



MANAGEMENT FILE

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MEA membership costs £18 a year for people living in the UK/BFPO.
For contact details, see foot of this page.



Cancer, chemotherapy, radiotherapy and ME/CFS

INTRODUCTION

People who have a long-term condition are inevitably going to find that they may develop other illnesses as time goes on – including serious conditions such as cancer.

However, there is no firm evidence from published epidemiological research studies to indicate that cancer is more (or possibly even less) likely to occur if you have ME/CFS, or that overall life expectancy is reduced by having ME/CFS.

What is relevant is the fact that some of the symptoms of ME/CFS can also occur in the early stages of cancer. So it is important to always check with your doctor if a new symptom occurs, or an existing symptom seems to be getting worse (eg a sore throat becomes persistent).

Early diagnosis and treatment of cancer usually results in a much better outlook.

The four most important points regarding management of cancer if you also have ME/CFS are:

- Accepting that whatever is being recommended regarding the treatment of the cancer should be followed through – regardless of what effect drugs, radiotherapy or surgery might have on your ME/CFS.
- Knowing that drugs, radiotherapy and surgery have side-effects –

especially fatigue, nausea and sickness and possibly cognitive problems – which are likely to interact with ME/CFS symptoms and temporarily make them worse.

- Having a good medical support network in place – a hospital cancer care team, community cancer team, GP, Macmillan nurse, etc.
- Having a good general home support network in place – practical, emotional and social – before the treatment commences.

Being told that you have a diagnosis of cancer is a very frightening piece of information. All of the three main treatments – drugs, radiotherapy and surgery – can at best be daunting and worst be frightening on top of the initial shock.

So it helps to be well informed about how the various treatments are going to affect you, and possibly your ME/CFS.

Below are some of the most important points to bear in mind as you go through the treatment process.

CHEMOTHERAPY – ANTI-CANCER DRUGS

Chemotherapy is the medical name given to a powerful group of drugs that are sometimes used in the treatment of cancer. They can be used alone, or in combination with radiotherapy and/or surgery. The choice will depend on the type and severity of the cancer being treated.

Anti-cancer drugs can be used to help shrink the tumour before other treatments begin. They can also be given at the end of other treatments to prevent the growth of cancer cells that may have spread further around the body. They are often given in short courses over a period of a few weeks followed by a drug free interval, which allows the normal healthy cells to recover.

This type of treatment is usually given in hospital – because powerful drugs are involved and they sometimes have to be given into a vein. But there are now hospitals that provide drug treatment in the patient's own home.

During treatment, it is important to try and limit any damage to normal healthy cells – so regular blood counts may be necessary.

The most commonly used anti-cancer drugs are called cytotoxics. But some cancers are treated with hormonal drugs and immune system therapy. It is interesting to note that one of the immunological treatments now being used, rituximab, has also been tested as a possible form of treatment for ME/CFS.

Cytotoxics are powerful anti-cancer drugs that act by killing off specific types of cancer cells. So they can cause unpleasant and sometimes serious side-effects.

Some of these potential side-effects – especially fatigue – may be very similar to the symptoms of your ME/CFS. So there is a possibility that some aspects

of your ME/CFS are going to be worse while you are having a course of chemotherapy. Sometimes this continues after treatment has finished.

Nausea is a problem in particular that often accompanies the use of chemotherapy and it may be severe. If so, there are various anti-sickness drugs that can be prescribed. And it may be better to start using them before nausea or sickness becomes a significant problem.

Some anti-cancer drugs cause harm to a developing foetus – so it is important to make sure any contraceptive needs are sorted out before starting treatment.

Being told that you will need chemotherapy is likely to be a frightening piece of news. The reassuring aspect is that many people manage to go through a course of chemotherapy without having any major problems.

RADIOTHERAPY

This involves a course of high-intensity ionising radiation that kills off cancer cells. Radiotherapy is directed to a very accurately defined area inside the body – where the tumour is/was present.

Radiotherapy is usually given daily over a period of weeks and it's normally very important to keep to the schedule – which may not be easy if you have ME/CFS.

The equipment used is expensive and requires specialist staff – so it is not always available in local hospitals and you may need to travel to a specialist centre.

Radiotherapy is normally a painless procedure but, as with chemotherapy, it can cause a number of side-effects.

In relation to ME/CFS, fatigue, problems with memory and concentration, and feeling sick can all occur. Fatigue is quite common and may build up as treatment goes on. It can then persist for some time after treatment has finished – as can some of the other side-effects. As with chemotherapy, there are anti-sickness drugs that can be prescribed.

Other possible side-effects are related

to the area of the body being treated – so radiotherapy to the head and neck area may cause hair loss (which is normally temporary), sore/dry mouth and throat (from damage to the salivary glands), skin problems and mouth ulcers.

If radiotherapy is given to the neck area it can affect thyroid gland activity – so regular thyroid function blood tests are required. Treatment to the large bowel may cause diarrhoea.

In some cases skin sensitivity or damage can occur – so detailed advice on skin care is essential if this is likely.

If the ovaries or testes are in the area being treated, this will cause infertility. So men may need to discuss the possibility of having sperm stored. Women can ask if their ovaries can be moved away from the radiotherapy beam.

SURGERY

This may or may not be necessary and will range from relatively minor surgery to a major operation. We know that operations and anaesthetics can sometimes cause a relapse or exacerbation in ME/CFS symptoms.

