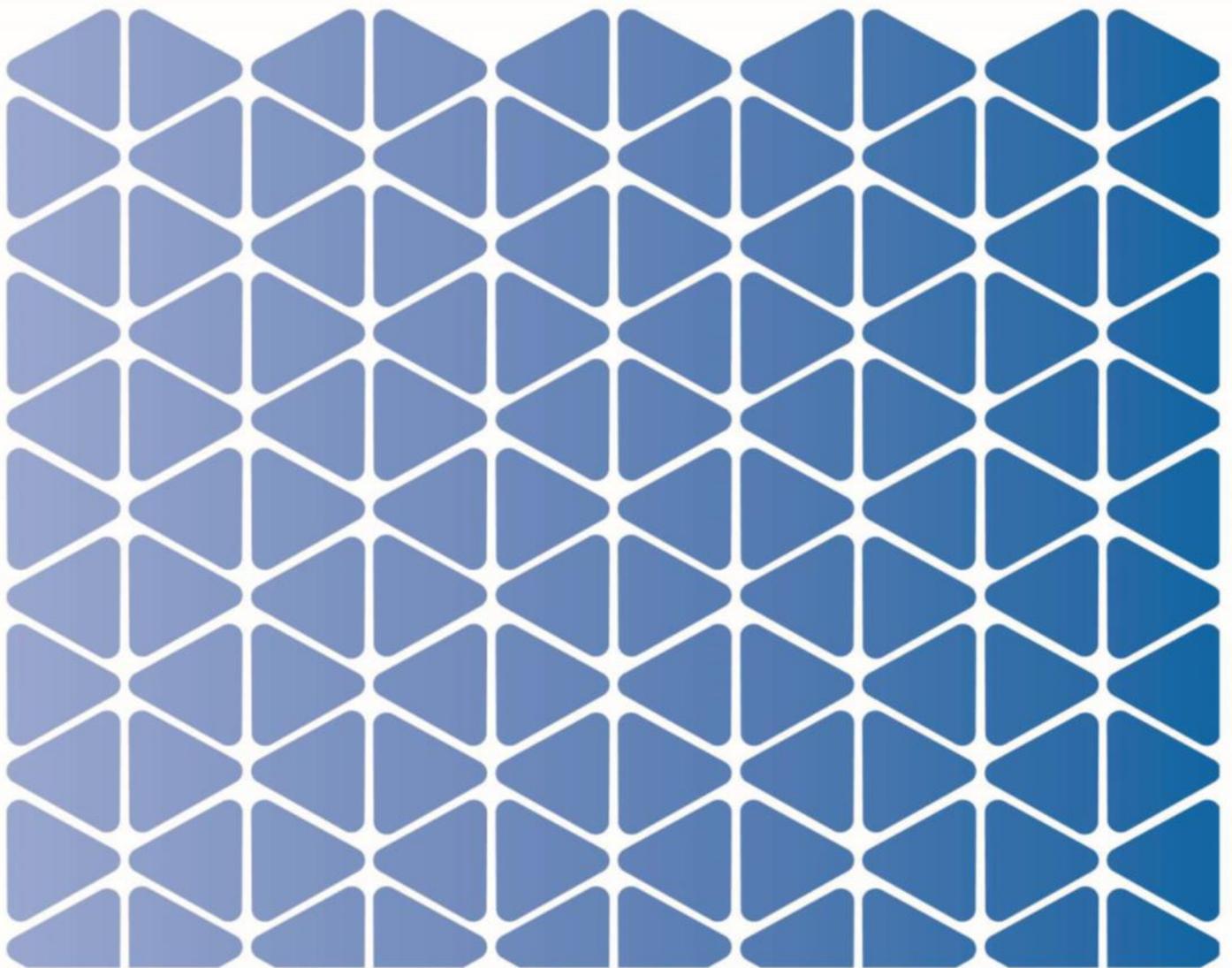




PATIENT INFORMATION

THE PAEDIATRIC CYSTIC FIBROSIS SERVICE AND CLINICAL PSYCHOLOGY



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Why is there a Clinical Psychologist in the Paediatric Cystic Fibrosis team?

Our service supports children and young people who have Cystic Fibrosis (CF), and their family. We understand that a diagnosis of CF, and living with CF, can bring unique challenges, and psychological support goes hand-in-hand with routine CF care.

Coping with complex health problems can be difficult for everyone at times, and our children, young people and parents can often experience feelings of sadness, loss, anger and worry. Different families cope in different ways, which can be helpful or unhelpful. Sometimes it helps to talk to people who know about CF, who are not a part of the family.

We offer support and advice at the regular clinic appointments, on Riverbank children's ward, as well as providing the opportunity to meet children and young people individually or with their family. We also provide support to parents and siblings who may be struggling with their family member's CF.



What does a Paediatric Clinical Psychologist do?

Our aim is to support children, young people and families to live well alongside CF, by helping them to make sense of the very understandable challenges and difficulties they may be facing. We listen to your concerns, and work collaboratively with you to try to find helpful ways forward. Some of the things that we often help with include:

- ❖ Adjusting to diagnosis
- ❖ Finding ways of coping with medical procedures, including blood tests
- ❖ Eating or feeding difficulties
- ❖ Managing the demands of living with CF
- ❖ Making decisions around your clinical treatment
- ❖ Difficulties taking medication or sticking with your treatment plan
- ❖ Managing difficult thoughts, feelings, or behaviours
- ❖ The impact that CF can have upon family life

Paediatric Clinical Psychologists do not carry out physical examinations, and we do not provide mental health diagnoses or prescribe medication. If you feel this would be helpful, with your permission we may refer you to someone who does.

What will happen if I meet with a Paediatric Clinical Psychologist?

Appointments usually take place at the Children's Clinic at Worcestershire Royal Hospital or the Alexandra Hospital, and last up to an hour. Alternatively, we can offer video or telephone appointments. We will talk with you about your concerns and how we may be able to help. We may ask questions about how you are getting on with managing CF, how you feel about CF, what is going well for you and what is not going so well.

Appointments take place in a private setting. It can often be helpful for your psychologist to let the rest of the CF team know about the things you may be struggling with, so that the team can provide the best care and support. We will discuss with you whether you are happy for us to share this information, or whether you would rather the details of what we talk about be kept confidential. We may ask your permission to speak with other relevant people, such as teachers.

After the first appointment, what would happen next?

Everyone's difficulties and circumstances are different. For some people, meeting on just one or two occasions may feel enough, allowing us to talk things through and suggest some things which may help. For others, we may meet on a number of occasions to work on particular issues. As the CF team cares for children from birth to 17 years of age, you may meet with your psychologist 'on and off' at different times during the course of your care.

Sometimes, it may be the case that another service offers the support that will best meet your needs. If this is the case, your psychologist will discuss this with you, make the appropriate referral and support you during this process.

How do I arrange to meet with a Paediatric Clinical Psychologist?

You can call or text Dr Amy Symonds, Paediatric Clinical Psychologist, directly on **07525 906557**, or you can let a member of the CF team know that you would like some support. They can then let Amy know, and she would contact you to discuss further.

Some people may need help to read this leaflet. If you need help, or would like this leaflet in a different language or format such as large print, Braille or audio, please ask a member of the CF team.

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.