Chronic Fatigue Service
Providing expert assessment and treatment for people with chronic fatigue syndrome.
» My sessions with my therapist have been invaluable. They have been underpinned by a spirit of empathy, collaboration and respect. Returning to work, managing the phased return and handling work in a healthy way have been the main themes around which treatment has been centred...my return to work would have been far more difficult without her help and support and to be honest I’m not certain I would have managed it successfully. « Alice
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service overview</td>
<td>4</td>
</tr>
<tr>
<td>Our philosophy</td>
<td>5</td>
</tr>
<tr>
<td>Who is our service for?</td>
<td>6</td>
</tr>
<tr>
<td>Interventions</td>
<td>8</td>
</tr>
<tr>
<td>Our care pathway</td>
<td>12</td>
</tr>
<tr>
<td>Outcomes</td>
<td>14</td>
</tr>
<tr>
<td>Research</td>
<td>16</td>
</tr>
<tr>
<td>Our facilities</td>
<td>17</td>
</tr>
<tr>
<td>Our team</td>
<td>18</td>
</tr>
<tr>
<td>Training and consultancy</td>
<td>21</td>
</tr>
<tr>
<td>Case studies</td>
<td>22</td>
</tr>
<tr>
<td>Referring to our service</td>
<td>26</td>
</tr>
</tbody>
</table>
Service overview

Our service provides assessment and treatment for adults and adolescents with chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis, and for patients with medically unexplained symptoms.

We offer evidence-based treatment that is routinely evaluated. Our aim is to increase the person’s functioning and reduce the severity and impact of their symptoms.

We also offer assessment and treatment for people with fatigue associated with chronic diseases like rheumatoid arthritis, multiple sclerosis, HIV or cancer.

Our team is at the forefront of research, continually testing new treatments and innovative ways of delivering them.

King’s Health Partners

Our service is part of the Psychological Medicine Clinical Academic Group. SLaM has joined with King’s College London, Guy’s and St Thomas’ NHS Foundation Trust and King’s College NHS Foundation Trust to establish King’s Health Partners, an Academic Health Sciences Centre. King’s Health Partners involves bringing clinical care, research and education much more closely together. Our aim is to reduce the time it takes for research discoveries and medical breakthroughs to become routine clinical practice. This will lead to better care and treatment for patients.

Visit www.kingshealthpartners.org for more information.
Our philosophy

Many people we see have been told that their symptoms don’t exist and some have been given negative messages about the possibility of improvement and recovery.

The focus of our approach is to improve the quality of people’s lives, reduce their fatigue and help them to fully engage in life.

Our dedicated team offer cognitive behavioural therapy (CBT) and graded exercise therapy (GET) which are tailored to the needs of each person.

Treatment is effective, with around 65% of people improving with either CBT or GET, and around 25% of people making a full recovery.

» Coming to the service changed our lives. It was unimaginable a year ago that she would have been back at school. We thank you, more than we will ever be able to say. « Katherine, parent
Who is our service for?

Our service is for people with clinically significant fatigue or medically unexplained physical symptoms. We help to improve their quality of life through a combination of rehabilitative treatments, including forms of CBT and graded exercise therapy.

Eligibility

- 14+ years (we work in conjunction with our child and adolescent service)
- Male or female
- Long lasting fatigue
- Profound disability
- Disturbed sleep pattern

» She had been virtually house-bound for five years, living in two rooms, unable to go out or even sit up for longer than a few minutes. Her quality of life was extremely poor and I was a full-time carer. After 15 months, although not yet fully recovered, she transformed beyond our wildest dreams. She is back at school and loving it, has friends and can lead a very gentle, but somewhere near normal, life again. A very big thank you. «

Sally, parent
National Services: Chronic Fatigue Service
Interventions

We provide a range of interventions to help improve our patients’ quality of life.

These may include:

- Diagnostic assessment
- Routine blood tests
- CBT
- Graded exercise therapy

**Specialist assessment**
An assessment to confirm the diagnosis is conducted, including a medical history, assessment of mental state and blood tests. We look for any other causes of fatigue or co-morbidity with other illnesses and discuss therapeutic options.

Initial investigations may include urinalysis, full blood count, urea and electrolytes, liver function tests, calcium, thyroid function, erythrocyte sedimentation rate, C-reactive protein, creatine kinase, and glucose or coeliac serology, for example antigliadin antibodies.

**Self-help treatment**
Each patient is allocated a therapist at their assessment, and given self-help material to help them build on their self-management while they wait for CBT or GET to begin. Following this treatment, some people may not require CBT or GET with a therapist.

