



## TIPS FOR LIVING WITH ME OR CFS IN NORFOLK.



- Recommended Steps and Info
- Frequently Asked Questions
- Tips and Signposting

Elevate is a support/self-help group for people affected by ME or CFS living in mid-Norfolk UK. It aims to elevate quality of life, support, awareness and hope as a volunteer led group.

[www.elevatedereham.co.uk](http://www.elevatedereham.co.uk)   [elevate@wfcdereham.org](mailto:elevate@wfcdereham.org)   07538 801778

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# 1 Receiving or confirming a diagnosis

If you have not yet been given a diagnosis of ME or CFS, but you suspect it is a health problem you have, we recommend that you have medical investigations to exclude any other possible causes. An official diagnosis will give someone more access to help and support, and may also help with benefits claims. There are two main ways that you might be diagnosed for free on the NHS:



## 1a. GP diagnosis.

Some GPs may diagnose the illness if they have sufficient knowledge to do so but it is far more common to have the diagnosis given or confirmed by specialists who will try to give newly diagnosed people as much follow-up as possible. This service is mentioned in the next step below:



## 1b. GP referral to the Norfolk and Suffolk ME Service.

As well as providing, or confirming diagnosis, this service should provide some degree of follow up to assist sufferers with managing their condition. If your GP does not know about this service you can provide him/her with the details below:

### **Norfolk & Suffolk CFS/ME Service.**

Herbert Matthes Block, Northgate Hospital

Northgate Street, Great Yarmouth, Norfolk

NR30 1BU

01493 809 977

<http://www.heron.nhs.uk/heron/organisationdetails.aspx?id=20172>

### **At time of writing (10/02/2014) There are clinics at:**

- Nelson Medical Centre, Gt Yarmouth
- Patrick Stead Hospital, Halesworth, Suffolk
- Bowthorpe Health Centre
- Shrublands Medical Practice
- Kirkley Mill Health Centre, Lowestoft
- St James Medical Practice Kings Lynn
- Stow Lodge Centre Stowmarket

Up-to-date info at <http://www.heron.nhs.uk/heron/organisationdetails.aspx?id=20172>

## 2 Learning About ME & CFS

**ME:** Myalgic Encephalomyelitis. ME can cause severely debilitating muscle weakness and reduced stamina, severe pain anywhere, faintness/dizziness, poor memory and cognitive function, disordered sleep, gastric disturbances, etc. In many cases, onset is linked to a viral infection. Other triggers may include an operation or an accident. Some people experience a slow, insidious onset.

**CFS:** Chronic Fatigue Syndrome. CFS is a label that is often used instead of, or alongside ME, or thought of as an umbrella term for a group of conditions that do not have widely available tests to distinguish between. Many feel CFS is an unhelpful name for an illness which often produces very debilitating feelings of exhaustion - rather than fatigue - abnormal muscle weakness/lack of stamina, severe pain, inability to concentrate, extreme faintness/dizziness etc.

In time further research will provide biomarkers to clearly distinguish between different type of illness labelled with CFS and/or ME.

A good place to find an up-to-date overview of the definition of ME and CFS is on the ME Association's website [www.meassociation.org.uk/2007/01/overview/](http://www.meassociation.org.uk/2007/01/overview/) The website also provides a wealth of information about management of the illnesses and research.

If you require information in a professional capacity, such as a doctor or solicitor, then we recommend that you write to the ME Association's head office at Buckingham.

[www.meassociation.org.uk/contact-us/](http://www.meassociation.org.uk/contact-us/)

## 3 Maximising Support and Helpful Advice

**3a. The NHS 'Norfolk and Suffolk CFS/ ME Service' will be able to provide assistance and support with the following:**

- Confirmation of diagnosis.
- Guidance in the management of your ill health
- Suggestions to you GP with regards to treatment.
- Medical report letters to support benefits claims.



The service offers an outpatient service throughout Norfolk and Suffolk, providing assessment, diagnosis, management, advice, education and support for people who have a diagnosis of CFS/ME. The team comprises of GPs with specialist interest (GPwSI) and knowledge of CFS/ME and specialist occupational therapists (OT) and physiotherapists (PT) who are supported by administrative staff. This is via face to face appointments, email and telephone and in a small number of cases, home visits.

