

Patient advice sheet

Chronic Fatigue Syndrome in children & young people

You have been referred to the Children and Young People's Community Chronic Fatigue Syndrome (CFS) Team for assistance with your symptoms. This leaflet is to inform you about who we are and what we do.

Understanding Chronic Fatigue Syndrome:

CFS is a condition that has fatigue or tiredness as one of the main symptoms. Other associated symptoms may be joint pain, headaches, sleep disturbance and mood changes.

A specific cause of CFS is not yet fully understood. However, some patients have noticed an onset of symptoms following a viral infection or prolonged adrenalin release due to sustained periods of mental, emotional or physical stress.

When a person has been unwell for a long time and has been unable to carry out normal activities, his/her body can become deconditioned making CF symptoms and mood feel worse.

The CFS Team for Young People:

The professionals who comprise the Community Paediatric Team include Paediatricians, Physiotherapists, Occupational Therapists, Psychologists, School Nurses and Home tutors. Occasionally a Dietician, may also be involved. The people that you will meet will be dependent on your individual needs.

The team members liaise regularly and can become involved at any stage. We will also keep your GP informed.

The primary aim of the Community Paediatric Team is to regain a lifestyle that is acceptable to you and your family.

Deciding the best way forward:

Following your diagnosis of CFS your Paediatrician will refer you to The Team. You will then be sent a questionnaire to complete which will provide us with more specific information on how your lifestyle and everyday activities are being affected.

Following this, you will then meet representatives of The Team to gain a more in-depth picture of your current level of sickness, activity and coping skills. They will take this information to the rest of The Team and discuss what would be the best way forward for your care and provide a suggested plan.

Planning Intervention:

Each young person will have his/her own Key Worker, who will discuss and plan the best way forward with you personally.

- Advice and programmes on how to manage energy and activity levels.
- How to deal with feeling scared, i.e. anxious, or feeling low.
- Getting back into school and social activities.

- Decisions about medicine which might help with pain or sleep should you need it.

This support will be co-ordinated between Health, Education and Psychology Services.

Your Progress:

Your Key Worker will be your main point of contact for ease of communication. They will most typically either be a Physiotherapist or Occupational Therapist.

Your Key Worker will review your progress with you, and The Team, at regular intervals to ensure that effective input is being provided.

School

We recognise that school is an important part in a young person's life, not only academically but socially too.

We also recognise that when a child has been out of school for a period of time, returning back can be daunting. Therefore, good communication between the CFS team, the school and the young person is essential.

If you have any questions about this leaflet please do raise them at your assessment.

Contact us:

Tel: 01494 426976 or 01296 566045
Email: buc-tr.cypphysio@nhs.net
website: www.buckshealthcare.nhs.uk/CYP

Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible, but please note that it is subject to change. Please therefore always check specific advice on any concerns you may have with your doctor.

Patient Advice Sheet

If you would like a copy of this information on audiotape, in large print or translated, please call the Patient Advice Liaison Service on 01296 316042 or email bht.pals@nhs.net

How can I help reduce healthcare associated infections?

Infection prevention & control is important to the well-being of our patients and for that reason we have infection prevention & control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. Please follow our infection prevention and control guidelines when visiting our healthcare sites. Further information is available on our website.

The flow chart below shows the process of action you can expect once a referral has been sent by the Paediatrician to the Community CFS team:

Questionnaire sent to family for completion and return to the CFS team prior to an appointment being offered.



Initial appointment with a Physiotherapist and/or Occupational Therapist involves:

- Explanation of process
- In-depth review of current functioning
- 2 week activity diary given for completion



The second appointment involves:

- Discussion of activity diary
- Joint setting of short/long term goals with young person and their family
- Care plan agreed, including involvement of other team members



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Visits arranged by 'Key worker' to review progress and to set further goals.

Continued liaison and review of care plan with other services as necessary.