

ME/CFS and anaesthesia

(myalgic encephalomyelitis or encephalopathy/
chronic fatigue syndrome)

This resource aims to provide people with ME/CFS who need to have an anaesthetic or sedation with information about what they might expect at the different stages of the surgical journey, and what they can do to prepare, in collaboration with their healthcare teams. It has been produced in collaboration with people with ME/CFS who have shared their experiences of having an anaesthetic with us. Their input has helped us identify the most common questions and concerns that people with ME/CFS may have about having surgery.

This resource may also be helpful to people who are affected by long COVID, because some of the symptoms associated with these conditions are similar to those experienced by people with ME/CFS.

What is ME/CFS?

ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is a complex chronic medical condition that affects multiple body systems. It often develops after a viral infection commonly in previously healthy individuals. It is thought to affect around 250,000 people in the UK – including children and adults – and is more common in females. ME/CFS impacts on all aspects of daily life. It is estimated that around 25% of people with ME/CFS have a severe or very severe form whereby they are largely or totally house-bound or even bed-bound.

More information can be found on the ME Association website:

www.meassociation.org.uk

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.

There is no effective drug treatment and management of the condition relies on activity and energy management (pacing) and controlling symptoms.

General considerations about ME/CFS and anaesthesia

I have ME/CFS and have been told that I need surgery with anaesthesia. Where can I find information about how anaesthetics affect the condition?

There is limited published evidence linking a worsening of ME/CFS directly to anaesthetic drugs. Understandably, people with ME/CFS may be concerned that anaesthesia may lead to a worsening or relapse of their condition, given their sensitivity to drugs that act on the brain and nervous system. The experiences that were shared to help produce this resource have shown that there can be great variability in how a person with ME/CFS might react to anaesthesia and surgery, with some experiencing prolonged worsening of their symptoms after surgery, whereas others do not experience any significant side effects.

Is it possible to know whether the anaesthetic will worsen my ME/CFS if I decide to have surgery?

It is very difficult to predict whether a person with ME/CFS will experience a worsening of the condition after surgery. Fatigue after surgery is common even in people without ME/CFS. Many factors can play a part, for example other risk factors for surgery (your body mass index (BMI) and being over or under weight, smoking, other medical conditions and heart/lung fitness), different anaesthetic techniques or drugs used, the type of surgery and the body's response to the surgery. Another important factor will be the severity of the ME/CFS at the time of the surgery.

“I care for someone with severe ME who needed surgery. The team at the hospital was great, and a personalised plan was put in place, but they did explain that they could not say whether his ME would worsen in the short or long term after the surgery.”

What can I and the healthcare team looking after me do to reduce the risk of my ME/CFS worsening after surgery?

It's important for the healthcare team to be aware of your condition as soon as possible. You may want to ask your GP, or specialist referral service if you are attending one, to write to the surgeon and the anaesthetic department at the hospital where you are due to have the surgery to explain that you have ME/CFS and may require some adjustments. You should ask for a copy of the letter to take along to any appointments to do with your surgery.

Once the healthcare team is aware of your condition, you can discuss with them the potential risks specific to you and agree a personalised plan which brings together the clinician's expertise and your knowledge of your own condition. This approach is known as 'shared decision-making'.

You can find out more at: <https://bit.ly/NHS-SDM>

The Centre for Perioperative Care (cpoc.org.uk) has produced a video for patients to demonstrate what effective shared decision-making should look like. You can watch it here: <https://bit.ly/YT-CPOC-SDM> What if the healthcare team is not familiar with ME/CFS? I am concerned that my condition will not be taken into consideration

It is true that many healthcare professionals are not familiar with ME/CFS and 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.

If your healthcare team is not familiar with ME/CFS, there is guidance for them produced by the National Institute for Health and Care Excellence (NICE): Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management (www.nice.org.uk/guidance/ng206). This guidance also contains information and recommendations (in section 1.17.7) about the care of people with ME/CFS who are admitted to hospital.

You may also wish to share this information leaflet with them.

“I have had surgery before, and I know that I take a long time to come around from the anaesthetic and that it can take me months to fully recover after surgery. However, I felt surgery was the best option for me. Although the team did not fully understand my condition, I was listened to and a plan was put in place for my care.”

Planning and preparing for surgery

How will I be assessed for surgery?

Anaesthetic departments have dedicated preoperative assessment clinics.

You should be invited to attend the clinic in the weeks leading up to your surgery. The team will assess your health and fitness before surgery and help address or manage any health issues in advance of your operation. You can ask your carers or a patient advocate to attend with you for support and reassurance.