There are clinics at multiple locations ([see list above](#)).

Your GP or healthcare professional may be able to refer you to this service using the details below. The service usually sends out a form for you to fill in.

**Norfolk & Suffolk ME/CFS Service, Herbert Matthes Block, Northgate Hospital, Northgate Street, Great Yarmouth, Norfolk, NR30 1BU 01493 809 977**

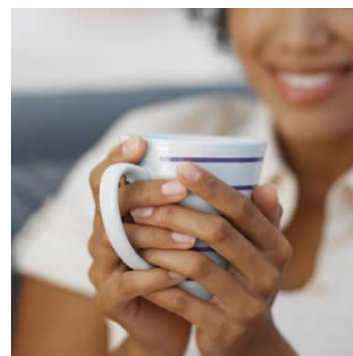
Up-to-date info at <http://www.heron.nhs.uk/heron/organisationdetails.aspx?id=20172>

## 3b. Local, Regional and National Support/Self-help groups.

### Regional - 'ME Support Norfolk'

'ME support Norfolk' provides:

- monthly meetings in Norwich - sometimes with visiting speakers
- a bimonthly newsletter
- benefits advice
- a helpline: 01263 861521
- a website <http://www.mesupportnorfolk.co.uk/>



### Local

The local groups can be particularly good at reducing isolation. Some groups encourage people to try creative activities at their meetings which may become therapeutic hobbies or just be a gentle way to spend time with other people.

### Mid-Norfolk:

Elevate (produced this document) has more of a focus on mid-Norfolk but not exclusively this area.

[www.elevatedereham.co.uk](http://www.elevatedereham.co.uk)    [elevate@wfcdereham.org](mailto:elevate@wfcdereham.org)

Mob 07538 801778



### North-Norfolk

01263 740044    [katieann39@btinternet.com](mailto:katieann39@btinternet.com)    [www.elevatedereham.co.uk](http://www.elevatedereham.co.uk)

### Norwich:

The regional group 'ME Support Norfolk' meets at Hellesdon, Norwich (more details above)

<http://www.mesupportnorfolk.co.uk/>    **01263 861521**

### ME Support Norfolk has 'contact people' at the following localities:

**Diss** - Judy Ford - 01379 650339

**Norfolk Norfolk** - Jeanette Harvey 01263 826275

**Gorleston & Gt Yarmouth** - Owen Turner - 01493 600070

## National Support Organisations

The national associations and support groups provide a lot of information, advice and some degree of support. How helpful their services are depends partly on the individual.

For example, the ME Association provides the following for an annual membership of £18:

- A helpline.
- Many printed guides some of which are free.
- A quarterly magazine with reviews of treatments, news of important research and changes to the benefits system.
- A medical advisor to write articles and answer questions sent in.
- The website provides a lot of free info [www.meassociation.org.uk](http://www.meassociation.org.uk)



**Action For ME** is similar in some ways to the ME Association but there are some differences in what they provide. [www.actionforme.org.uk](http://www.actionforme.org.uk)

**The 25% ME Group** caters specifically for the severely affected. [www.25megroup.org](http://www.25megroup.org)

You will find a longer list on Elevate's website [www.elevatedereham.co.uk](http://www.elevatedereham.co.uk)

## 3c. Support For Carers

### Norfolk Carers Information

[www.norfolkcarersinfo.org.uk/en](http://www.norfolkcarersinfo.org.uk/en)

### Carers Agency Partnership

Freephone: 0808 808 9876 Monday – Friday, 8.00am-8.00pm

A range of services are being provided through the Carers Agency Partnership (CAP) which represents key organisations in Norfolk that provide services for carers. CAP works together with the Carers Council for Norfolk (CCN), a partnership of carers and carers' organisations that directly represents carers across the county.

### Carers are welcome at Elevate

Carers are very welcome at the Elevate meetings where they may find morale support and helpful advice through talking to other carers. However we do not recommend that this substitutes getting information and support from the above source and others.



