act 2010 [Section 6(1)] states a person has a disability if they have a physical or mental impairment and "the impairment has a **substantial and long-term adverse effect** on [the person's] ability to carry out normal day-to-day activities." In law, a diagnosis of sickle cell disorder (SCD) is not automatically classed as a disability, though SCD meets several of the criteria given in guidance. These include:

- Some normal day-to-day activities (lifting, walking, repetitive movements, sitting or standing for long periods) cause pain.
- Some normal day-to-day activities (lifting loads, walking, long hours, shift work) cause fatigue.
- Chronic pain is strongly associated with depression, so some with SCD who develop depression will also meet the legal criterion of mental impairment, which further impacts their abilities.

Where the effect of the impairment is controlled by medication (sickle cell pain relief); by medical treatment (hydroxycarbamide, penicillin, or regular blood transfusions), or by aids (compression socks to reduce risk of deep vein thrombosis) the effect of these is ignored in considering if the impairment is a disability, so SCD workers will still be considered disabled even if their condition is controlled. The law states that the adverse effect has to be 'substantial', but guidance to the act states that this simply means it must be more than minor or trivial. This may mean not just being unable to do an activity but also only being able to do an activity with difficulty:

- The difficulty might arise from stress (e.g. working beyond hours, insufficient or poorly scheduled breaks or not sleeping or resting enough) as stress could trigger a sickle cell painful crisis.
- The difficulty might develop under certain temperatures (e.g. sickle cell crises are triggered in cold environments or by use of air conditioners).

Given the nature of SCD it is likely that most people with the diagnosis will fall within the definition of disabled for the purposes of the Equality Act 2010.

Reasonable Adjustments in Practice

A patient who has a chronic illness, acute condition or disability such as SCD is entitled to expect their services to make reasonable adjustments to ensure that they are not at a disadvantage. These adjustments can be to premises or can involve the provision of equipment (such as a specialist chair), or they can be adjustments to work practices to ensure equity and they can also entail adjustments like asking for an interpreter or advocate. In all cases it is necessary to identify what it is that puts the SCD patient at a disadvantage and address those issues for equity.

Good practice: Black Lives Matter

In hospitals in the United States, they have begun a series of voluntary anti-racism and anti-bias trainings for their staff. Patients can indicate if they wish to be treated by such a professional and have related that this makes them feel more comfortable that the medical and psychological care, they will be receiving is equitable. In the UK, good training packages such as those focusing on 'Multi-Racial Health Care' exist, educating on social and cultural dimensions of Black healthcare which NHS practices can build on. Additionally, patients related that they appreciated those professionals who checked in on them and understood the impact of events like Black Lives Matter, and were actively working to change NHS cultures to be more inclusive and respectful of diversity with staff members and how they related to patients. It is also important that health care professionals seek training, as not matter what ethnicity, they might have unconscious biases that affect the care that they give to patients. Patients have related that they feel that their ethnicity, nationality, refugee status, gender, as well as factors like socio-economic backgrounds and lifestyles, affected the treatment and care they received from healthcare professionals.

Good practice: Independent advocates

Patients have related anxieties due to needing to go into hospital alone and may delay important treatment because of fears of maltreatment, impact of racism or risks of becoming infected with COVID-19. While it is important for professionals, like consultants and nurses, to reassure the patients of how they will be kept safe and properly cared for, it is **important that an independent advocate for the patient is designated if the patient requests this.** This role could have been undertaken by community sickle cell counsellors in the past but has tended to be undertaken by family members, friends or sickle cell organisations or support groups presently. They provided important psychological support for patients at their most vulnerable. During COVID-19, patients appreciated regular virtual contact with those advocates as well as the designation of advocate who played an independent role in the hospital but could check-in with the patient, such as a pastor or an Iman. If a patient is alone, do ask them if they would like an independent advocate.

How can the symptoms of SCD be prevented?

Certain factors are more likely to precipitate a painful sickle cell crisis. These include working in cold offices, working outdoors in windy/cold conditions, air-conditioning, pollution, infections, dehydration, strenuous exertion, stress, sudden changes in temperature, and drinking alcohol. Advice to people living with SCD on preventing crises includes keeping warm, eating healthily, taking moderate exercise, resting when tired, taking plenty of fluids, seeking urgent medical advice if they have a fever, avoiding smoking and alcohol, keeping up to date with medications and vaccinations, and reducing stress. Nevertheless, it is important to emphasize that *even where such precautions are taken* people with SCD may have unanticipated episodes of illness.