Your preoperative assessment may be via an online digital health-screening questionnaire or a remote consultation with a nurse. If you are asked to attend the clinic in person, you should be able to request a quiet room with a bed if you need it.

Patients deemed more complex or undergoing high-risk surgery will also be assessed by a senior anaesthetist. As a patient with ME/CFS, you are likely to have this level of assessment, or you can ask to be seen by an anaesthetist if this is not offered to you.

Some patients undergoing certain types of surgery may be offered a specific physical test to assess their fitness and risk, known as cardiopulmonary exercise testing (CPET). This is a test that has already been used in research studies to show that people with ME/CFS have an abnormal physiological response to exercise and that it can cause a worsening of symptoms. So, if you don't think you will be capable of coping with this test, you should discuss alternatives with the preoperative assessment team.

Will my history of sensitivity to medications, chemicals and anaesthetic drugs be considered?

Your full history of any adverse reactions and the nature of the reaction should be recorded when you have your preoperative assessment, so that it can be considered when planning your anaesthetic. Although different sensitivities to drugs are common in ME/CFS, this is person specific and there is no evidence of any specific anaesthetic leading to reactions or flaring of ME/CFS in all patients. Therefore, it is important that you explain in detail any sensitivities to drugs that are specific to you.

You also need to let the preoperative assessment clinic know about any complementary medicines or supplements that you take.

I have/may have dysautonomia as part of my ME/CFS, which affects my blood pressure and heart rate. Should I let the team know about this?

Dysautonomia occurs more frequently in patients with ME/CFS than the general population. It's very important that you let the healthcare team know about this condition and any medications or treatments that you are taking to manage it. If necessary, you should have it properly diagnosed and assessed by your GP as soon as you are told that you will need surgery. It should be considered and recorded as part of your preoperative assessment and planning.

Dysautonomia is a disorder of the autonomic nervous system which controls automatic processes such as breathing, heart rate, temperature. This can lead to PoTS, an abnormal increase in heart rate when standing up from sitting.

You will need to keep well hydrated before your anaesthetic and you will be given instructions about when to stop eating and drinking on the day of surgery. You should follow these instructions carefully. You may also need additional intravenous fluids during the anaesthetic to manage the condition. You may have lower-than-normal blood pressure or an increased heart rate after the surgery, both of which may require you to stay in a high-dependency unit (HDU) immediately after surgery for closer monitoring.

A high-dependency unit (HDU) is a unit for patients who require more intensive observation, treatment and nursing care than can be provided on a ward.

The team should discuss and agree this with you as part of your personalised plan.

I'm on opioid pain killers for my ME/CFS or fibromyalgia. Will that affect my pain relief after surgery?

If you are taking regular opioid medication you should let the team know, because additional or alternative pain relief may be required to manage your pain after surgery. Where possible, a nerve block to numb the area of the surgery will be used. The preoperative assessment team will liaise with the hospital's pain team and your anaesthetist to produce an appropriate postoperative pain relief plan for you.

Fibromyalgia is a chronic pain condition common in people with ME/CFS.

More information on nerve blocks can be found at: www.rcoa.ac.uk/patientinfo/peripheral-nerve-blocks

More information on opioid medication for chronic pain can be found on the Faculty of Pain Medicine at: www.fpm.ac.uk/opioids-aware

I'm on unlicensed (off label) medication for my ME/CFS, for example, low-dose naltrexone (LDN). Will this affect my anaesthetic?

As this type of medication is not used in NHS hospitals, you must let the team know that you are taking it. This type of medication blocks the effects of opioids and can reduce the effectiveness of your pain relief after surgery, which is often opioid based. You should stop this medication two days before your anaesthetic and you can resume taking it only once you no longer need to take pain relief for the surgery.

Will I have to increase my fitness before surgery? I am concerned that I will not be capable of doing this because of my ME/CFS

Improving fitness before major surgery has been shown to reduce complications and speed up recovery. However, this is not something that most people with ME/CFS will be able to do. You will need to explain this to the healthcare team and continue to apply 'pacing'.

If your condition has prevented you from exercising for a long time, this may increase your risk for major surgery. The surgical and anaesthesia teams will discuss with you any potential risks specific to you.

Pacing refers to a safe and effective form of activity and energy management for people with ME/CFS. More information can be found at: <https://bit.ly/MEassociation>

Will my ME/CFS be considered when deciding the time of my operation?

