

Living Well with Sickle Cell Programme

Would you like to:

- ✓ Learn more about living well with Sickle Cell Disorder (SCD)?
- ✓ Learn new techniques on how to better manage your health?
- ✓ Meet others who know what it's like to live with SCD?

If you answered 'Yes' to any of the above questions, then the **Living Well with Sickle Cell Programme** may just be for you!

This online programme is a seven-week self-management course, starting on **16th May 2023**, for people who live with Sickle Cell Disorder and its resulting health issues.

For further details about the programme and how to register your interest, please read the following information.



Living Well with Sickle Cell Programme

What is it?

The Living Well with Sickle Cell Programme is a seven-week self-management course for people who live with Sickle Cell Disease and its resulting health issues such as fatigue, pain, depression etc.

Weekly 2½-hour sessions are designed to help you cope with your health condition, find solutions to common problems & feel more in control.

The majority of the course is delivered by specially trained lay people who live with health conditions, including Sickle Cell, themselves. Health professionals from Whittington Health's Sickle Cell service deliver one session.

What can the Living Well with Sickle Cell Programme offer me?

People who have come on self-management courses like this one have reported that it has made a big difference to them, they appreciate having met others who are living with health conditions and they feel more positive and able to manage their health.

People with Sickle Cell face many similar issues such as fatigue, pain, frustration, stress, and depression. The course looks at how to manage these whilst working alongside your healthcare providers.

Benefits include:

- ❑ A 'Tool kit' of techniques that you can try out for yourself.
- ❑ Different topics covered each week.
- ❑ Times to share and discuss.
- ❑ Building confidence that you can cope with your condition and work towards what's important to you (your personal goals).
- ❑ Being with others who know what it's like and can share tips
- ❑ Focusing on taking control of your health rather than it controlling you
- ❑ Taking small, gradual steps.

Whittington Health NHS Trust

Chair: Baroness Julia Neuberger

Chief Executive: Helen Brown

Participant's Feedback:

"Meeting people has helped me understand more about myself and ways of managing things... It has been a well-run course, and everyone has been very helpful and caring." **Ali**

"It has helped me become more aware of my condition and how it affects me, and to feel that I can manage it to some extent through pacing, diet and relaxation techniques." **Derrick**

"It gave me more information and confidence to do normal things in life." **Susan**

Course Content

The course focuses on what you *can* do, rather than what you can't. Weekly sessions cover useful topics such as managing symptoms, dealing with pain and tiredness, coping with depression and other feelings, relaxation techniques, healthy eating, exercise, setting realistic goals and communicating effectively with health professionals. The programme is designed to give you a taster of a number of self-management strategies so that you can take away and practice the ones that you feel are most helpful to you.

Frequently Asked Questions

How much does it cost?

These courses are FREE. You don't pay anything to attend any of our courses.

Who is the course for?

The courses are for people who:

- live, or have a GP, in Barnet, Camden, Enfield, Haringey, and Islington

and

- have been diagnosed as having Sickle Cell

If you would like to discuss whether this course is for you, please do call us (see contact details).

Do I have to be referred by someone?

No, you don't. Although healthcare professionals do refer people to us, many of our participants have simply contacted us themselves.

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Do I have to attend all the sessions?

To get the most out of the course it is best to attend as many sessions as you can, but we understand this might not always be possible.

Do I need to talk about my own condition?

There will be times when you will be asked to share how your condition affects your life and what you would like to change. However, it is up to you what you want to share and how much detail you want to give. All discussions are confidential.

Where are the Courses held?

The courses are held on-line on Zoom. You will be sent a link and instructions for how to access the course. You will need a laptop/ computer or mobile phone with a camera which can access the internet to join the course.

Will I get a break during the session?

There is a break half-way through each session and additional short breaks can be agreed as a group. You are free to lie down or get up and move around whenever you need to.

Do I need a carer / assistant with me on the course?

If you need a carer, you will need to join the course with a carer, however you will need to inform staff prior to the course. Please do bear in mind that if you are related to your carer, it may be difficult for you to discuss certain issues freely. This is your time to focus on how you would like to manage your health. If you decide you would like your carer to be present, they may like to take part as a participant themselves. Please let us know beforehand if you are likely to have a carer or assistant.

I have specific communication requirements – can these be accommodated?

If you have specific communication requirements, please do contact us beforehand. For example, we can arrange for a BSL interpreter or large-print materials to be available.

Do you provide equipment?

We are unable to provide technical or electronic equipment. Please let us know if this will be an issue for you, as we may be able to put you in contact with an organisation that can help.

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What happens after the end of the course?

We hope that once the course is over you will start putting the skills and knowledge you have learned into practice to help you manage your health and feel more confident. Approximately twice a year, we arrange for participants who have completed a course to meet up (on-line or in person) for an informal get together.

Can I feedback my views about the course?

Yes, we are always seeking feedback about our courses to help us improve them. At the end of the course, you will have an opportunity to feedback and you are always welcome to contact us at any time (see contact us).

Contact Details:

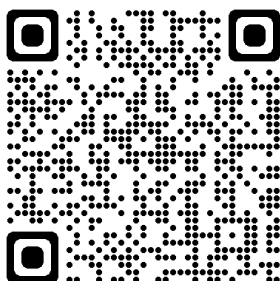
If you are interested in attending the Living Well with Sickle Cell Programme, please contact us:

Telephone: 020 7527 1558

or

Email: whh-tr.self-management@nhs.net

Or use this QR code to take you directly to our on-line form:



For further information, visit our website:

<https://www.whittington.nhs.uk/selfmanagement>

Referrals

Please note the course is part of the Expert Patients Programme (EPP). Referrals can be made on the website above or as per your organisation's normal EPP referral process. Please ensure to specify Sickle Cell as the main health condition.

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We look forward to hearing from you!

Self-Management Support and Behaviour Change Team
Whittington Health NHS Trust

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.whitthealthPALS@nhs.net

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