**Cognitive behavioural therapy**
CBT is an effective treatment for people with mild to moderate CFS and ME, and for those with medically unexplained symptoms.

CBT home-based sessions are offered to people who are severely affected by their illness and are too ill to attend the unit. It is a collaborative treatment, where the patient and a CBT therapist work together using a variety of techniques and strategies which adhere to empirically validated therapy protocols. Interventions are adapted to the needs of the patient and may include establishing a consistent pattern of activity and rest, gradual increase in activity levels, sleep management and addressing unhelpful thinking patterns.

**Family-focused CBT**
This approach is facilitated by members of the family and the person is encouraged to engage in activities they find difficult, like seeing friends and going to school. The whole family are supported in making changes that are necessary to facilitate a return to education.

We have an ongoing clinical and research service for 11 to 18 year olds with CFS and ME. Our research results are utilised in improving our treatment.

**Graded exercise therapy**
GET is regular physical activity or exercise, starting at a baseline level and gradually increasing until people’s goals are achieved. The duration of exercise is gradually increased to 30 minutes, and then the intensity is increased over time, aiming for a heart rate of 60-75 per cent. Stretches and strengthening exercises are also included in the program.

This type of therapy has been found to improve functioning, decrease disability and symptoms through carefully monitored, graded increases in physical activity and exercise.
» Her health has improved faster than we could have hoped for. I would hesitate to say she is cured, but I feel that we are over the worst and are in a better position to deal with any setbacks that we might encounter in the future. « Carer
Our care model

**THERAPIES**
- Evidence-based treatments
- Individual treatment plan
- Progress reviews using validated clinical measures
- Home visits and telephone therapy
- CBT
- GET
- Family-focused CBT for adolescents

**FAMILY AND CARERS**
- Involvement in treatment
- Advice and support on how to help with recovery
- Education about CFS or fatigue associated with long-term health conditions

**ASSESSMENT**
- Assessment of possible physical causes
- Assessment of psychological factors
- Routine blood investigations
- Formulation including biological, psychological and social factors
- Comprehensive report

**PATIENT**
- Understanding why fatigue has developed and what maintains symptoms
- Promoting a healthy lifestyle by introducing new ways of thinking about exercise, diet and work
- Increasing independence by setting achievable goals
- Broadening social support
- Improving quality of life

**EDUCATION AND VOCATIONAL OPPORTUNITIES**
- Advice and support in planning return to work or education
- Liaise with employers, human resources and occupational health staff as required

**WORKING WITH OTHERS**
- Discharge planning
- Liaising with other health and social care providers
- Working collaboratively with other specialist services
- Providing information, reports and liaison as appropriate, for work or housing purposes
Our care pathway

1. Referral received and funding approval
2. Assessment
3. Criteria not met
4. Recommend treatment package
5. Treatment
6. Review
7. Discharged with care plan approach
8. Follow-up at three and six months
Outcomes

The Chalder Fatigue Scale is the primary outcome measure used by our service. We also measure disability, mood, work-related outcomes and illness perceptions.

Expected outcomes may include:

› Resuming daily activities
› Establishing a sleep routine
› Addressing associated anxiety or depression
› Challenging problematic beliefs which interfere with progress, which may relate to the rehabilitation programme, perfectionism or low self-esteem
› Making lifestyle changes which may help to prevent relapse at a later date

Graph 1 This graph demonstrates our patient’s improvement over time, after a course of CBT.

Graph 2 This graph shows a comparison of work and social adjustment scores before and after therapy. A significant improvement was seen post-therapy and continual improvement was noted up to six months after therapy was completed.

Graph 3 We compared the effectiveness of family-focused CBT and psychoeducation for adolescents with CFS. We found that those people who received CBT were attending school more than those people who had received psychoeducation at discharge, but at the final follow-up everyone was attending school for a similar amount of time.
[“57% of our patients said they were very much better, or much better at the end of treatment.”] Quarmby et al 2007

2. Work and social adjustment scale scores

3. School attendance in adolescents with CFS

SCORE ON WORK AND SOCIAL ADJUSTMENT SCALE

PROPORTIONAL SCHOOL ATTENDANCE

MIXED UP COORDINATES
Research

Our partnership with King’s College London has pioneered some of the leading programmes in CFS, and we are continually improving our understanding of chronic fatigue and medically unexplained symptoms to develop new and better treatments.

