



## EMSTN Southside Patient Engagement Keeping Well This Winter Presentation

Winter 2020/2021

# Introduction

- First of all we send you greetings and best wishes from all East Midlands Sickle Cell Network Southside teams based at Leicester Royal Infirmary, Northampton and Kettering General Hospitals.
- We know its been an extraordinary time for all of us and many of you will have been shielding for a long period and now returning to work and school in what may seem like uncertain times. We wanted to share some information that may be of benefit over the winter period.
- Many of you will have remembered the great time we had together at the patient and family education and engagement event at Leicester Space Centre last June. We had hoped to hold a patient engagement event annually but COVID has restricted us at the present time. Instead we have put together this presentation to share information that you may find useful to help keep yourselves well over this challenging winter.



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# Keeping Well With Sickle Cell

To keep well it's important to avoid factors which can trigger sickling: cold, lack of oxygen, dehydration, hard exercise, fever and infection. It can also help to:

Ensure your vaccinations are up to date

Eat a healthy, balanced diet

Treat infections and fevers promptly



Try to keep your clinic appointments with the hospital whether that be via telephone or face to face

Regularly take your prescribed medicines, ensure you have analgesia available at home and request new prescriptions before you run out

Make sure you attend for your TCD scans (under 18's) blood tests and Hydroxycarbamide monitoring as this will help to monitor your condition

Drink plenty of fluids as per individual requirement

Avoid getting cold; wrap up warm.

Take regular exercise (but avoid over-exertion)

# Keeping Well With Thalassaemia

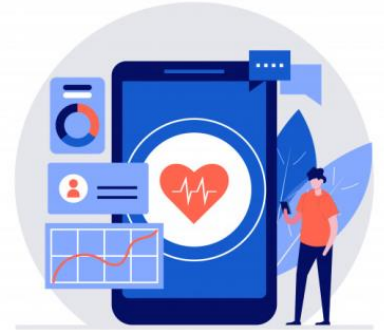
	Eat a healthy balance diet – there are no special dietary requirements		Try to avoid infection, and treat symptoms quickly.
	Regularly take any medicine prescribed by your Doctor and request new prescriptions before you run out		Ensure your vaccinations are up to date
	Regular exercise including weight bearing and aerobic exercise as it can strengthen bones and reduce risk of osteoporosis		Attend all of your outpatient appointments – whether telephone or face to face appointments or scans. Rearrange any you cannot attend.
	Avoid smoking and drinking excessive amounts of alcohol as this can help keep your bones and heart healthy		Regularly attend blood tests appointments – chelation monitoring and annual review as this will help monitor your condition

# Useful Apps For Your Phone

Have you ever looked at the many smart phone apps that are available for your phone that can help children, teenagers & adults managing their condition day to day.

These include .....

- Numerous medication management /reminder apps
- Apps that remind you about Hydration
- Relaxation & Meditation apps to help with stress and relaxation
- Sickie Buddy – For children to learn and to live with their sickle cell
- Sickie-o-scope – a symptom diary app
- Little George – Little George and the Dragon – helps children manage their sickle pain



**Sickle-O-Scope**  
apps@addmedica Health & Fitness  
Everyone

Add to wishlist



**SickleBuddy** 4+  
Kofi Anie  
Free



**Little George** 4+  
Twin Vision  
★★★★★ 4.0 • 4 Ratings  
Free



# Vaccination

Being up to date with your vaccinations is really important particularly for patients with sickle cell and those with thalassaemia who have had a splenectomy. This is because they are more susceptible to a range of infections.

Its important to have all of the routine childhood vaccinations.

Then in addition to have

- The Pneumococcal polysaccharide vaccination (PPV23) at five yearly intervals
- The Annual influenza vaccination - via injection or children may have it intra nasally
- **Its important that you have your Covid vaccination when you are invited for it**

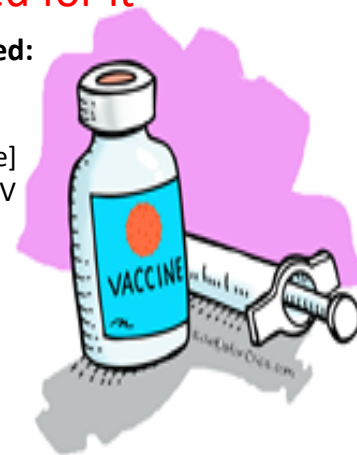
**Adults who have not received primary vaccination as part of the national schedule in the UK should be offered:**

- One dose of Hib/Men C and one dose of pneumococcal polysaccharide vaccine (PPV23); followed by,
- One dose of MenACWY conjugate vaccine one month later
- Two primary doses of MenB vaccine one month apart [this can be at the same visits as the other vaccinations above]
- A single 0.5 ml dose of pneumococcal conjugate vaccine (PCV13) which should be given at least six months after PPV

Adults with SCD should also be offered:

- Pneumococcal polysaccharide vaccination (PPV23) at five yearly intervals
- Annual influenza vaccination
- Complete course of Hepatitis B vaccine if they have not previously received it and are non-immune (HBsAb)

Information from Vaccination Green book - current at time of writing Nov 2020 . Check online for updates.