The team should consider your specific needs when booking you in for surgery. If you are having major surgery, your case may be the only one for either the whole day or the whole morning or afternoon, in which case little can be done about timing.

If you are having day-case surgery and you struggle with energy levels first thing in the morning, you should ask the team if it might be possible to book your surgery at the end of the morning list or at the start of the afternoon list if possible. That way you will also have sufficient time to recover and could be discharged the same day.

"I was given an early morning slot, which I knew I would struggle with. However, they allowed me to bring my friend to support me."

"Although not everyone in the team understood ME/CFS fully, they did make adjustments for me. I was given a bed to rest while I was waiting for the surgery, rather than sitting on a chair for hours."

I feel anxious about having surgery. Is there anything that I can do?

It is normal to feel nervous ahead of surgery and patients with ME/CFS will in addition be worried about how the anaesthetic and surgery might affect their condition.

Sharing your concerns with friends, your partner or family, and coming up with a personalised plan with the preoperative assessment team and anaesthetist ahead of the surgery, will help, as will physical and mental preparation.

“I felt that my condition was poorly understood and that made me very worried.”

If physical activity is difficult for you, you might try relaxation techniques such as breathing exercises, mindfulness or guided imagery, which can help you imagine yourself recovering calmly and doing well.

The RCoA, in partnership with the British Society of Clinical and Academic Hypnosis (BSCAH), has produced a series of recordings that you might find useful to help you relax before surgery and to develop a positive mindset about your procedure and recovery.

You can access the recordings here: www.rcoa.ac.uk/patientinfo/preparing-your-mind-surgery

Many hospitals have ‘schools’ for patients scheduled to have certain types of surgery, where you can learn about the procedure that you are having and how to prepare for it. Understanding what you might expect to happen can help you feel more in control and manage your anxiety.

On the day of the surgery

I am very sensitive to noise and light and I’m concerned that the theatre environment will be very noisy with very bright lights. Can adjustments be made for this?

You should explain these issues to the preoperative assessment team and again to your anaesthetist and surgeon on the day of surgery. This will be discussed in the staff briefings just before the operation list starts, and they will ensure that the anaesthetic room lighting is dimmed, monitor volumes are turned down and the minimum personnel required are in the room. These requests are not unusual because similar adjustments are made for other medical conditions that involve sensitivity to light and sound.

I’m concerned that my dysautonomia will worsen while fasting before and during the surgery. What can be done about this?

Fasting is kept to the minimum required for safety for all patients and you should continue to consume clear liquids for up to two hours before your anaesthetic or as instructed by the team. If you have dysautonomia, you may add salt or electrolyte tablets to the water as per your usual routine. If you are undergoing major surgery, you may be given protein supplements and a carbohydrate powder to mix with water to take the night before and again two hours before surgery. These steps will help maintain your energy levels throughout the procedure.

Should I take my usual medications on the day of surgery?

The type of medication that you are taking will have been recorded by the preoperative assessment team who will tell you when to stop taking it. You should follow these instructions carefully. Your anaesthetist will also be aware of the impact of these medications on the anaesthetic and make any necessary adjustments, for example, by having available additional intravenous fluids or medication to optimise your blood pressure and heart rate if necessary.

“What really helped is being able to explain to the anaesthetist that I might need additional fluids and a little bit longer to recover from the anaesthetic. Once the team was informed, they put what was needed in place for me.”

After surgery

I have been told that patients with ME/CFS can take a long time to come around from the anaesthetic. Will the recovery staff be aware of this?

It's not uncommon for many patients to take longer to come around from the anaesthetic. Operating theatre staff will inform recovery staff about your condition and any special considerations when they hand you over to them. In addition, teams have daily briefings where the needs of individual patients are discussed and recorded.

I may not be able to communicate verbally for some time after coming around from the anaesthetic. Will adjustments be made for this?

Any additional needs that you may have will have been discussed at the team briefings and the recovery staff can provide you with non-verbal means of communication if necessary.

“When I came round from the anaesthetic, I felt so tired that I could not speak and communicate with the nurses.”

Will I have special monitoring after surgery?

All patients have continuous monitoring in the recovery area and then less frequently on the surgical wards. The level of monitoring required for you will be determined by the type of surgery and the severity of your ME/CFS. For example, you may be admitted to a high-dependency unit so that you can be closely monitored after surgery and any issues addressed quickly.

I have heard that mobilising soon after surgery is very important for recovery. I am concerned that I will not have the energy to do this after surgery. What can be done about this?

Adequate pain relief, alongside drinking, eating and mobilising as soon as possible after surgery, are important for reducing complications such as blood clots and speeding up your healing and recovery and, importantly, for allowing you to go home as soon as possible.