Medical Issues and Medical Emergencies for Sickle Cell Disease/Disorders (SCD)

Acute painful episodes or sickle cell crises: These acute episodes of pain may occur in any part of the body and may be brought on by cold, stress, over-exertion, dehydration, or without any obvious precipitating factors. The pain may last a few hours or up to 2 weeks or even longer, and may be so severe that a person needs to be hospitalized. It is important to listen to the person with SCD who will come to know whether the pain is mild and will pass (where employers can promote inclusion in the workplace by permitting rest and re-integration into work later that day) or moderate (where rest at home may prevent a more serious crisis and reduce overall work time lost) or severe when they need to go to hospital.

Acute chest syndrome: Signs include chest pain, coughing, difficulty breathing, and fever. It can appear to be similar to flu like symptoms. However, it is important to see a consultant immediately.

Chronic Pain: Some people with SCD experience chronic pain, that is, pain that is long-term, lasting over months or years and beyond a time frame that suggests healing or final resolution of the pain will occur. This is different from, and in addition to, acute painful crises. People with SCD may be involved in pain management courses and/or psychological therapies to help learn how to recognize types of pain and how to manage them.

Fever: People with sickle cell disorder are at increased risk for certain bacterial infections. A fever of 101° Fahrenheit (38° Celsius) or higher, could signal an infection. People with sickle cell disorder and fever should be seen by a consultant without delay.

Haemolysis: In people with SCD their red blood cells are destroyed prematurely and only last 20 days in the bloodstream rather than the usual 120 days. This means they are anaemic and are therefore more likely to suffer fatigue, be lethargic or have difficulty concentrating. Those who have regular exchange blood transfusions every 4-6 weeks may become tired towards the end of the transfusion cycle.

Strokes: The risk of stroke is much higher in people with SCD. Apply the FAST approach:

Facial weakness: can the person smile, or has their mouth or eye drooped?

Arm: can the person raise both their arms above shoulder height?

Speech problems: can the person speak clearly and understand what you say?

Time: to dial the emergency number for an ambulance.

It can be difficult to differentiate the symptoms of stroke from those of a sickle crisis, where pain can result in restriction of movement.

Obstructive Sleep Apnoea some people with SCD experience hypoxia or low oxygen levels at night which may contribute to poor quality sleep or no sleep at all, leaving them still tired in the morning. This is in addition to tiredness arising from their anaemia.

Priapism*:* An unwanted painful erection of the penis, unrelated to thoughts about sex. Again, priapism may also contribute to poor quality sleep. Urgent medical help should be sought if it lasts more than two hours.

Good practice: Sickle cell as part of medical education
It is important that COVID-19 is not confused with sickle cell and patients are kept safe on wards and in A&E. Patients appreciated those professionals who understood the signs and symptoms of sickle cell and the common symptoms during a painful crisis so they could react quickly as needed. Those professionals often had sickle cell education as part of their nursing or emergency training and also knew how other conditions, like COVID-19, would manifest on Black skin (e.g. redness, rashes and skin lesions). These professionals also understood the importance of pain management and that only patients with SCD are experts of their bodies and mind during a pain crisis. Patients appreciated the care and empathy that they were treated with while in physical and mental distress.

Stress: Living a stress-free life is very difficult when people may be impacted by job losses, debt, have to use public transport, need to continue work, have to care for children and are bereaved. People with SCD may also have to visit their GP or visit their hospitals on a regular basis. As well as treatment for acute symptoms some people with SCD may have hospital appointments for regular treatments such as exchange blood transfusions or blood tests. Professionals need to use this time to check-in on both physical and mental health of the patients.

Good Practice: "Are you doing okay?"
In some NHS Trusts they ask a series of open-ended questions to understand if social and and/or psychological support should be sought for a patient. They ask, "Are you doing okay?", "Has anything changed in your life since the last time we spoke?" and "Is there anything that you are worried about?" This allows the patient or parent to talk about more than just physical symptoms of sickle cell. Patients also appreciated the sickle cell specialist nurse or community nurse checking in on them to see if people were doing okay. This was related as particularly important for parents, asylum seekers, those destitute, patients currently unemployed and those patients living on their own.