Our ongoing research topics include:

› A pilot study evaluating the treatment of severely affected house-bound adolescents with CFS
› A prospective study examining predictors and moderators of outcomes after a course of CBT for patients with CFS
› A prospective study examining the role of cognitive and behavioural factors in the development and perpetuation of fatigue in people with breast cancer
› A prospective study examining a psycho-physiological model of CFS in adolescents
› A prospective study examining the role of cognitive and behavioural factors in the development and perpetuation of fatigue in people with rheumatoid arthritis
Our facilities

Our service is based at the historic Maudsley Hospital, which is internationally renowned for excellence in research, treatment and teaching in mental health. The hospital is based in South London and has close links to public transport.

Our service is located on the first floor of Mapother House, and is accessible by lift. We have 11 treatment rooms, which provide our patients with the privacy to ensure they are treated with dignity and respect.

» My head is a lot clearer 80% of the time and my attitude is 100% better. « Ashley
Our team

Our multidisciplinary team includes psychiatrists, psychologists, physiotherapists, psychotherapists, doctors and researchers.

**Professor Trudie Chalder**  PhD, MSc, SRN, RMN, Cert in Beh Psychotherapy
**Director**

Professor Chalder is the director of the Chronic Fatigue Service as well as a professor of cognitive behavioural psychotherapy with the Department of Psychological Medicine, at the Institute of Psychiatry, King’s College London.

**Other roles**
Professor Chalder gives national and international lectures on CFS. She has been closely involved in developing and evaluating treatments for adolescents and adults with CFS. These studies have contributed to recommendations made in the NICE guidelines.

Professor Chalder has also taken part in international collaborations with Professor Hege Erikson (Norway) and Dr John Wells (Ireland).

**Background**
Professor Chalder qualified as a registered general nurse in 1981 at Grimsby General Hospital. In 1984, she completed her registered mental nurse training at Tooting Bec Hospital, London. She completed her Master of Science (MSc) in 1990 at City University in London. In 1998, she went onto complete her PhD at the Institute of Psychiatry, King’s College London.

**Research**
Professor Chalder’s research interests are focused on developing cognitive behavioural models and treatments for medically unexplained symptoms and symptoms related to chronic disease.
Dr Alastair M Santhouse  MA, MB BChir, MRCP, MRCPsych
Consultant Psychiatrist

Dr Santhouse is a consultant psychiatrist at SLaM. He also works at Guy’s Hospital, where he looks after the mental health needs of patients with concurrent physical and psychological problems.

Other roles
Dr Santhouse is the Trust lead on the implementation of the NICE guidelines on CFS.

Background
Dr Santhouse trained at Cambridge University and then Guy’s Hospital. He joined the medical rotation at the Royal London Hospital and gained membership at the Royal College of Physicians (MRCP). From here, Dr Santhouse trained in psychiatry at the Maudsley Hospital and became a member of the Royal College of Psychiatrists (MRCPsych). He was appointed as a consultant in psychological medicine in 2003.

Research
Dr Santhouse has regular speaking engagements related to toxicology courses for emergency physicians, and lectures and teaches medical students.
Our team *continued*

**Professor Simon Wessely**  
MA, BM B Ch, MSc, MD, FRCP, FRCPsych, F Med Sci  
Director of the King’s Centre for Military Health Research  
Professor of Psychiatry

Professor Wessely is head of the Department of Psychological Medicine at the Institute of Psychiatry, King’s College London, and an honorary consultant liaison psychiatrist for the Trust. He is also the director of the King’s Centre for Military Health Research.

**Background**
Professor Wessely has specialised in the treatment of unexplained symptoms and syndromes, including CFS, for more than 25 years. In 1994, he established the Trust’s Chronic Fatigue Service, the first ever NHS facility delivered solely for people with the disorder. The service is one of the largest specialising in the condition and has won local awards for innovation. It played a central role in developing, researching and then demonstrating the success of CBT for CFS – one of only two treatments endorsed by NICE to manage and treat the illness.

**Research**
Professor Wessely remains active in research and has authored or co-authored more than 550 publications. Apart from CFS and military health, his areas of research cover subjects like irritable bowel syndrome, screening, liaison psychiatry, deliberate self-harm and suicide, crime and schizophrenia, the history of psychiatry, psychological debriefing and stress management, post-traumatic stress disorder, psychological reactions to terrorism, mobile phone sensitivity, and health service research.
Training and consultancy

Our team is experienced in providing national and international training in the assessment and treatment of CFS and medically unexplained symptoms.