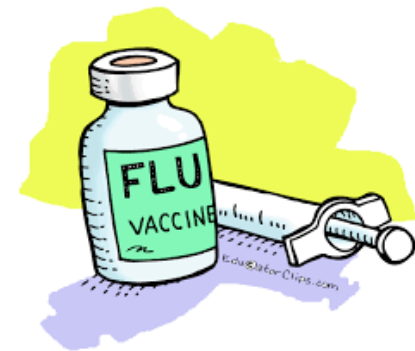


# Keeping Well This Winter

In addition to the usual keeping well advice like wearing additional layers of clothing and drinking plenty. In winter you also need to think about ....

- Having your flu Vaccination – for adults this is the normal flu jab at your GP surgery for children this can also be the Intra nasal flu vaccine given at school. Children who are on Hydroxycarbamide can still have the Nasal LIVE flu
- In addition this winter be sure to be wearing your face masks when you are in public places and following the public health advice.

Wash your hands – Cover your face – Make Space





# Corona Virus : COVID 19



Most people with coronavirus have at least one of these symptoms.

- a high temperature
- a new, continuous cough
- a loss or change to your sense of smell or taste.

## If you have any of these symptoms

- Get a test to check if you have coronavirus as soon as possible.
- Stay at home and do not have visitors until you get your test result – only leave your home to have a test.
- Anyone you live with, and anyone in your support bubble, must also stay at home until you get your result.
- Its also important to let your local Haematology Team / Specialist Nurse know that you are unwell and have had a test and the result of it.
- Book a COVID a test online on GOV.UK. website If you have problems using the online service, call: 119 if you're in England, Wales or Northern Ireland Lines are open 7am to 11pm.

<https://www.gov.uk/coronavirus>

# Shielding

We know many of you have spent a considerable period of time shielding and want to acknowledge how difficult that period must have been.

During Lockdowns, many of our adult patients will still be included in the extremely vulnerable group so it is important to find out if you are, and if so you are advised to follow the extra precautionary shielding measures.

The most up to date information can be found on the Gov.uk website.

<https://www.gov.uk/government/news/clinically-extremely-vulnerable-receive-updated-guidance-in-line-with-new-national-restrictions>

Information about what support is available to those in the clinically extremely vulnerable group can also be found on the Gov.uk website

<https://www.gov.uk/coronavirus-shielding-support>



# Psychological Aspects of Covid 19 Shielding

Having a long term health condition such as Sickle Cell anaemia or Thalassemia is known to have a potential impact on mental health, mood and day to day functioning.

Some people may find that the current pandemic (Covid 19) has increased existing mood issues or they may be experiencing new symptoms such as:

## Low mood

Common symptoms of low mood include loss of appetite, feeling more irritable, tearfulness, loss of pleasure, difficulty concentrating and poor sleep. Some people may even feel suicidal and hopeless about the future.

Shielding, changes to daily life (e.g. not working, not seeing family members, not being able to do usual activities) may lead to feelings of isolation and feeling disconnected from others.

## Anxiety

Symptoms of anxiety include worrying more than usual, sudden feelings of panic, feeling on edge or fearing that something bad may happen.

Triggers for anxiety and panic could include reading / watching the news, having to go to hospital for treatment or coming into close contact with others at home or elsewhere.

# Shielding : What can I do?

It is normal for the current pandemic to affect us all to some degree. However if you are concerned because your mood has changed significantly or you are finding it difficult to cope there is support you can access.

Talk to friends or family. Although this may sound obvious it can be more difficult to reach out when we are feeling low in mood, it is easy to withdraw and feel that others do not understand.

Contact your Clinical Nurse Specialists or your Haematology Consultant. They will find out more and see what kind of support you might need. They may, with your permission refer you to Medical Psychology or another service for psychological therapy or support.

Talk to your GP – they can assist you with a review of your mood and advise you of psychological therapy or support options in your area. They can also prescribe medication if appropriate.

If you need urgent mental health support contact Leicestershire & Rutland Central Access Point (CAP) 0116 2953060.