***Travel to Hospital*:** Many people with SCD face a challenge in commuting to hospital and related that this takes "military precision". They already have chronic anaemia and fatigue, so a punishing commute leaves them tired even before their hospital visits. Loss of function of the spleen means they are especially vulnerable to respiratory infections when in close contact with other patients, for example, on public transport or waiting in queues. Exposure to cold in waiting outside for public transport, or switching between warm and cold environments in using public transport, is a risk for triggering a sickle cell painful crisis. Access to a car, to a parking space closest to the building where the person is being treated and to a disabled parking space is necessary. Paying for transport or parking is an extra expense that some patients may not be able to afford. If there are any changes to a sickle cell centre, where they have to go for treatment or routines, they need to know about this especially with risk of COVID-19.

Good Practice: Protecting Patients
Patients who have been told to shield, rightly feel anxious about breaking that advice and coming into a hospital environment. One service maintained regular contact with their clients to explain safety measures and if services had moved or changed during the pandemic. They also did away with car-parking fees so patients would feel encouraged to continue to use services. At the height of the pandemic, one sickle cell centre would tell security staff that sickle cell patients coming for treatment should not be queuing in the cold to get into the building after answering COVID-19 screening questions. Patients with sickle cell were instead fast tracked (they could jump the queue) and get screened inside. The unit also used to send a healthcare professional with a wheelchair to the door or car park if needed for patients. If patients were screened for COVID-19 and had a fever, they were put apart in a special room until testing. They were not put on COVID-19 wards.

Psychological support: There is a close connection between physical and mental wellbeing in patients with sickle cell. If patients state that they are feeling 'low' or 'depressed', it is important to refer them to psychological services. There they should be screened (given a questionnaire) by a psychologist to see if they need further support. This can mean talking to a professional within the hospital setting or being referred to the Improving Access to Psychological Services (IAPT) which provides services for people who are feeling depressed or anxious. Feeling low or depressed could be due to circumstances which can improve with the right support, or it can need professional treatment before people recover.

Good Practice: Men and women
Men and women can describe and talk about their wellbeing in different ways. Men also have different experiences from women and they appreciated services that were sensitive of this. It takes a lot of courage to speak about mental health and services should encourage a culture of openness and tolerance to how people cope during a pandemic. This might mean that patients may not talk about mental health but describe engaging in behaviours such as, for example, smoking, drinking, taking drugs or gambling. It is important not to be judgmental but listen and offer support.

Psychiatric treatment: People with SCD may also have psychiatric conditions but patients can feel a lot of fear around being diagnosed with a mental health condition. It's important to emphasize that people with SCD can have a good quality of life with any mental health condition, as long as they get treatment. Another fear that patients have, is that they will be medicated or 'locked-up'. It's important for health care professionals to explain the details of treatment as well as legal rights that protect the patient, like the Mental Capacity Act (2005). This is a law that means that over the age of 16 an adult should always be supported to make their own decisions for their best interest.

Good Practice: Support for Wellbeing
Patients with SCD or/and caring for someone with the condition, related that it was important to look after their physical as well as mental health. They related that as well as not being able to engage in self-care, they can be affected by feelings of loneliness or isolation. Part of their practices of mental wellbeing, especially during periods of shielding and lockdown, were to ensure that they had strong community support networks. Additionally, they said it was important to reach out virtually to sickle cell charities, patient/carers support groups, single parent networks or COVID-19 mutual aid groups. They appreciated socially distanced visits (sometimes just waving through a window before a food drop off), phone calls and Zoom meetings as a way to stay connected. Refugees, asylum seekers and those destitute noted how important it was that they found these networks as they could make referrals for them to other services. They related that they don't always feel that they have a right to NHS services or can ask for help from sickle cell or other charities.

Good Practice: When to see your GP
If patients feel like their mental health or wellbeing is being affected, it's important to signpost this to their GP. The GP is responsible for physical and mental healthcare and should refer patients on to specialised services. In one practice, the GP asked the patient with SCD if they wanted to speak to a Black, Asian or Minority Ethnic (BAME) psychologist via phone or online. The patient said that they were fine speaking to any professional but really appreciated that the GP made time to ask this question. They stated that they felt that the GP was respectful of their experiences as a Black person.

Social support: Caring for a child with the sickle cell condition (which can be acute, chronic or a disability) is hard work and requires hyper-vigilance from parents, who may already be feeling more anxious about provision of care as well as their caring abilities during a pandemic. Many parents and carers are not always aware that local services and charities exist that can offer respite services or may feel fearful of social workers coming into their home. It is important to highlight good practice and learn from positive experiences, as this can lead to better wellbeing for the family. While services might be seeing an individual child or adult patient, during periods of shielding and lockdown, it is the family that are providing day to day care. They are an important resource of wellbeing and support for the patient, and services need to check on their wellbeing too.