## 3d. Financial Support

Depending on the severity of a person's health when diagnosed with ME or CFS, it's likely that various benefits will be available.

### Benefits Advice

The weaknesses in the 'Work Capability Assessment' for ESA are leading to a high percentage of appeals being successful. Guidance and/or assistance with the filling in of forms and/or appeals can be invaluable and save you a lot of time and stress.

Benefits advice may well be available through [ME Support Norfolk](#) 01263 861521 or through their benefits advisor/assistant Dan Ward who visits Elevate on a regular basis.

Alternatively [Equal Lives](#) 01508 491210 [info@equallives.org.uk](mailto:info@equallives.org.uk) <http://www.equallives.org.uk/information-and-advice/welfare-benefits/> is sometimes able to provide assistance in this area but they are likely to have more limited knowledge of issues specific to ME or CFS.

'Benefits and Work' is an independent organisation providing comprehensive downloadable guides for assistance with forms and appeals. [www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)

### ESA - Employment & Support Allowance

<https://www.gov.uk/employment-support-allowance> This should cover basic living expenses, excluding payment of rent. It has two groups:

#### ESA 'Work Related Activity Group'

Can involve "work focused interviews" exploring job goals, improving skills, work-related issues. Sometimes a small amount of work, perhaps voluntary, training or community service is encouraged.

**ESA 'Support Group'** This provides financial support for those unable to work at all.

**PIP** Personal independence Payment <https://www.gov.uk/pip>

This is to help with the extra cost of living with a disability such as paying carers and getting about.

#### Personal Health Budget

The council may provide additional funding to help pay for carers (see 'home care' below.)

#### Carer's Allowance

If you are a carer over 16 years old who is spending at least 35 hours a week caring for someone with ME or CFS you may be eligible <https://www.gov.uk/carers-allowance/overview>

### Other Financial Support

#### Grants for individuals:

The following grant may help fund disability aids such as mobility scooters, home adaptations, etc if these aren't covered by PIP or a 'personal health budget', savings, or other income. A support



letter from an OT or a supporting charity may help or be expected with some of these charities when making an application.

Independence at Home <http://www.independenceathome.org.uk/>

Act Foundation <http://www.theactfoundation.co.uk/>

Newby Trust <http://www.newby-trust.org.uk/>

Talisman <http://www.talismancharity.org/>

## 3e. Home/Social Care Needs

### Social Services

If you need carers, social services may do a community care assessment to see if you are eligible for a 'Personal Health Budget'. If you are awarded this you can use it to pay for various forms of care. You may have the option of choosing a care agency from which carers will be provided rather than letting social services decide which is used. We recommended that you ask a local support group, and/or anyone you know who is receiving care, which agency(s) they would recommend as the quality of care is variable.

### PA Carer

An alternative to using care agencies is to find a PA (personal assistant) type carer. This can still be funded by the 'personal health budget' but you will either need to find a PA carer privately or pay a recruitment agency such as Equal Lives. Equal lives can also be paid to assist with the setting up of a payroll and other essential administrative tasks of employing a PA type carer; this would take the work off your hands as long as you have the budget to pay for the services.

To contact social services in Norfolk you can call customer Services Centre on 0344 800 8020 or visit the website where you can find more info. <http://www.norfolk.gov.uk/> and look on the adult care section.

### Emergency Care

If you need care in an emergency e.g. the relative who cares for you is suddenly admitted to hospital, social services has a "Swift Response Team" and "The Night Owls" who may be able to help you. Contact social services in Norfolk on 0344 800 8020.

# 4 Treatments

## a Pacing and Mainstream Treatments

The illness has an individual element – your particular version is probably not the same as anyone else's in all its respects. As a result, you may find that a treatment that relieves particular symptom(s) for someone else may not do the same for you – indeed it could even make you feel worse. On the other hand, something which someone else found to be of little use could be useful for you. Both mainstream and complementary medicine practitioners have some ideas which you could consider.

