

# TRANSITIONING TO ADULT CARE

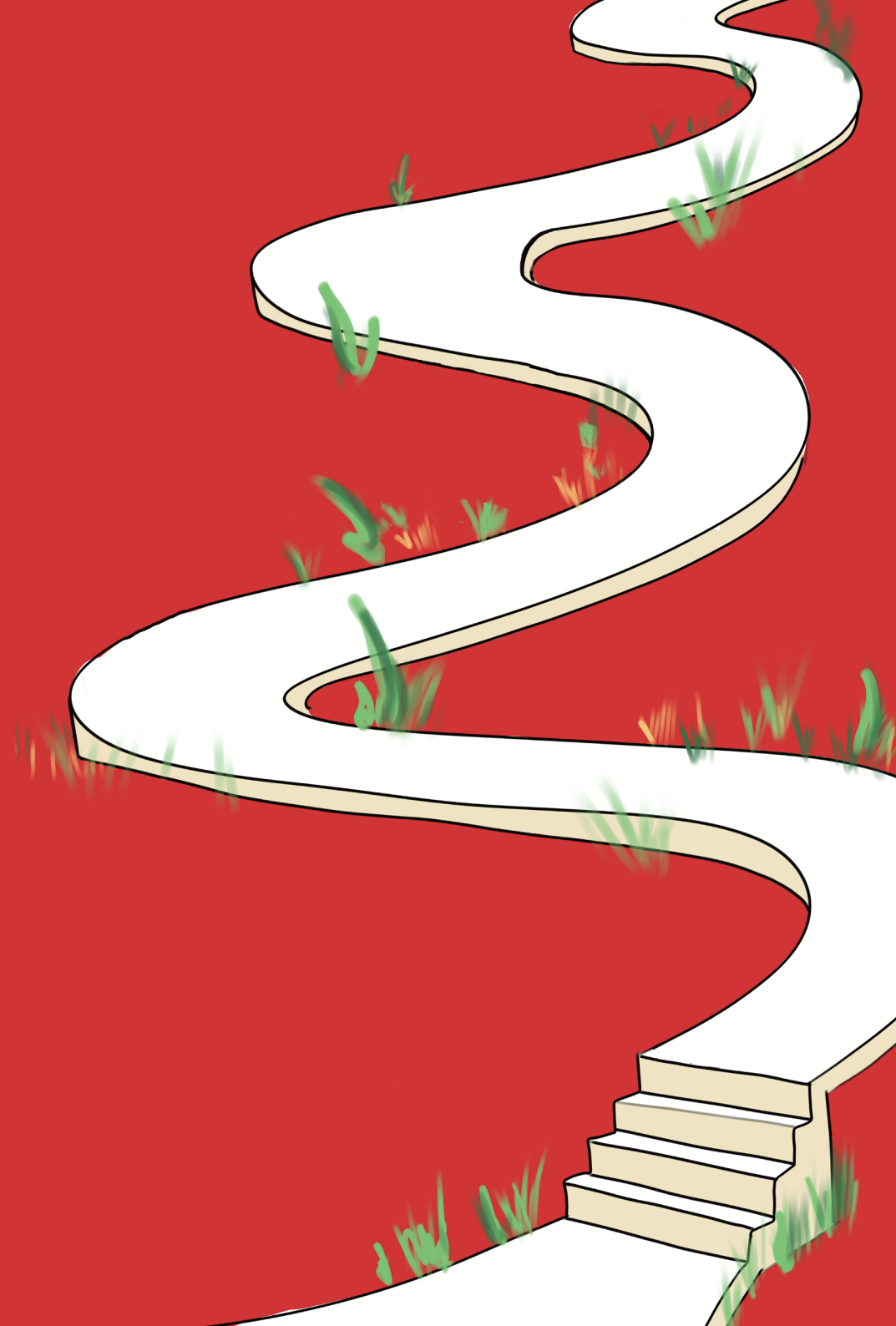


*A Booklet For 12 – 18 Year Olds*

## INTRODUCTION

Transition in healthcare is the gradual process of moving from pediatric care to adult care. It is necessary because Adult Clinicians are best placed to look after adult bodies so your care will be better suited to your needs.

It can be daunting, but know that there are people there and resources (like this booklet) to help you every step of the way. You can view this as a chance to gain more independence and control over your own well-being!





# DAILY LIFE

You most likely already know, but there are some things that you should do everyday to take charge of your own health and reduce the frequency of pain crisis. These are:



## Stay Hydrated

Hydration is super important, make sure to drink water regularly – ask your doctor how much is recommended if you're unsure.



## Nutrition

Try to eat healthy, balanced meals. A great recipe book curated to support the nutritional needs of people living with Sickle Cell is:

Cianna's Smile's  
[Nutritional guide and recipe book for Sickle Cell](#)



## No Extreme Temperatures

Keep yourself warm in the cold, and if it's really hot, find ways to cool down.

## Rest, Don't Overexert Yourself

Make sure you're getting enough sleep every night and take regular breaks when exercising. It's okay to go to parties and have fun but don't tire yourself out. **No drugs or alcohol!**



## Avoid Stress

Stress is inevitable especially as you get older and go through school, but try to do things to relax and speak to your teachers, friends and family about how you're feeling – it helps!



