



MANAGEMENT FILE

by DR CHARLES SHEPHERD, our medical adviser

This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine. MEA membership costs £18 a year for people living in the UK/BFPO. For contact details, see foot of this page.

the ME association



February 2020

GOING INTO HOSPITAL

Being admitted to hospital is likely to be a stressful and tiring event, especially when you have ME/CFS. And, while a surgeon may regard some operations as being 'minor', it is unlikely to have that effect on someone with ME/ CFS! So how can you try to make sure that everything goes as smoothly as possible?

QUESTIONS PRIOR TO ADMISSION

If you require an operation, various Department of Health initiatives have been introduced to give patients more choice about where and when they go into hospital.

That's fine in theory, but it's not always the case in practice. So it is worthwhile doing some background research on your local hospitals to see if there are any features – infection rates, travelling, parking, visitor access – that makes one hospital more ME-friendly than another.

But the most important consideration is always going to be where are you going to get the best standard of care? This is something that your GP should be able to advise on.

PRE-OPERATIVE ASSESSMENTS

Many hospitals now arrange a routine out-patient appointment with either a doctor or specialist nurse a few weeks prior to your admission. The main purpose of this appointment is to make sure that you don't have any medical problems – things like high blood



pressure or anaemia – that need to be sorted out before the operation takes place.

Patients can also use this appointment to raise any queries or concerns they might have about what is going to happen, how long you are likely to have to stay for etc. This appointment also provides an excellent opportunity to explain to the doctor that you have ME/CFS, may be taking medication that interferes with anaesthetics, and the fact that anaesthetics and operations are well recognised as factors that can cause a significant relapse or exacerbation of ME/CFS symptoms.

PREPARING TO GO INTO HOSPITAL

If you want to check out any practical information about the hospital, it's worth having a look at their website or asking if they have an information

booklet. Some hospital departments and wards even have their own website sections or information booklets aimed at helping people to understand what will happen on the ward during your admission.

ADMISSION TO HOSPITAL

Once you know the date of admission, try to make sure that you are in the best physical state possible, and don't do anything that is physically or mentally demanding in the days before you go in.

If you are going to have a routine operation, the chances are you will be given reasonable warning of the date and be admitted the day before. If things are more complicated, you may need to be admitted a few days before for blood tests, etc.

Explain to the nursing sister on the surgical ward that you have ME/CFS. All the staff should then be aware of the

problems that this illness can cause and the fact your post-operative recovery may not be quite as rapid as they would expect.

You should also find that you have a specific (more junior) nurse on the ward who is your main point of contact. Before going to theatre you'll be seen by a member of the surgical team and an anaesthetist – neither of whom may know very much about ME.

HOW TO EXPLAIN WHY ME/CFS CAN BE AFFECTED BY OPERATIONS AND ANAESTHETICS

There are several reasons why operations and anaesthetics can cause problems for people with ME/CFS. Among those worth mentioning here are:

- Blood flow (perfusion) disturbances to the brain occur in ME/CFS and blood flow (along with oxygen) to the brain can be significantly reduced during an operation.
- People with ME/CFS frequently have problems with temperature control (thermoregulation) – probably as a result of a disturbance in the way the hypothalamus gland in the brain regulates body temperature.



- Drugs used for anaesthetic purposes may act on brain chemical transmitters systems – some of which are also affected by ME/CFS.
- An operation plus an anaesthetic is quite a stressful event – even for people who are otherwise fit and well. In addition, lowered levels of cortisol in some people with ME/CFS may affect the body's ability to cope with major stressors.

DAY CASE SURGERY

An increasing number of surgical operations are now being carried out as day cases – where the patient is only in hospital for a day. Common examples include uncomplicated cataracts, hernias and varicose veins.

While day case surgery is fine for people who are in otherwise good health, it may not be an ideal solution for someone with ME/CFS – especially if you are living alone and there's nobody to take you into hospital, or (more importantly) be at home when you come back.

Among the practical problems that can occur with day case surgery are having to arrive very early in the morning (when your level of functioning may be at its worst), finding that beds are in short supply, having to hang around for quite a long time before the operation takes place, and returning home later in the day/early evening when you may not be feeling very good after the operation and an anaesthetic.