Good Practice: When to ask for social support
Parents with children of sickle cell (especially if they have sickle cell themselves) have had a particularly difficult time with caring and educational responsibilities over periods of shielding and lockdown. This may make feelings of isolation and loneliness worse or lead to worsening wellbeing. Parents with sickle cell who have been told to shield might also be home schooling their children or caring for them to stay safe. One parent got in touch with the local council because they felt overwhelmed and stated they needed social support. The local council arranged for a social worker to do a needs assessment and carer's assessment. They then made sure that that parent got some respite care when they needed it or during periods of hospitalization. Another parent contacted a sickle cell charity, who made sure that the mother could chat to them about how she was feeling. They agreed they would ask for a volunteer to look after the child to give the mother a break for a few hours each week.

Good Practice: Social Support
If a child has to be taken out of schooling because of shielding or a person cannot return to work, patients have related that the sickle cell charities have been useful resources in explaining the situation to schools and to their employers. Many people are dealing with unemployment and the social security system and have related that sickle cell charities have been very helpful in understanding the welfare system and provision of help to fill out forms. If people have to self-isolate because they have the virus and are employed or self-employed and unable to work from home, they can also request support from the local council, under the Test and Trace Support Payment, if they are on a low-income.

Families and mental health: Most families in which someone has a mental health condition manage quite well, but for others having a mental illness can make parenting, caregiving and family life much more difficult. For a minority of families, parents might not be able to respond very well at all to their children's needs when their illness is at its worst. It is important to support such families, as children's long-term health and wellbeing can be affected. Aside from the symptoms of the illness itself, there are also often significant feelings of shame and guilt that people can feel when they or someone else in their family has a mental health condition. Families can find it hard to talk with each other about how their mental health is affecting them and so they can often misunderstand what one another's experience is like or how their experience is seen by others.

It is also quite common for parents to blame themselves if their child has a mental health condition, and vice-versa. This can put significant strain on relationships, affect the emotions and self-esteem of everyone in the family and make recovery more difficult. Families can also feel the negative effects of stigma around mental illness, and this includes children and young people feeling stigmatised because of their parents' illness. This can lead to families hiding mental illness from the

outside world, which can mean that they are trying to cope in very difficult circumstances without any support.

Good practice: Mental health and families
Do work together with families in this situation towards a better understanding of mental health, to help them realise that it is not their fault if they or someone in their family has a mental health condition, and that having such a condition does not make anyone a bad parent, a bad child or a bad sibling. Do note that hiding a mental health condition doesn't make it go away, and it doesn't mean other people in the family or friends won't be worried. Empower patients and their families to have a better understanding of their condition, symptoms and experiences and to communicate these with each other. This can help to reduce the burdens many families feel around not only SCD but also mental health. Normalise discussions about individual and family mental health by asking how families are coping together as a unit? Ask if they as individuals, or as a family, need any extra support. Emphasize that this is normal and we all need some support from time to time, especially if we have a mental health condition.

COVID-19 fears and vaccinations

People with SCD have been identified as a 'severely clinically vulnerable' and been asked to shield at various points during the pandemic. It is not always possible for patients to shield as some people with SCD and parents of children with the condition have to work, buy essentials, care for children and go into hospital settings. This means that a patient and their family might be very fearful and anxious about COVID-19 and what to do if they get the virus and how they will be treated. These fears have been amplified by the fact that, due to inequalities, ethnic minorities have been particularly affected by COVID-19 and BAME staff in NHS hospitals in particular.

Good Practice: We will give you the best care
One sickle cell centre informed patients of the latest information that they had about COVID-19 and survival rates for patients. They reassured patients that although they were clinically severely vulnerable and had to look after themselves, especially if they had underlying health conditions like diabetes, high-blood pressure or had compromised immune systems due to missing spleen, if they did get the virus, they would receive the best care possible. They also explained how BAME staff had the latest Personal and Protective Equipment (PPE) and how they were protecting their physical and mental health.

Good Practice: Vaccinations
People with SCD are regularly encouraged to get vaccinations, especially because many have weakened immune systems due to the removal of the spleen. This is very important but patients have related a loss of trust in NHS services, disempowerment and fears of being "used as guinea pigs". It is important to be respectful that taking a vaccination should be an informed choice and a patient has to be given all information before making that choice. Do give the patients the latest scientific evidence about COVID-19 vaccinations before it is offered to them. Explain if more than one or regular vaccinations will be needed. Do also ensure that a patient knows that even if they have had COVID-19, it means that a vaccination is needed. Some patients related believing they had immunity after a recovery from COVID-19 but this is not evidenced, they can get reinfected and the virus can mutate.

