Wellbeing in Paediatric Chronic Fatigue Syndrome (CFS/ME) Study
Frequently Asked Questions (FAQs)

CFS/ME and depression

What is CFS/ME?

CFS/ME is defined as ongoing fatigue, causing disruption of daily life, persisting after routine tests and investigations have failed to identify another medical explanation for the fatigue. Other common symptoms include unrefreshing sleep, problems with memory and concentration, headaches, nausea (feeling sick), dizziness, muscle and joint pain, and sore throats. Children and young people with CFS/ME will have had fatigue which stops them doing normal activities for at least 3 months. The fatigue and other symptoms get worse after activity.

For more information about CFS/ME please see the NICE guidance https://www.nice.org.uk/guidance/cg53 and the Action for ME website https://www.actionforme.org.uk/children-and-young-people/introduction/ .

Does CFS/ME cause depression or does depression cause CFS/ME?

We don't know the answer to this question. We know that around 1 in 3 children and young people with CFS/ME also have symptoms of depression. But 2 in 3 children and young people don't have symptoms of depression. It makes sense that an illness that affects the lives of children and young people as much as CFS/ME does would make a person feel low in mood. We also know that fatigue is a symptom of depression, and it is important, when Healthcare Professionals are doing an assessment, for them to explore whether depression might be a better explanation for the fatigue, instead of CFS/ME.

What the study involves

What happens in the study?

Once you have talked to one of the research team, and had a chance to ask questions about the study, you will be asked to complete a consent form. This asks for your permission (and your parents' permission) to use your data for our research. You and your parents will then be asked to fill in a few short questionnaires. The researchers will interview you, and your parents (together or separately, you can decide). This will involve asking some sensitive questions about your mood and behaviours. The interviews can be done on the telephone, over Skype, or in person, at your home or at the hospital or the University of Bath. We will contact you again to ask you to fill in another set of questionnaires 6 months after the interview.

__How long will I be involved in the study?__
You will be involved for up to a maximum of 9 months after taking part in the interview depending on when the 6 month follow-up questionnaires are completed.

__I have already completed a consent form with the clinician, why am I doing another one?__
The form that you completed with the clinician asked for your permission for us to contact you. The form we ask you to fill out after you have agreed to take part is a consent form, which confirms that you have read and understood the participant information sheet, and formally agree to participate.

__I have completed similar questionnaires before, why am I doing more?__
Before your first appointment at the clinic, you will have been asked to complete a set of questionnaires. We will get the information from the questionnaires you already filled in. Some of the questionnaires we ask you to complete before the interview will be similar to those, but will be slightly different. At the six month follow-up, you will be asked to answer some of these questionnaires again so that we can see how you are doing then.

Recruitment and participation

__Who can take part?__
We are inviting all young people (aged 12 to 18) and their parents, who are seen in the clinic and have a diagnosis of CFS/ME to take part in a research project about well-being chronic fatigue syndrome (CFS/ME).

__How can young people access this study?__
Children and young people will be invited to take part in the study during or after their assessment by the Paediatric CFS/ME Service at the Royal United Hospital in Bath. See http://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/index.asp for more information about the Paediatric CFS/ME Service.

__Can I take part if I am severely affected by CFS/ME?__
Yes, you can take part if you are severely affected. As long as you have a confirmed diagnosis of CFS/ME, are aged between 12-18 years, and are able to complete the diagnostic interview and the screening questionnaires, you can take part in the study.

Will young people with co-morbid conditions (such as diabetes) be able to take part in the study?

Children and young people with CFS/ME and other illnesses can take part as long as the illnesses do not explain their fatigue.

Can I take part in the study if I am an adult with CFS/ME?

The study is for young people aged 12-18 years old.

Can I take part in the study if I have left school and I am working?

Yes, as long as you are 18 years old or below.

Can I take part if I was previously referred to the service and am re-referred to the service?

Yes, as long as you were told about the study during your most recent initial assessment with the clinician.

How many young people will be recruited to this study?

The aim is to interview 161 participants. Some participants have been interviewed as part of the MAGENTA study.

Are parents interviewed too?

Yes, the researchers will interview parents together or separately from yourself, you can decide. If the parents are interviewed separately, this is usually a shorter interview with less questions.

Can I find out the results from my interview?

We will let the healthcare professional from the Paediatric CFS team know the results from your interview and you can ask them about it at your next meeting.

Can I withdraw from the study after deciding to take part?

Yes. You are free to withdraw from the study at any time before, during or after completing the interview. You can also ask for any information already gathered to be destroyed, up to the point when it has been analysed.

Results of the study

What will happen at the end of the study?

At the end of the study, we plan to share the findings of this research with other professionals working with young people with CFS/ME so that they know how many young people with CFS/ME have problems with their mood, and how best to identify them using questionnaires.

Can I find out the results of the study?

Yes. When you complete the consent forms, there will be a box that you can tick if you would like to receive a report on the study findings by either post or email.

What will happen to my information after the study is published?

The information about you will only be accessed by members of the research team. It will be securely stored for 5 years. It will be analysed, in anonymous form, to help us to find out the answers to our research questions.

Impact on treatment

Will participating impact the treatment I receive from the Bath Specialist CFS/ME service?

No, participation is completely voluntary. Whether you choose to take part or not will not affect the treatment you receive from this service.

Is this instead of an appointment with a clinician?

No. Taking part in this study involves an interview with a researcher, and is not a replacement or an alternative to attending an appointment with a clinician.

If you want to find out more, please contact the lead researcher, Maria Loades, at m.e.loades@bath.ac.uk.