### Guidelines

Guidance for diagnosis and management of people with ME/CFS can be found in The ME Association publication ME/CFS/PVFS An exploration of the key clinical issues, written by Dr Charles Shepherd and Dr Abhijit Chaudhuri of the University of Glasgow. Although aimed at healthcare professionals, you may also be helped by reading it and you will be better-informed should you and your doctor decide to follow one of the treatment regimes.

As the booklet was aimed at 'mainstream' medical professionals, the 'Treatments' section of the booklet focuses mainly on 'mainstream' treatments; there is a short discussion on complementary methods. You can obtain the booklet directly from The ME Association.

### Lifestyle and Attitude

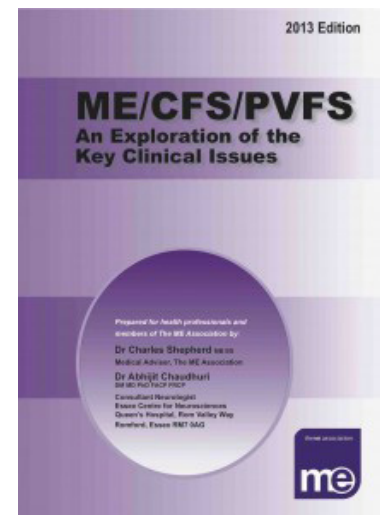
A person who was previously fit and active who contracts ME/CFS will find that it imposes restrictions on their way of life. It is important to come to terms with this. Many find that the 'battle on regardless' attitude which they have applied to ill health in the past will almost certainly fail, and may prolong the period of incapacity. This does not mean retiring to bed in the belief that absolute rest is the best remedy (although bedrest is appropriate in the acute stage) but that you should attempt to pace yourself, endeavouring not to become so active that you are permanently exhausted. For more guidelines on pacing please [see section 5b on pacing below](#).

It is important to remain positive about the prospect of recovery. Nobody has managed to determine which factors affect the rate of recovery, so from this position of ignorance you have as much chance as the next person of making useful progress. The period of illness varies from person to person, and even in someone who has had it for a long time it can, for no apparent reason, start to show real signs of improvement.

Adopt sensible changes in your lifestyle and develop a plan: Following a thorough assessment, go on to develop an individual management plan. It is unlikely that one person alone will be able to provide all the answers to all of the problems you face; one idea is a team approach co-ordinated by a key worker with experience and knowledge ME or CFS – perhaps your GP with access to specialist advice ([Please see section 3 for info on the Norfolk NHS CFS/ME Service](#))

Whether wishing to remain at work or school whilst enduring a period of ill health, or whether intending to return after a period away, the suggestion is to apply the [principles of pacing](#). This will need the co-operation of your employer or school. Aim for part time attendance with a gradually increasing workload and a flexible approach.

Many people find a [relaxation technique](#) of benefit (see 'Managing stress and relaxation' below.)



## 4b. Pain Management

Pain management in people with ME can be a major issue because pain can be severe and the usual first steps a GP will take to manage pain may not be very effective. There are further medical steps that can be taken but it is important to note that good pacing of activity may sometimes help both in the prevention/alleviation/management of pain. However sometimes people with ME experience pain however well they manage their condition.

GPs typically prescribe, in order of strength, Paracetamol, Co-codamol, Ibuprofen and the Naproxen which is an NSAID (Non-steroidal Anti-inflammatory Drug.) Sometimes they may also try neuropathic pain reducing medication such as Amitriptyline or Gabapentin.

Amitriptyline is an antidepressant but for neuropathic pain relief it is usually prescribed at a dose of 10-30mg which is a lot lower than the dose used for treating depression. It may also help with sleep but it is likely to cause a lot of drowsiness at first and doesn't suit everyone long-term; it can even be detrimental in some cases.

Any of these medications may have mild - moderate and occasionally severe side effects and you should immediately discuss any concerns with your GP.

### Painkiller Patches.

These are relatively new and are worn all the time like plasters to slowly release medication into the bloodstream. They can be more effective and are sometimes taken in addition to medication mentioned above.

