

'Breaking the Cycle'

A pain management programme for people with sickle cell disease and thalassaemia

This leaflet explains more about the pain management programme for people with pain related to sickle cell disease or thalassaemia. It aims to help you understand what is involved in the group and whether it is right for you. If you have any further questions, please speak to one of the red cell team.

What is 'breaking the cycle'?

Breaking the cycle (BTC) is a pain management programme for people with persistent pain related to sickle cell disease or thalassaemia.

Persistent pain is pain that you have regularly for longer than six months. It may be the type of pain you manage at home, rather than severe crisis pain which might bring you to hospital. Persistent pain can also be called 'chronic' or 'everyday' pain.

We know lots of people with sickle cell disease and thalassaemia have persistent pain, which can make activities, sleep and other aspects of life harder and can affect your mood.

BTC is a group programme which runs one day a week for eight weeks. The same people come each week and all live with sickle cell or thalassaemia. Many people tell us meeting others in similar situations is an important part of the programme and really helps them to get the most from the group. The programme aims to help you learn new ways to manage your pain and reduce the impact it has on your life. At the start of the programme, you will be invited to think about your own goals so you can use the sessions to work towards things that are important to you.

The programme covers:

- The difference between short-term (acute) pain, like a sickle cell crisis, and long-term, persistent pain
- Our understanding about what happens when you have pain that doesn't go away
- How activity and pain affect each other and how to have helpful patterns of activity
- How to exercise or increase movement with persistent pain and sickle cell/thalassaemia
- How to return to or continue with activities that are important to you
- Managing flare-ups when persistent pain gets worse
- The way pain affects emotions and how to cope with feelings of frustration, anger, worry and depression
- The way pain affects relationships with family and friends, and how to improve communication with others about pain

- Ways to help you to manage living with continuing pain such as relaxation or mindfulness.

BTC is run by a clinical psychologist and a specialist physiotherapist. The sessions are a mix of information, discussion and trying out the strategies you have discussed. It is also important to practise using the ideas at home.

It's important that you can commit to coming to the course every week (unless you are ill on the day) as new topics are covered each week so if you don't come it will be hard to catch up.

After the programme you will have follow-up sessions at one month, six months and one year to help you continue to use the ideas you've learnt and identify continuing goals.

You can also contact the team at any time between these sessions.

Will it help me?

BTC is based on other cognitive-behavioural pain management programmes (PMPs), which are used across the UK to help people with pain. We have adapted the programme for pain related to sickle cell disease and thalassaemia.

Cognitive behavioural PMPs look at the relationship between your thoughts, feelings, behaviour and what is happening in your body, including pain. PMPs have been found to be one of the best ways to help people living with persistent pain.

PMPs cannot take away your pain but can help you learn ways to reduce the impact persistent pain has on your life and help you to feel more confident living the life you want to, with pain.

We think of our patients as the experts in their condition. BTC uses a 'self-management' approach, helping people to learn ways to manage their pain themselves, so they can carry on using the skills they have learnt long after the programme has finished.

Who can attend or receive the service?

Anybody who is currently being seen by the St George's University Hospital NHS Foundation Trust haemoglobinopathies team can be referred or can self-refer to our services. We accept referrals from other hospitals as we are a specialist service and because not all hospitals have access to a programme like this specifically for people with sickle cell and thalassaemia. If you receive your care at another hospital, then please ask your haematologist or GP if they will refer you to our service.

If you are interested in attending BTC, we will need to meet with you first to make sure the programme is right for you. We can also talk to you about other services that might be helpful.

Where do I need to go?

Sessions usually take place at the Phoenix Centre on the perimeter road at St George's Hospital. See the website for a map or let us know if you need one.

Patient transport can usually be provided if you are eligible for this (you can call transport assessment and booking on 020 8725 0808) and there is blue badge parking near the Phoenix Centre. Please see the trust website for information on parking and travel by public transport.

Does it cost anything?

There is no charge for attending appointments with the service.

What do I need to bring with me?

You don't need to bring anything. You should wear comfortable clothes that allow you to try out some gentle stretches and movements.

Is there anything else to know?

We are a small service with limited numbers of appointments. If you do not come for your appointment and you don't let us know beforehand, this makes it harder for us to give you and others, a good service, so please let us know if you cannot make your appointment. We will usually write you a summary letter after your assessment appointment(s) and after you have finished group sessions. We will send a copy of the letter to you, your haematology consultant and your GP. If you have concerns about this, please discuss it with us.

We work closely with the rest of the red cell haematology team at St George's and will share relevant clinical information with the rest of the team when it might be useful for your medical care. Other than the letters mentioned above, information will not be shared outside the team unless there is a risk of harm to yourself or others. If you have any questions or concerns about confidentiality, please discuss them with us.

Useful sources of information

The British Pain Society has several publications for people living with long term pain.
www.britishpainsociety.org

Contact us

If you have any questions or concerns, please contact the Red Cell Pain Management and Psychology Service on 07798 581198 (Monday to Wednesday, 9am to 5pm). Alternatively, you can email the team on SCDpain@stgeorges.nhs.uk or visit the St George's website at <http://tinyurl.com/SCDpain>

Please note - We do not offer an out of hours service. If you need urgent help, please contact your GP or go to your nearest emergency department (A&E).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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