This Poster was produced by Bradford Teaching Hospitals psychology team but offers us all some ways to support our well being during Covid 19

## 5 ways to support your own well-being during COVID-19



Bradford Teaching Hospitals  
NHS Foundation Trust

You may be experiencing a great deal of worry and uncertainty, it might feel difficult or stressful at times, and this is ok. Here are some important ways we can all take care of our well-being:

<b>Connect</b> 	Keep in touch with friends or loved ones in ways you can, such as by phone.
<b>Acknowledge Feelings</b> 	Gently notice and acknowledge your thoughts and feelings, trying not to be judgemental. We are often hard on ourselves which makes us feel worse, not better.
<b>Be kind to yourself</b> 	Show yourself the same kindness you would to a good friend.
<b>Share your worries</b> 	Talk to a member of staff that you feel comfortable with. They might be not able to fix things, but it can help us to feel less alone.
<b>Notice pleasant things</b> 	Try to notice what is ok or pleasant about this moment, perhaps you can notice what you feel grateful for. It can help boost our well-being even in tough times.

MID 2004061 / NHS April 2020

# Shielding : Other Sources of help and support

The following few links may be helpful if you would like to find out more about specific issues or experiences. There are many more services so please ask for more information if there is something specific you need advice or help with.

**Anxiety, depression, mental health information and apps**  
(please note, some apps charge to download)

<https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines>

<https://www.nhs.uk/apps-library/category/mental-health/>  
<https://www.psychologytools.com/resource/living-with-worry-and-anxiety-amidst-global-uncertainty>

**Suicidal feelings**

<https://www.samaritans.org/how-we-can-help/>

**Mindfulness and relaxation**

<https://www.headspace.com>

**Distress Tolerance**

<https://getselfhelp.co.uk/distresstolerance.htm>

**Refugee and Asylum Services**

<https://sparkandco.co.uk/>



**"I feel like life is not**

**worth living and I don't**

**know where to turn.**

**What should I do?**

**Who can help me?"**

Call **999** or go to **A&E** if:

- Your life is at risk
- You do not feel able to keep yourself safe

Call **Central Access Point** 24 hours a day, 7 days a week on **0116 295 5060** if:

- You have an urgent mental health need during the COVID-19 pandemic

Call **NHS 111** or ask for an urgent **GP** appointment if:

- You need help urgently for your mental health, but it's not an emergency
- You are struggling to cope

**"I am struggling to**

**cope and feeling down.**

**What can I do?"**

**Healthy Together 0-19 service (School Nursing)** - a confidential, secure text messaging service (ChatHealth) for advice and support on areas including exam stress, mental health, anxiety, self-harm and sexual health. Text: **07520 615386** if you live in Leicester or **07520 615387** if you're in Leicestershire or Rutland.

**Kooth** - your online wellbeing community for free, safe and anonymous support and counselling. [www.kooth.com](http://www.kooth.com)

**talk2sort Mediation Service** - if you are aged 11-19 and you and your family are having problems at home or with your relationships, this service could help. [www.thebridge-eastmidlands.org.uk/services/talk2sort](http://www.thebridge-eastmidlands.org.uk/services/talk2sort)

**"I am feeling more**

**worried than usual.**

**How can I feel better?"**

**Childline** - call **0800 1111** or speak to a counsellor online at [www.childline.org.uk](http://www.childline.org.uk)

**The Mix** - a friendly support service offering telephone and instant messaging support to anyone under 25. Call **0800 808 4994** or go to [www.themix.org.uk](http://www.themix.org.uk)

**Family Action** - provides practical, emotional and financial support. Contact FamilyLine by calling **0800 802 6666**, by texting **07537 404 282**, by emailing [familyline@family-action.org.uk](mailto:familyline@family-action.org.uk), or via live web chat: [www.family-action.org.uk](http://www.family-action.org.uk)







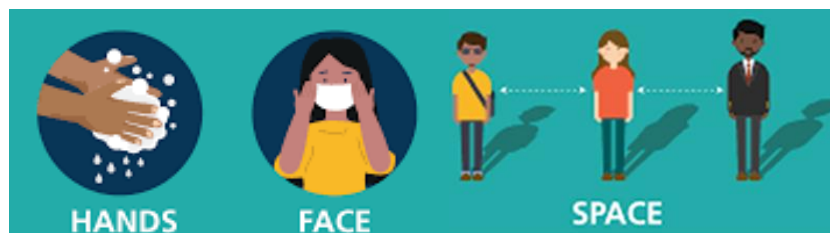
# Going To School & Staying Safe



- Lock down has been tough on children generally, but especially for those who have been shielding. Fortunately we now know children are less affected by COVID-19. Its therefore important for them to resume their education and the social interaction with friends albeit in a different way.
- Each school has produced and implemented its own local policies from The Government and Public Health England Guidance. These policies and measures put in place for all children in school are adequate for children with sickle cell and thalassaemia too.
- We know that many families who were shielding, may have concerns and many have spoken to the team about them. Our Specialist doctors now have better information from The Royal College of Paediatrics and Child Health (RCPCH) regarding shielding. This can be viewed on The RCPCH website.