You may well benefit from a GP referral to a pain clinic. We know of one in Norwich:

Pain Management Clinic

Norwich Community Hospital,

Bowthorpe Road,

Norwich, NR2 3TU.

One of our members describes her experience of the pain clinic and the painkiller patches:

*"As the name suggests they're experts on what can help you...When I got to the point that I was taking the maximum daily allowance of codeine based drugs (Cocodamol) combined with strong NSAIDs (Naproxen), my GP sent me for advice. I'm now on Buprenorphine pain killing patches, which I wear all the time, changing weekly. Even with these I still need to supplement with the usual GP prescribed drugs occasionally, but the patches take care of a large part of the all over body pain I have. Talk to them about it.*

*Personally I've been on the patches several years now, but when I started I believe they were quite new. I'm not sure how commonly they're prescribed. As I was taking the maximum oral painkillers virtually every day, they were no longer a viable option, particularly as I was experiencing side effects. However, just to warn you, when I began the patches I experienced some nausea and dizziness for the first day or two after application, just for the first few patches, then it settled down. I don't have any known side effects now. They absolutely rescued me! They come in 3 strengths so depending on your condition, they'll prescribe a dose and that's the patch you'll get which you simply change once a week. Obviously your doc can alter the dose if needed. "*

## 4c. Alternative and Complimentary Therapies.

There is very little sound scientific evidence that these work for people with ME or CFS but if you would like to try one we recommend that you try to find a reputable practitioner. The Health Professions Council website <http://www.hpc-uk.org> has details of qualified and properly registered dieticians and other practitioners in some of these areas. [The ME Association](#) has produced a document providing more detail on alternative and complementary approaches.

## 5 Self-help

When it comes to managing ME or CFS there's no such thing as a 'one size fits all' approach because the condition varies a lot from person to person.

However there are some general guidelines and tips which you may find helpful.

There is a lot you can do to help yourself but one of those is to be willing to accept help from others where appropriate as your own resources are limited.

There are different aspects to managing ME and CFS:

- a. Not being too independent.**
- b. Pacing**
- c. Pleasure**
- d. Managing stress and relaxation**
- e. People**
- f. Positivity**
- g. Perseverance**
- h. Diet**
- i. Moods and mental health issues.**
- j. Alternative and complimentary therapies?**



### 5a. Not being too independent.

Obviously receiving diagnoses can help by at least showing people what they're dealing with. We have provided information, earlier in this guide, about diagnosis of ME or CFS and follow up through the NHS Norfolk and Suffolk ME Service (see page 4). They will make recommendations of how to manage your condition, liaise with your GP about treatment and medication and write medical reports which may support benefits claims.

However there can be a long waiting list for this service and follow up can be limited so it can help to learn as much as you can about the management of your illness and daily living. Of course you should always discuss health concerns with your GP.

You may also find you can help yourself by getting in touch with support groups and other organisations (see page 6).

## 5b. Pacing

Norfolk's NHS ME/CFS Service will recommend and guide people through careful pacing of activity as well as they are able to. Your GP or consultant may prescribe medication to help manage symptoms such as pain and sleep management. GPs may also suggest cognitive behaviour therapy or graded exercise therapy (GET). The ME Association says in its 'Ten Key Aspects of Management' Jan 2012, "The MEA is not convinced that GET programmes that involve progressive and inflexible increase in activity - regardless of how a person is coping or feeling - are appropriate. They may even harmful. In fact, feedback to the CMO report on activity management found that while nearly 90% found pacing helpful only 35% reported benefit from graded exercise - with almost 50% reporting that graded exercise had made them worse. Similar results were reported in the MEA Management Report - which contains feedback from over 4,000 people with ME/CFS.



Below are some general guidelines that help many people with ME or CFS to some degree.

(This info is NOT intended as a substitute for medical advice and treatment from your own doctor. We recommend that you always consult your doctor or healthcare professional about any specific problems. We also recommend that you discuss this info where appropriate with your doctor.)

