North East & Yorkshire Haemoglobinopathy Coordinating Centre

Accessing Psychology

For people living with sickle cell disorder, thalassaemia or rare inherited anaemia

Information for patients, families and carers

Haematology - Haemoglobinopathy Coordinating Centre

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Introduction

This leaflet describes the Psychological Service for people under the care of the Red Blood Cell Disorder Service

It answers some common questions about what psychological support is, and how you can access it.

How can psychology help?

Psychological support refers to the help given to people who are struggling with their psychological wellbeing related to thoughts, feelings and how day-to-day life looks.

Living with a red blood cell disorder can be hard – you may feel a lot of difficult emotions and face tough challenges.

For example, you might:

- Feel low in mood, feel anxious or panic at times, or feel frustrated and angry
- Dealing with severe pain or other distressing symptoms related to crises
- Finding your medical treatment difficult to manage
- Worry about how your health affects your relationships, work, and leisure activities
- Fear about or difficulties making decisions about medical procedures

Do not worry if the difficulties you are having are not listed, these are just examples.

Feeling some worry and upset is normal when living with a long-term health condition, and everybody copes differently. However, if these feelings are making you overwhelmed or lasting for a long time, it may be helpful to see a member of the psychology team.

Practitioner psychologists (clinical or counselling) are part of the Red Blood Cell Disorder team, and work alongside the other medical staff involved in your care.

What do practitioner psychologists do?

A psychologist can support you to:

- Think about your thoughts and feelings and how these might affect the things you do
- Understand any difficulties you are having
- Understand how these difficulties affect you
- Strengthen your coping skills

Psychology appointments are safe, private spaces for you to share what is on your mind with a professional who is trained to help you.

Being open and honest is encouraged, but you will not be forced to talk about things that you do not feel comfortable sharing, and this will be respected.

Please note that psychologists do not prescribe medication however we may be able to help with decisions about taking medication.

Who is the Psychological Service for?

The service is available for all patients with sickle cell disease, thalassemia or rare inherited anaemias under the care of the Red Blood Cell Disorder Service.

What will happen at my first appointment?

Your first appointment is a chance for you and the psychologist to meet each other and talk about the things you are worried about.

The appointment will last up to an hour. You can bring a family member or a friend to the appointment, if you would like to.

At the end, we will decide whether further appointments would be helpful and this might include helping you access other psychological support or assessment specific to your current problems.

Where will I be seen?

Psychology appointments can take place face-to-face, over the phone, or by video call. Your local team can advise about the availability of appointments and will always try to accommodate what works best for you where possible.

What about confidentiality?

The service is confidential. The things you talk about with the psychologist will not be shared with anyone who is not involved in your care. Sometimes it can be helpful for your information to be shared with other healthcare staff, but you will be asked before we do this. You might not want some information to be shared and the psychologist will talk about this with you.

We must share your information with your GP or other services if we believe that you or somebody else is in danger. While we will try to discuss this with you first, this may not always be possible in order for us to act urgently to keep you and others safe. If you have any questions about confidentiality, your psychologist will be happy to talk to you about this.

How can I be referred?

You can access the psychology service via a referral from a member of your specialist haematology team.

How can I get in contact?

If you have any questions you can get in touch with the Haematology Psychology team. Your local team will provide contact details for you.

If you need to cancel appointments at short notice, please contact the Psychology Service admin team on the number provided by them.

Please use the QR code or link below to take you to the Patient Information Leaflet (PIL) section of the North East and Yorkshire Haemoglobinopathy Co-ordinating Centre Website

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