We offer training and consultancy in the assessment, treatment and management of CFS and fatigue in chronic illness. Our training is suitable for psychiatrists and mental health professionals, and is available at the basic or advanced levels. We also have experience in teaching skills to non-mental health professionals. Bespoke training to suit different services is also available.

The following workshops may be provided:

- CFS
- Fatigue in chronic diseases
- CBT for chronic medical problems
- Medically-unexplained symptoms

For more information about training contact Suzanne Roche on 020 3228 5075 or email suzanne.roche@slam.nhs.uk

» The staff are very professional, patient, understanding, noticeably kind and tailor the treatment for each person, with attention to detail and quality care. «  James
Caleb

“I was getting a lot of illnesses, off and on.”

I was doing my GCSEs at school and getting ill a lot. I had two weeks of glandular fever and never really recovered from that. The tiredness and achiness continued and, though I got through my exams, I couldn’t face moving on to college afterwards.

I remember seeing various doctors for tests but they couldn’t really work out what was happening. Even when I was diagnosed with CFS, it wasn’t that cut and dry. The condition wasn’t widely known at the time, there wasn’t much treatment available, and there were very different opinions about it anyway – like questions about whether it was a physical or mental illness. It was a really confusing, difficult time.

From what I remember, we heard about the South London and Maudsley NHS Foundation Trust in the local newspaper. A family friend saw a mention of treatment for chronic fatigue specifically, so my mum spoke to our GP and I was referred that way.

“I started cognitive behavioural therapy sessions fortnightly.”

My whole family travelled down to London the first time. There was me, my sister and my parents, and we all spoke about what had been happening and had the chance to hear about the available treatments. We lived in Lincolnshire so we were all travelling down from there, but it was a good opportunity for my family to give their version of events and it was good that they could hear about the treatments first-hand rather than through me.

I think the CBT sessions were fortnightly in the beginning, then they went to monthly, and towards the end they were once every two to three months. There were definitely times when I wouldn’t have been able to do this therapy or do the travelling, but by this point I was eager to try anything that might be helpful. I felt well enough to deal with it and ready to get better.

My mum came with me to start with and later I travelled on my own.

“We focused on my daily routine and on trying to develop a more positive outlook.”

In sessions, we concentrated on my daily schedule. I kept a food diary, sleep diary and a record of my activities, which were useful for reference because it meant I could look back over the weeks, remind myself about my routine and see what had changed. The diaries helped me to be more conscious of what was going on every day and more accountable for my schedule, among other things.
We also spoke a lot about my general outlook on life and how I could be more positive about activities and opportunities. The technique was to be more conscious about how I was feeling, to challenge any negative thoughts that came up for me and hold onto a positive attitude rather than write things off straight away. It was good to get myself thinking more positively about things, and after a while I felt I was getting somewhere.

“From the start, I could see this was going to be different.”

I’d never had a fixed course of action before I went to the Trust – I was happy to try out lots of different treatments, but I was in a situation where I’d jump from one thing to the next. This was different though. It was a set course that was structured, proven and specialist, so from the beginning I felt more positive about the outcome. I knew there would be support on a continual basis. Even having my next therapy session written down in the diary was something relatively new.

The other important thing was that I knew the department specialised in CFS. Actually, more than that, they had a dedicated team for chronic fatigue in young people, so I was confident they were the experts in the field.

All of this encouraged me into believing something positive was going to come from the programme. Believing in the therapy was hugely important for me. I knew it would be productive. I was going somewhere where people were experienced. I also got on really well with my therapist, which was another big part of the success.

“Now I’m as normal and healthy as anyone else.”

I continued the therapy for about two years. Like I said, I was coming down to London two to three times a month at first and that reduced to once every two to three months by the end.

While I was going through the treatment, I started at college part-time – that became full-time – and since then I’ve been to university and am now in a full-time job. Things didn’t happen immediately. I wasn’t 100 per cent, even when I was back at college, but over time I got stronger and healthier. The treatment at the Trust was so supportive and it was definitely the catalyst. Now, I’d say I feel as normal and as healthy as anyone else.
Tamara

“There were a series of things that impacted on me.”

I was working very hard trying to promote an album. I’m a musician and I was playing and promoting my music most days, teaching until 7pm, driving to do a gig afterwards and then getting up early in the morning to go for a run. Part of the expectation of being a successful musician, for me, was to look good and be quite thin, so I was exercising a lot and wasn’t eating as much as I should.

This was all done with the best of intentions, pushing myself to make a success of my music, but it was impacting on me. Other emotional things were part of the picture too. My boyfriend moved in with me, which I found stressful, and I was working with a drummer in a band – a 25-year-old – who died from a tumour. He had some surgery but I didn’t realise the prognosis wasn’t good. That was a really big blow.