Pain: SCD is an unpredictable condition, variable over time and between different people. This creates uncertainty for the person affected. The painful crises can come on quite suddenly. Pain can make a person irritable, unresponsive and uncooperative. The pain of a sickle cell crisis can be mild, moderate, severe or excruciating. Since pain is such a common experience for people with SCD it is

vital that NHS services recognize this and develop a plan to support the patient when in pain.

Good Practice: Pain, advocacy and best practice
When patients are in a pain crisis, they are extremely vulnerable and it is important that first responders and A&E departments are regularly trained about SCD and how expressions of pain and mental distress can be cultural. Everyone deals with pain in a different way. Some people become silent or moan, others lash out verbally or physically and some people lose control over their bodies, are terrified and begin screaming. It is important to understand that this is not personal nor directed to a health care provider. Patients have said that they appreciate first responders or health care professionals who calmly tell them, "I understand you are a sickle cell patient and you are in pain. I am going to assess and treat your pain as quickly as possible." They make that distinction between the person and experience of pain. They also followed **NICE** and pain relief guidelines found in '**Standards for Clinical Care of Adults with Sickle Cell Disease in the UK'** where it is recommended that **pain relief should be received with 30 minutes of presentation then assessed every 30 minutes until pain relief has been achieved** and then every 4 hours. On a ward, if an independent advocate cannot be found, the outreach nurses might have to advocate for patients and ensure that they are not being labelled as 'aggressive' or 'problem patients' which often has a racist element. Patients have related how such labels can affect their daily care needs, such as toileting and pain management, which they have related as humiliating. Education around racism, anti-bias and racist microaggressions is important in such a context, as well as an examination of patient complaints through PALS. There should be regular audits and trainings to encourage a culture of openness and respect towards patients and NHS staff.

Medication: The key is to listen to the person and empower them. Where pain is mild or moderate the aim should be to keep the person at home. This may be achieved by combining pain medication with opportunities for rest and, for example, time out in a safe environment at home or at work. Some people with SCD use opiate painkillers when they have severe pain.

Good Practice: Medical Appointments
In order to remain well people with SCD may have commitments to medical appointments. These may be regular (monthly-six monthly) outpatient appointments for checks with their consultant. The consultant may order laboratory tests or scans that then require further hospital attendance. If the person with SCD is taking the anti-sickling drug hydroxycarbamide, they may have appointments as part of safety monitoring of that drug. They may also have regular (every 4-6 weeks) exchange blood transfusions that help keep them well. Transfusions may mean attendance at hospital a couple of days before the transfusion, in order to have blood cross-matched, and attendance on another day for the transfusion itself. One centre called their patients and sent them updates about how to get to their services and all safety provision in place so they would feel assured that their blood transfusions could occur safely. They were also aware of the fact that patients might be experiencing bereavement and made sure that if one of their patients had passed, they checked in on patients.

Wellbeing: Do think about the total physical and mental health wellbeing of a patient which is inclusive of their family. If needed, we have provided a resource where a plan can be made with an individual SCD patient or their family to map out where they need support and identify those who can give that support. This can be a plan for wellbeing and advocacy in services and should empower SCD patients and their families.

A Plan for Wellbeing and Advocacy in Services

Name: Date of Birth: **Condition 1:** Sickle Cell Anaemia (HbSS) **Condition 2:** **Condition 3:** [People with SCD may develop other long-term conditions or have mental health needs] Date of Plan: Review Date: [Suggest annual review]	 Photograph [taken when the person is well and free from pain]
NEXT OF KIN CONTACTS **Contact Name:** **Relationship:** **Contact number:** **Contact Name:** **Relationship:** **Contact number:**	**CONTACT NUMBERS** **Emergency Contact Name:** **Emergency Contact number:** **Hospital Consultant Name:** **Hospital Consultant Number:** **Specialist Nurse Name:** **Specialist Nurse Number:**
RESPONSIBLE ADVOCATE: Name: Building/Department: Contact Number:	**ADVOCATE CONTACT AGREEMENT**

REASONABLE ADJUSTMENTS AND ADVOCATES:

Generic

Person-Specific Adjustments

Example 1: Provided with advocate during hospitalisation for crisis while family unable to visit

Example 2:

Example 3:

MEDICATION

A person with SCD may be prescribed opiate-strength medication as part of overall pain management in hospital. Strong medication such as morphine has side effects and the person may have difficulty sleeping, and may have withdrawal-like symptoms such as sweating, being confused, and feeling dizzy. In some cases, they may be prescribed reducing doses for a few days post-discharge to wean off the drugs slowly. Hospital staff and GPs can help by ensuring fit notes cover the week following hospital discharge. HR and managers should respect the need for time to recover, as returning to work too soon without recuperation time can lead to a relapse.

