ME/CFS and anaesthesia

Short version (the full version can be found here: www.rcoa.ac.uk/patients/patient-information-resources/factsheets-medical-conditions-relating-anaesthesia/me-cfs-anaesthesia

About the condition: Myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) is a complex chronic medical condition that affects multiple body systems. It often develops after a viral infection commonly in previously healthy individuals. More information can be found on the ME Association website (https://meassociation.org.uk/). There is no effective drug treatment and management of the condition relies on activity and energy management (pacing) and controlling symptoms. Many of the symptoms are also present in Long Covid, therefore this information may also be useful for patients with Long Covid.

Symptoms include all or some of the following:

- debilitating fatigue which, is worsened by activity
- post exertional malaise after activity in which symptom exacerbation is often delayed and is disproportionate to the activity
- cognitive dysfunction and ‘brain fog’
- disrupted sleep
- muscle, joint or nerve pain
- dysautonomia (orthostatic intolerance and/or postural tachycardia syndrome [PoTS])
- drug sensitivities
- problems with regulating body temperature.

Key things to know about ME/CFS and anaesthesia:

- there is little published evidence on the effects of anaesthetics on ME/CFS
- there can be great variability in how a person with ME/CFS might be affected by surgery and anaesthesia. Many factors can play a part, for example the type of surgery, the health of the patient and the severity of the ME/CFS at the time of surgery
- it’s very important for the healthcare team at the hospital to be aware if a patient has ME/CFS as soon as possible, so that a personalised plan can be put in place well ahead of surgery. This will then be shared with the different teams in the hospital
- it’s important for patients with ME/CFS to have a comprehensive preoperative assessment to assess their condition before surgery and any additional support and adjustments which might be required for them
- not all surgeons or anaesthetists will have experience of looking after patients with the condition. However, you should feel reassured that surgical and anaesthesia teams are trained to deal with a variety of unplanned situations and emergencies
- patients with ME/CFS may take longer to come round from the anaesthetic and may need to stay overnight and require closer monitoring after surgery.

Things you can do ahead of surgery:

- as soon as you know that you need to have surgery, you should ask your GP to send a letter to the surgeon and anaesthetic department explaining your condition. You should also take a copy of the letter with you to any appointments to do with your surgery
- if the healthcare team is not familiar with the condition, you can share this resource with them or the long version and direct them to the National Institute for Health and Care Excellence (NICE) guidance on ME/CFS (www.nice.org.uk/guidance/ng206). This guidance also contains information and recommendations about the care of people with ME/CFS who are admitted to hospital (in section 1.17.7)
- if you are not offered a preoperative assessment, you should call the hospital's anaesthetic department to request one
- make sure that you let them team know about any medication and supplements that you take
- you should also let the team know about any specific condition that you have, such as dysautonomia, fibromyalgia or sensitivity to lights so that adjustments can be made for you in good time. There are staff briefings at the start of operating lists where individual patients' needs are reviewed
- share any previous experiences you have had with anaesthetics, so that these can be considered as part of your personalised plan
- Ask the team if it's possible for a family member or a carer to be with you and support you in the period immediately after surgery. They can also help communicate your needs to staff if you are unable to communicate after surgery
- make sure that you inform your GP, carers and family members of your planned surgery so that there is additional support for you if you need it when you return home.

Disclaimer

Tell us what you think

We welcome suggestions to improve this leaflet. If you're a patient or carer, we'd love to hear from you. Please complete this short survey at: www.rcoa.ac.uk/patientinfo/me-cfs-anaesthesia#tell-us.

If you have any general comments, please email them to: patientinformation@rcoa.ac.uk.

Your feedback helps us understand who is using our information, how useful it is and how our resources have helped you. Thank you.

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This leaflet will be reviewed within three years of the date of publication.