“I was getting bouts of dizziness when I didn’t feel well.”

The defining moment was the realisation that I just wasn’t as healthy as I used to be. I did a restaurant gig and sang until I lost my voice – I had a cold and couldn’t get over it, and my voice wasn’t coming back. Another time, I was on the phone after a run and wasn’t able to stand up afterwards because I was so dizzy. The dizziness was intense for three days. I thought ‘this just isn’t right’.

There seems to be a very active phase of CFS when it starts to really kick in. I was getting weird sensations in my body and I stopped being able to read music. It’s like there were lots of lights and electricity in my head, I was holding that much in there at any one time. My mind just packed up really.

My partner said I needed to go for some blood tests. I went, but nothing was found.

“CBT put me on the road to setting achievable targets.”

I have a very good GP and she told me that she’d heard good things about the Maudsley, so I went to see them. The CBT had good feedback, and I wasn’t finding the answer anywhere else, so I thought I’d give it a try.

I can’t remember how many sessions we had exactly – eight to 10, I think, every two weeks – but I felt the benefits pretty quickly. CBT is very structured, and you can see why because you deal with things as and when they come up and can measure them along the way. It put me on the road to setting achievable targets. Rather than going into things with really high expectations, I’d take things step by step.

Actually, I have to admit… at the start, I was really keen to find out if the CBT was going to cure me. My therapist framed things in a very realistic way, which I found frustrating at the time because I wanted to be sure that there would be a time when I’d have no symptoms at all, but it was the right thing for her to do. I think she was setting me up to continue with my own progress after we’d finished.
“The chronic fatigue affected my health but also dented my confidence.”

Socialising and starting up exercise again was difficult. I’d got used to my body not feeling right so I had to build up my stamina and confidence slowly and find my way around setbacks.

The CBT was very practical in that respect. It made such a difference to how things were for me every day and I built up to being more active again. Washing my hair and washing the dishes was so exhausting but, when I considered them as tasks like anything else, I could fit them into my day much more easily. I acknowledged rest in my schedule too, while limiting the amount I took.

The therapy also allowed me to share my fears because I found all of this very frightening. I’d become incredibly isolated. Things like being sensitive to light and noise, it’s surprising how that affects your social life as it limits where you can go.

“It’s important to find the treatment that works for you.”

After the therapy finished, two years ago, I met my therapists again three times at three-month intervals to discuss how things were going, which was really helpful. Since then, I’ve done some more talking therapy, I’ve seen a homeopath and I’ve been practising a Taoist type of yoga and meditation.

Treatment is clearly a personal thing and meditation isn’t right for everyone, but I’ve found it hugely beneficial. I’ve built up to around 45 minutes a day and it’s really de-stressing and helps with anxiety. It’s about observing yourself and not getting stuck. I’d recommend mindfulness meditation to others if they are interested because it’s accessible and isn’t based on a spiritual philosophy.

Acupuncture has also been incredible for me. Your body just gets into a pattern of not being well. I used to be terrified of needles, but that’s gone.

“There’s a real potential for people to change their lives at the Maudsley. I’m very grateful for their pioneering work.”

Day to day, things have moved on in a big way. I eat regularly and always have snacks in my bag. I’ve also started eating meat again because I felt I wasn’t getting enough energy from a vegetarian diet.

I’ve been gigging, travelling, running... I’m able to do everything I need to do with lots of energy. One really important thing is that I don’t consider myself as someone with chronic fatigue syndrome anymore. I don’t tell anyone about it and people don’t see me as being ill.
Referring to our service

We accept referrals from consultant psychiatrists, community mental health teams, GPs and GP consortia.

**Chronic Fatigue Service**
Maudsley Hospital
Mapother House
De Crespigny Park
London SE5 4RS

T: 020 3228 5075
F: 020 3228 5074
suzanne.roche@slam.nhs.uk
www.national.slam.nhs.uk

It’s easier than ever to find out more about our national services.

› Make secure online referrals
› Access detailed information about each of our national and specialist services, including service contact details
› View care options, interventions, outcomes and costs
› Read profiles of our experts
› Catch up on our latest research
› Discover the experiences of people who have used our services
› Sign up for our e-newsletter

Offering over 50 national and specialist services for adults and children, accepting referrals from across the United Kingdom.

Visit www.national.slam.nhs.uk today.
» For people whose symptoms interfere with their quality of life, there is a real possibility of change. «

Professor Trudie Chalder