So, if day case surgery is being considered, these are some of the points you need to ask about.

If day case surgery seems as though it is going to be too stressful, ask if you could be admitted the night before and then go home the day after.

ANAESTHETICS

The MEA has a separate information leaflet on anaesthetics.

The key advice here is to:

- Make sure the anaesthetist is aware of the fact that people with ME/CFS are often more sensitive to the effects of drugs that interfere with brain chemical transmitters and nerve to muscle communication (ie neuromuscular transmission).
- Let the anaesthetist know if you have any heart symptoms (eg palpitations) or blood pressure problems (eg feeling faint on standing) – as this might affect the choice of anaesthetic.
- Check if a local anaesthetic containing adrenaline is going to be used. Adrenaline needs to be used with care in people with ME/CFS – especially if you have autonomic nervous system problems that cause heart symptoms such as palpitations.
- Ask about the possible use of a shorter-acting general anaesthetic – this is something that anaesthetists sometimes recommend for people who have neurological disorders.

Anaesthetists, incidentally, are experts when it comes to getting drips into veins. So, if there is any problem with drips, diplomatically ask if an anaesthetist could have a go!

ALTERNATIVES TO SURGERY AND GENERAL ANAESTHETICS

Modern surgical techniques, especially so-called 'keyhole' surgery, means that some operations are far less traumatic than they used to be.

Advances in knowledge also mean that some surgical procedures are now being replaced by drug treatments, or therapy that does not involve an incision. For example, some types of kidney stone can now be broken up inside the body using a machine called a lithotripter – replacing the need for a major surgical operation.

Developments in anaesthetics also

mean that some types of operation can now be carried out by using just a local anaesthetic – which may be an option worth asking about.

DIET AND NUTRITION

Appetising nutritious food should help the recovery process – but the standard and variety of hospital food varies enormously.

If you have any concerns about hospital food, or are on a special diet, you can ask to speak to the hospital dietician. If the hospital food really is poor, see if your friends or relatives can bring in something that's appetising.

AFTER THE OPERATION

There are several important reasons why people need to start mobilising again as soon as possible after an operation.

In particular, lying in bed will increase the risk of developing a deep vein thrombosis (blood clot) in the legs. Inactivity can also increase the risk of developing a chest infection.

On the other hand, over-enthusiastic post-operative activity may not help your ME/CFS. So it's a question of talking to the nurses and physiotherapists about striking the right balance. And,

Medical information contained in this leaflet is not intended to be used as a substitute for medical advice or treatment from your own doctor.

The MEA recommends that you always consult your own doctor or healthcare professional about any specific problem.

We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.

if you are finding it difficult to start mobilising again, ask about doing some leg exercises in bed that should help to reduce the risk of blood clot formation.

When it comes to pain relief there are anecdotal reports of morphine resistance sometimes occurring in people with ME/CFS. Whether this is actually more common in ME/CFS remains uncertain.

RETURNING HOME

Hopefully, the operation will go to plan and you can then return home where you can convalesce and recover. It

should then be possible for your GP and district nurse to deal with routine post-operative care.

Preparations at home for your return will need to be thought through well before admission – especially any sort of practical and social support that is likely to be required in the days and weeks after you return home.

FURTHER INFORMATION

- ◆ For more information on operations and anaesthetics, see pages 217-219 of my book *Living with ME*. (Vermilion, 1999).



ME CONNECT
We're here to help

Do you need to talk?

 ME Connect is the telephone helpline service of the ME Association. It provides information and support for people with ME and those who live with or care for them. ME Connect provides a safe and understanding environment for people with ME so that they know they are being heard and understood.

ME Connect is a member of the Helplines Partnership which promotes high standards.

CALL 0344 576 5326

10am-12noon
2pm-4pm, 7pm-9pm
every day of the year



Calls cost the same as other standard landline numbers (starting 01 or 02).
If you have a call package for your landline or mobile phone then calls will normally come out of your inclusive minutes.