## IMPORTANT NOTE

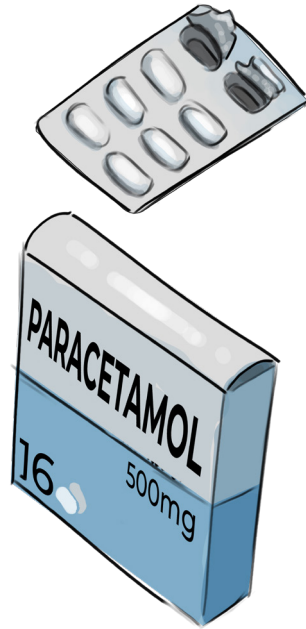
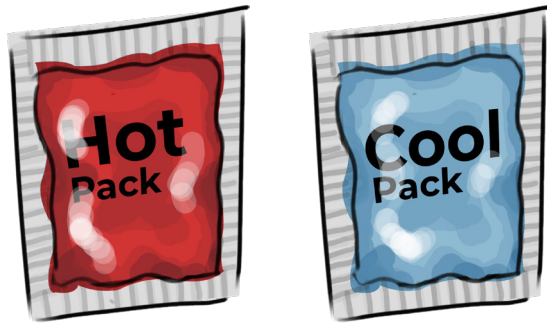
If you are 16–18, and planning on going to college or moving away for university, be sure to inform your healthcare team, register with a GP near where you will be staying and research your college/university's support services and DSAs (Disabled Student Allowances).



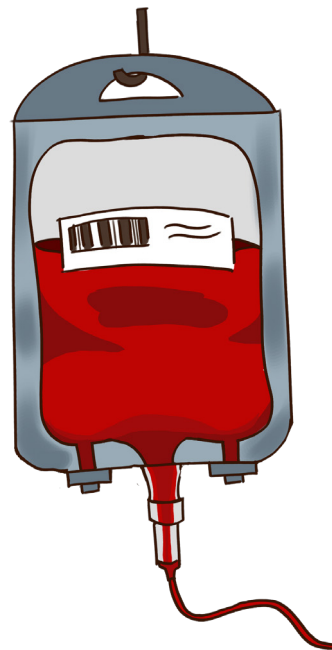
## Treatments

Common treatments for a crisis include over-the-counter pain medication like paracetamol or ibuprofen.

At home, applying hot or cold packs to painful areas can also help relieve pain.



In more severe crises, blood transfusions and opioid painkillers like Morphine are given in hospitals.



## Medication

Use this space to write down your medications, treatments or specific medical terms you need to remember or would like to understand better.

A large, empty rectangular box with a black border, intended for writing down medications, treatments, or medical terms.A small illustration of a pill bottle with a green and orange label, and two blue pills next to it.

## Who to Contact in an Emergency

As you discuss your transition with your healthcare team, use this space to write down contacts for emergencies or emotional/wellbeing support:

A large, empty rectangular box with a black border, intended for writing down emergency contacts or support information.A small illustration of a smartphone with a red border, displaying 'Calling...' and '999' on its screen.

# Advocating For Yourself

Here are some tips:

## Ask Questions

You should have meetings with your healthcare team in preparation for your transition. You treat these as extra practice by asking questions and discussing your concerns.

If you don't understand something, you can ask for clarification by saying:

*'I'm not sure I understand. Did you mean....(repeat information back to them)....?'*

Or  
*'Sorry, that was a lot of information. Can you repeat the main points?'*

Or, if you are unsure of how to respond:  
*'Okay, let me think for a bit'*

(take notes if you need to)

## Knowledge Of Your Condition

You will go from getting treatment from specialists in Sickle Cell Care to general wards so it is important that you learn about your Sickle Cell treatment, how to manage it and who to contact in case of an emergency.

## Be Prepared

As an adult, if you're experiencing a crisis and have to visit the A&E, you might have to explain your symptoms to people that do not know anything about Sickle Cell Condition.

To prepare yourself, you can ask for a tour of A&E and put together an emergency bag and emergency contact list.

Keep a copy of your care plan on your phone.

If you are a student, ask about your school's disability support services.

Of course, you can also bring a trusted family member or friend with you to help.

If you don't have someone, your local council is obligated to provide someone to advocate for you if you have difficulty. Contact your council's Social Care Services and ask about their Advocacy Services.

Hospitals also have volunteers that can accompany you if you are alone – just ask at reception!

## Pastoral & Mental Health Support

Balancing school, social life, family and your health can get really stressful. Be sure to utilise your school's pastoral services and seek out mental health support. It's important to talk to someone, if something is bothering you, don't keep it to yourself.

**The NHS offers mental health support for young people.**

**Find out more here:**

<https://www.nhs.uk/mental-health/children-and-young-adults/mental-health-support/how-to-get-support/>

## Know Your Rights

People with Sickle Cell, especially those of Afro-Caribbean heritage, have reported poor experiences of care in general hospitals, so it is important to know your rights.

They are as set out in the [Clinical Care of Adult Standards of Care](#).

**Note:** *Pain has to be assessed and given pain relief within 30 minutes of arriving in A&E.*

**As you get older and slowly transition into adult healthcare services, self-advocacy is an essential skill to have.**

**For more tips visit:**

<https://www.whittington.nhs.uk/default.asp?c=47427>

<https://thehealthandhealingnarrative.com/2025/12/01/how-to-advocate-for-yourself-as-a-patient-in-the-nhs-a-practical-guide/>



## Personal Notes:

Use this space to write down any questions you have for your doctors or to take notes about things you've learnt about your health, your experiences, your concerns etc.



## More Resources:

Sickle Cell Society

[Supporting People Affected by Sickle Cell Disorder](#)

NHS

[Children and young people's mental health services](#)

[What is PALS \(Patient Advice and Liaison Service\)?](#)

The Patients Association

[Free Healthcare Helpline | The Patients Association](#)

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