<https://www.rcpch.ac.uk/resources/covid-19-shielding-guidance-children-young-people>

Its great to be  
back at school with  
your friends



Remember  
Hands – Face – Space  
in school & out to play





# Preparing Teenagers For Transition To Adult Services

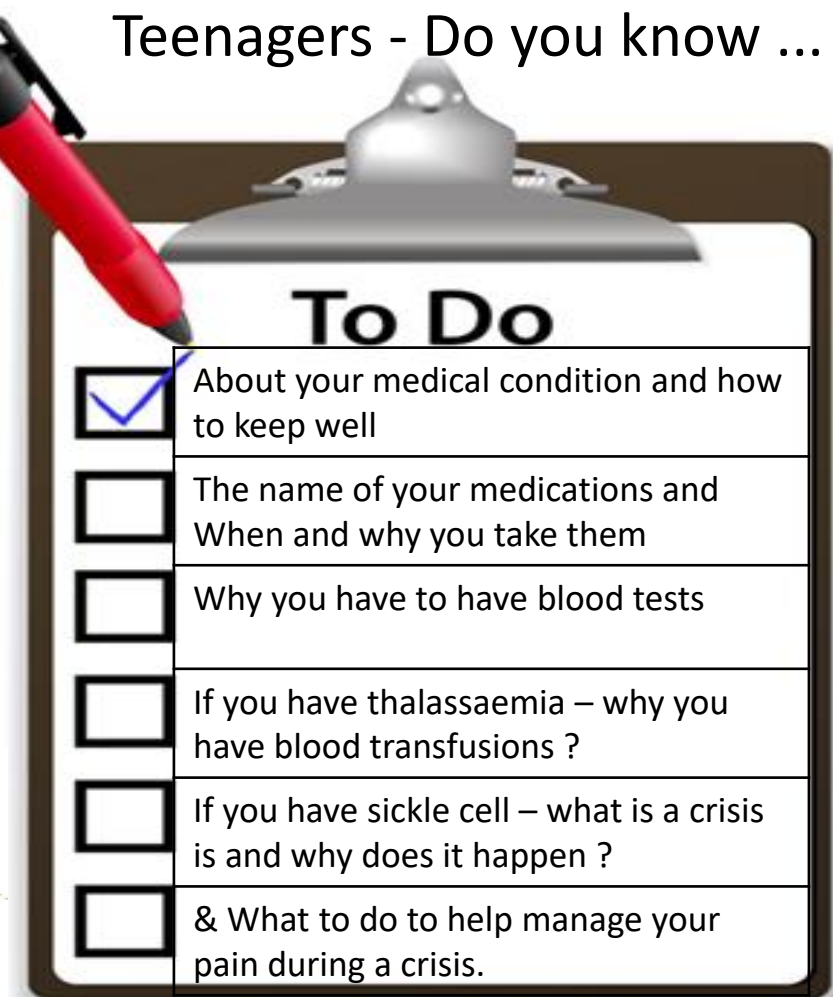
Parents have a really important role in helping prepare your children for the transition from Childrens to adult services. We will start to talk about it in clinic appointments but the conversations you have at home are very important.

Your specialist nurse will be happy to talk to you about how you can do this.

By the time children reach adolescence they should have a good understanding of their own medical condition and how it affects them. They should know what to do to stay well and why its important.

Its good to encourage teenagers to become more independent and take more responsibility with their own medication.

Teenagers - Do you know ...



**To Do**

<input checked="" type="checkbox"/>	About your medical condition and how to keep well
<input type="checkbox"/>	The name of your medications and When and why you take them
<input type="checkbox"/>	Why you have to have blood tests
<input type="checkbox"/>	If you have thalassaemia – why you have blood transfusions ?
<input type="checkbox"/>	If you have sickle cell – what is a crisis is and why does it happen ?
<input type="checkbox"/>	& What to do to help manage your pain during a crisis.