The MEA Association has leaflets dealing with Anaesthetics, Pain Relief, Surgery and Going into Hospital.

COPING WITH YOUR CANCER TREATMENT

There are some things that you are going to be able to control as you go through chemotherapy, radiotherapy or surgery. But there are others that you won't be able to control. So try to plan ahead with the help of the health professionals who are looking after you.

Below are a few practical suggestions that should help you to cope with having cancer and the various cancer treatments, along with some of the questions that you will probably need to ask your medical advisers.

Don't be afraid to ask

Besides the hospital specialist (oncologist, radiotherapist or surgeon) who is supervising your cancer treatment, there will be other members of

the team – possibly including a named cancer nurse, who you can speak to when necessary. So keep a contact telephone number with you at all times.

At your hospital appointments, ask about the treatment that you are going to have, what it is supposed to do, how long it is going to take, what sort of side-effects are possible and probable, and how they can best be alleviated.

You need to know about which potential side-effects are important (eg a sore throat or mouth ulceration may mean that your white blood count is too low; increasing fatigue may mean anaemia) and when you need to seek advice.

There are also some excellent patient support charities for people with cancer – both general and specific.

Just like The ME Association, they have telephone helplines and websites that provide good quality information about all aspects of treatment and the side-effects that may occur – mouth problems and sickness in particular.

It is also worth considering making contact with other patients with your type of cancer, through on-line or local face to face support groups, as the best advice can often come from those who have experienced the treatment firsthand.

The Macmillan online community is very good and covers all types of cancer. Macmillan information booklets are available in hospitals and can be accessed online.

Know when you are ill

This may not always be easy when you have ME/CFS with flu-like feelings, sore throats and temperature control problems. But infection is always a potential problem with chemotherapy (and sometimes with radiotherapy) because cancer treatments can also affect the production of healthy white blood cells in the bone marrow, which protect against infection.

A fall in the white cell count increases the risk of picking up infections. So it's a good idea to have a

thermometer at home, and know how to use it to check your temperature if you have infective-type symptoms that feel different to normal ME/CFS.

Try to avoid infections

Following on from the last piece of advice, it is clearly a good idea to try and avoid infections. This means keeping away from people who have colds or flu and children with infections – chickenpox in particular.

Having a flu vaccination before treatment commences may be advisable – so check with your doctor. It's also worth making sure that you are not eating anything that could cause an attack of food poisoning.

Eat well

Chemotherapy and radiotherapy can cause nausea, loss of appetite and your sense of taste may change. This is also a very difficult time to try and put on weight – which may have been lost prior to treatment being started.

Even so, it's important to eat a healthy balanced diet that is going to keep your energy levels up and contains plenty of protein. If you find that there are times when you cannot eat as much as usual, and you are losing weight, you will need some advice on how to get more energy and protein into your diet without necessarily having to eat more food.

If you are having difficulty with swallowing there are a various nutritional products and high energy drinks that you could try. Ask your GP, dietician

or pharmacist for more advice.

Macmillan Cancer Support provides good quality advice for people who need to maintain their weight, as well as those who need to build up their weight – where the advice is different. You should also have access to a hospital dietician who is used to dealing with patients who have cancer.

Alcohol and smoking

Most people with ME/CFS find that they are alcohol-intolerant, but if you do like a glass of wine check that this isn't going to interfere with your medication. For head and neck cancers, alcohol and smoking are both best avoided as they can irritate the lining of the mouth.

Smoking is a definite 'no' if you are having chemotherapy or surgery as it will significantly increase the risk of developing a chest infection at a time when your natural defences are lowered.

It is also advisable to stop smoking during radiotherapy because research has shown that this makes the treatment more effective.

Financial help

People with cancer are entitled to free prescriptions – which can save a lot of money. You (and your carer) may now be entitled to various state sickness and disability benefits.

The MEA has an information leaflet that summarises all the main sickness and disability benefits.

Alternative and complementary therapies

You may find that some of the more popular complementary treatments, such as aromatherapy, are available on the NHS. Although they cannot obviously be used to treat the actual cancer, they may be helpful in relieving symptoms and helping with relaxation.

Unfortunately, as with ME/CFS, there are also charlatans claiming to treat or cure cancer with all kinds of expensive and unproven treatments, which may also be promoted as an alternative to conventional cancer treatment. As a result of the Cancer Act, they should not be advertised to the public – but they are. So if you are tempted to try anything unusual do speak to your doctor first.

Think about yourself!

The next few weeks and months aren't going to be easy – so this is one time in your life when you are entitled to be a bit selfish. Let your friends and relatives know that you are about to go through a rough patch – physically and emotionally. And, yes, there are some things that you may need them to do to help.

Finally, don't forget to give yourself a treat from time to time. You deserve it!

SOURCES OF FURTHER HELP

Macmillan Cancer Support

www.macmillan.org.uk

Helpline: 0808 808 0000

Cancer Help UK

www.cancerhelp.org.uk

Helpline: 0808 800 4040

Breast Cancer Care

www.breastcancercare.org.uk

Helpline: 0808 800 6000

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Medical information contained in this leaflet is not intended to replace medical advice or treatment from your doctor. We recommend that you always consult your doctor or healthcare professional about any specific problem. We also recommend that the medical information we provide is shown to and discussed with your doctor, as appropriate.