Your condition, especially if you have dysautonomia, may make early mobilisation more challenging. However, hospitals are used to patients having low blood pressure after major surgery and have procedures in place for managing this and helping you mobilise safely.

The extent to which you mobilise will have to be carefully managed and you should apply your 'pacing' approach in the period immediately after surgery. You should discuss this with the preoperative assessment team and the anaesthetist ahead of the surgery.

Will the recovery staff be informed that I may have sensitivity to noise, light and strong smells?

You should have informed the preoperative assessment team previously so that these issues are recorded in your notes and personalised plan. You should then mention it again to your surgeon and anaesthetist on the day of the surgery, so that they can share any adjustments required at team briefings. You should be able to request a copy of your plan from the preoperative assessment team to take with you and share with your family and GP if you wish.

The recovery staff will have been at the team briefings at the start of the operating list and will be aware of any special adjustments that they will need to make for you. There will also be a handover to them by your anaesthetist at the end of your operation.

“I mentioned that I was sensitive to light and the staff turned the lights off or lowered them for me.”

Steps will be taken to optimise the environment to minimise your exposure to noise and light. It might be difficult, however, to limit your exposure to strong smells.

“On waking up I had a really bad ME crash and the lights felt like daggers in my eyes.”

I have been told that I will need to stay overnight after surgery. I suffer from sleep disturbance, which greatly affects my fatigue. What adjustments can be made for this?

You should inform the preoperative assessment team and the anaesthetist on the day of the surgery about this. Where possible, a single room will be allocated on the ward for you. It will be useful to bring ear plugs and a sleep mask with you. If you usually use melatonin to aid your sleep, you can bring it with you or it can be prescribed in hospital if needed.

Being discharged and recovering at home

Will I have a prolonged episode/flare-up on my return home?

As mentioned in the section 'General considerations about ME/CFS and anaesthesia', it is difficult to predict how anaesthesia and surgery might affect patients with ME/CFS. Surgery can lead to significant fatigue in many healthy patients regardless of underlying medical conditions. The fatigue you might experience after surgery might be a flare-up of your ME/CFS or a normal response to the stresses of surgery.

You should discuss your concerns with the preoperative assessment team and your surgeon well ahead of the surgery, so that any necessary support from district nurses, carers, community occupational therapists and physiotherapists can be requested in advance. This should avoid delays with your discharge home.

You should also inform your family or social services/home care provider that you may need additional support for some time on your return home from hospital.

Will my GP be aware of my pending operation and the support I may need afterwards?

Your GP should have received a letter from your surgeon, but it would be sensible to inform them yourself once you have a date for the surgery, and discuss any concerns that you have about your recovery.

I have chronic pain as part of my ME/CFS. Will my pain worsen after surgery?

This is difficult to predict. However, the hospital's pain team should have a robust pain relief plan in place for you during your hospital stay and on discharge. If you were already on opioid medication or other chronic pain medication before surgery, they will take that into account when planning your pain relief after surgery.

“I suffered a number of ME crashes in the weeks after surgery, which was quite unusual for my usual ME pattern. These eventually eased a bit, but the pattern of my ME crashes seems to have changed now.”

“In the weeks after surgery I actually experienced an improvement of my ME symptoms, which surprised me.”

“What really helped my recovery at home was planning. I did some research and I knew that I might take a long time to recover. My Mum and my husband were able to take time off work to support me and that allowed me to rest and pace myself through recovery. I also had a very supportive GP.”

Further information and questions

Where can I find further information about anaesthesia and preparing for surgery?

Information about different types of anaesthetics can be found at:

www.rcoa.ac.uk/patientinfo/leaflets-video-resources

Information about the risks associated with anaesthetics can be found at:

www.rcoa.ac.uk/patientinfo/risk

Information on preparing for surgery can be found at: www.rcoa.ac.uk/fitterbettersooner

Information about the surgical journey can be found on the Centre for Perioperative Care's website at: www.cpoc.org.uk/patients

Information about pain medicine and pain conditions can be found on the Faculty of Pain Medicine's website at: www.fpm.ac.uk/patients

Questions you might like to ask your anaesthetist and the preoperative assessment team

1. Will my personalised plan take into account my ME/CFS and any required adjustments?
2. Will the anaesthetic drugs need to be adjusted for me?
3. Do I have any specific risks?
4. Will I need to stay in the high-dependency unit?
5. Will I be expected to go home straight after the surgery?

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.

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