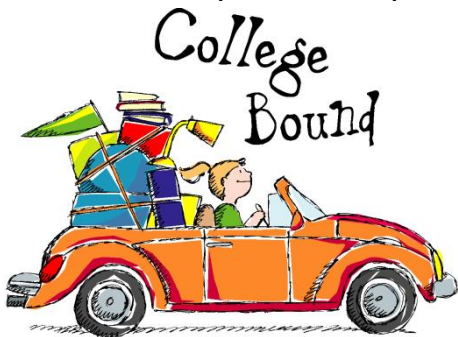
# University Students Living Away From Home

Your existing Haematology Consultant should have referred you to the team local to your university – if you have not heard from the new local team – please get in touch with them using the contact details found on the following pages.

Please ensure you register with a local GP. You will need the GP for general health appointments and in order to get your repeat prescriptions.

In Leicester Chelation and Hydroxycarbamide prescriptions will need to be requested through the team at UHL – on 07950 891490 (we may ask you to come for a blood test for monitoring purposes).

Make sure you know where your local hospital is – in Leicester this will be UHL Leicester Royal Infirmary – see the contact page.



Please let the University Student Disability Services know you have a chronic condition. They are there to support you while you at University.

DMU Disability Services  
The Student Gateway, Gateway House  
T: +44 (0) 116 257 7595  
E: [disability@dmu.ac.uk](mailto:disability@dmu.ac.uk)

University of Leicester – Access ability Centre  
T: +44 (0)116 252 5002  
E: [accessible@le.ac.uk](mailto:accessible@le.ac.uk)

# UHL – Leicester Adult Patients

## Contact numbers if you are unwell and need advice .....

Emergency Haematology Helpline Number – 0808 178 2212  
(24 hours per day/ 7 days per week)



Adult Nurse Specialist – 07950891490

Working days are Tuesday – Friday 9am-5pm)

Sickle cell and Thalassaemia Office 0116 2586081

Monday – Friday 9am – 5pm



- Due to the pandemic if you are having COVID symptoms and need admitting you will be admitted onto Ward 40 (Osbourne building).
- For non COVID admissions you will be assessed on OAU or ED. Prior to being moved to the wards.
- No relatives will be allowed to attend or visit at present unless under exceptional circumstances and pre-discussed with the ward manager.

# UHL – Leicester Child Patients

## Contact numbers if you are unwell and need advice .....



### Childrens Nurse Specialist - Mobile 07958 010060

Available for non urgent advice on Wednesday and Thursdays – or leave a message.

- If your child is unwell with pain or temperature contact ward 27 first by telephone. Do not attend the ward until you have spoken to the ward by telephone.
- If it is an emergency that needs immediate attention call 999
- If you wish to speak to a Nurse for non urgent advice please telephone the children's specialist nurse.



Ward 27 at Leicester Royal Infirmary  
Tel 0116 2585959

Sickle cell and Thalassaemia Office  
0116 2586081 - Monday – Friday 9am – 5pm





# NGH - Northampton Adult Patients

Contact Numbers if you are unwell and need advice .....



Adult Nurse Specialist Mobile 07496 510672



- Haematology Day Unit  
01604 545031
- Out of hours Talbot Butler  
01604 545534
- Emergency Assessment Bay  
01604 545851
- Haematology secretaries  
01604 523261

## NGH - Northampton Child Patients Contact Numbers if you are unwell and need advice .....



Childrens Nurse Specialist Mobile 07950 884126



- Disney Ward for open access 01604545518
- Dr Koodyeidath & Dr Breene secretary 01604 545521



Kettering – KGH Adult Patients  
Contact Numbers if you are unwell and need advice .....



Adult Nurse Specialist Mobile 07496 510672

- Emergency Assessment  
Bay 01604 545851
- Dr Gandla secretary  
01536 491661



Kettering – KGH Child Patients  
Contact Numbers if you are unwell and need advice .....



Childrens Nurse Specialist Mobile 07950 884126

- Skylark Ward  
01536492291  
01536493771
- Dr Arora Secretary  
01536493374



## Further Information and Support



54 Station Road, London NW10 4UA  
Phone: 020 8961 7795  
Email: [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org)

<https://www.sicklecellsociety.org/helpline>



19 The Broadway, Southgate Circus, London, N14 6PH  
Phone: 0208 882 0011  
Email: [info@ukts.org](mailto:info@ukts.org)

<https://ukts.org/contact/>

The Sickle Cell Society and UK Thalassaemia Society are a great source of up to date news, information and support – even during the COVID 19 restrictions they are still working to provide up to date resources for you so please take a look at their websites.

Thank you for taking time to read this information – if you have any question please do get in touch with us.