PAIN MANAGEMENT

The aim is to strike a balance between responding appropriately to medical emergencies and maintaining an inclusive work and home environment where a person with SCD, for example, is not frequently off work for all episodes of pain. Many people with SCD experience mild pain at work or home and have developed the resilience to cope with this and carry on. Sometimes if the pain is moderate this may entail self-medicating with painkillers or using individually tailored pain management strategies such as use of hot water bottles, self-massage, or distraction techniques (e.g. watching TV, listening to music). In some cases, a period of rest at work in a quiet safe area may be sufficient to recover and even return to work the same day. In other cases, being permitted to go home and rest for the remainder of the day and perhaps the next day may (or flexibility such as working from home the next day) can prevent a full sickle cell crisis developing and much greater time off then being required. In cases of severe pain, the person may need to go home or refer themselves to hospital. In cases of excruciating pain an ambulance should be called immediately.

NO PAIN					MOST PAIN
	Self-medication or individual techniques	Self-medication or individual techniques plus "time-out" in quiet safe environment	A couple of day's rest at home in order to prevent a worse crisis	Can go home and manage their own referral to a day care unit	Dial 999 for an ambulance. Know which hospital is their main treatment centre.

ONLY THE PERSONW WITH SICKLE CELL CAN SAY HOW SEVERE THEIR PAIN IS AT ANY GIVEN TIME.

OTHER PARTICULAR NEEDS/ISSUES

This section can contain information specific to the person's individual condition (for example, information about mental health, strokes, leg ulcers, eye problems, hip problems, priapism, headaches, seizures, deep vein thrombosis or other possible complications of sickle cell disorder).

Building support and advocacy

Name of Person:	Signature:	Date:
Occupational Health:	Signature:	Date:
Sickle Cell Specialist Nurse:	Signature:	Date:

Space for a relevant list. This might include a list of medications they have been prescribed for mental health treatment or SCD. Alternatively, it might be space to note which staff have received relevant training to support the patient.

e.g. Name of Prescribed Drug e.g. Name of Staff Member	Dosage Date of Attendance

Space to include examples of good practice in wellbeing that a patient can follow:

Illustrative Example 1: *Patient is transitioning from childhood services to adult care. They were put in contact with sickle cell support group who put the family in touch with a mentor to explain how to manage pain at home, when to go to hospital and what to expect in A&E if alone.*

Example 2. . . . . .

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Example 3

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Patient remarks:

Further Information:

OSCAR Sandwell 120 Lodge Rd, West Bromwich, B70 8PL **Tel:** 0121 525 0556 **E-mail:** rachel.mcfee@oscarsandwell.org.uk **Facebook:** OSCAR Sandwell **Website**: http://www.oscarsandwell.org.uk/	**NHS – Shielding Patients List** **Website:** http://www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/advice-for-people-at-high-risk/ **UK Government Advice on shielding** **Website:** http://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19 **UK Forum on Haemoglobin Disorders** http://haemoglobin.org.uk/covid-19/
OSCAR Birmingham 22 Regent Pl, Birmingham, B1 3NJ **Tel:** 0121 212 9209 **E-mail:** admin@oscarbirmingham.org.uk Website: http://oscarbirmingham.org.uk/	**COVID-19 and Wellbeing-NHS** **Website:** http://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-staying-at-home-tips/ **Mental Health and Wellbeing-NHS** **Website:** http://www.nhs.uk/conditions/stress-anxiety-depression/
Sickle Cell Society 54 Station Road, London, NW10 4UA **Tel:** 020 8961 7795 **E-mail:** info@sicklcellsociety.org **Facebook:** Sickle Cell Society - UK **Website:** http://www.sicklecellsociety.org/	**Carers breaks and respite care** http://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/ **Test and Trace Payment Support Scheme** http://www.gov.uk/government/publications/test-and-trace-support-payment-scheme-claiming-financial-support