Pacing was found to be helpful by 90% of people with ME/CFS who provided feedback to the 2002 Chief Medical Officer's report into ME/CFS (Section 4.4.2.3)

The ME Association produces a good leaflets on management and pacing: "Ten Key Aspects of Management" and "Energy Management". You can get these directly from the ME Association or you may see them the at an Elevate get-together in Dereham. You may also like to look at a longer booklet produced by Action For ME is available as a [PDF by clicking here. www.actionforme.org.uk/get-informed/about-me/treatment/pacing/index](http://www.actionforme.org.uk/get-informed/about-me/treatment/pacing/index)

The basic principles of pacing when you have ME or CFS are:

- Having ME or CFS can be like having a rechargeable battery which goes flat quicker. Technically it's not accurate to say that all a person's energy is stored - a lot of energy is produced as you do things and as cells function. However research is showing that people with ME have problems in their mitochondria in cells which means that their cells are not able to produce energy as well as in a healthy person. There are also findings of highly abnormal build-up of acids in muscle cells in some people with CFS/ME. Other research demonstrates debilitating post-exertion effects. There may be links to problems in the autonomic nervous system, reduced circulating blood volume and POTS but all of this is still in the process of being researched. [See the Elevate research portal for more information \(click here\).](http://www.elevatedereham.co.uk/me-cfs-research/)
- Any part of body can more easily become dysfunctional and/or very painful if overused and this affect is often partly, or entirely delayed hours or days. This post-exertion effect has recently been confirmed by research: <http://www.ncbi.nlm.nih.gov/pubmed/23813081>

- Sometimes over-exertion causes or exacerbates insomnia and irregular sleep patterns.
- Excessive over-exertion can result in a relapse lasting anything from one day to weeks. Some people refer to this “boom and bust behaviour”.
- Learning the limits of your endurance with various activities and having rest breaks can reduce the risks of energy depletion, worsened symptoms and relapse.
- Common advice is that fairly safe margin is to do about 75% of how much you think you do in order to stabilize and be more able to carefully increase activity at some point.
- Rest breaks can be very helpful but resting does not necessarily mean doing nothing at all; some people find that very difficult, or that they quickly fall asleep. Sometimes resting parts of your body and brain can be achieved by engaging in a gentle activity such as listening to music. If the resting activity uses different parts of the body to those you had been using prior to the resting, then it will give the exercised parts a rest.
- Doing too much of one particularly activity in one day, or within a few hours, can wear out certain parts of your body resulting in localised pain and dysfunction, or can exacerbate your condition generally. It can help to cycle through different types of activity if possible and also break up long activities into small sections.
- If you have certain times of day when you feel or perform best it may help to do activity more during these times.
- If you pace well and have adequate rest then in time there is a good chance that your condition will become more stable and improve although sometimes this process can be very slow and have setbacks.
- When you have become more stable you can cautiously make small increases to activity. Increasing activity too soon or too rapidly can cause relapse.
- The illness varies a lot from person to person and at different stages. There is no ‘one size fits all’ approach to pacing; it should be tailored to the individual. This process may be helped by an occupational therapist who is well educated about ME/CFS and these are available through the NHS Norfolk and Suffolk ME Service (Details above.)
- I can help to “listen to your body” for clues as to what changes you may need to make to your pacing technique.
- For people in the early stages of the illness, where it seemed to follow a viral infection, anecdotal evidence seems to point to the benefits of plenty of rest, sometimes bed rest, for reducing the severity of the illness later on but this should be ideally overseen by an ME specialist.
- If long periods of bed rest are taken, as much mobilisation as possible is recommended, and if necessary passive limb exercises, to counteract the possible negative effects of immobilisation and inactivity.
- Most people who manage their ME/CFS well improve in time.
- Keeping a simple diary may help you to identify causes of bad patches and relapses which you can avoid in the future. It can also help to record changes in medication and lifestyle. Rating symptoms on a scale of 1-10 may help.



## 5c. Pleasurable Activity

- Try to do some activities purely for pleasure - which aren't detrimental to your health - and make this a high priority. Without enough pleasurable activity your mental health is likely to suffer which could have a knock-on effect on your physical health. The bed-bound sometimes find there are crafts that they can do in their hands.
- Creative hobbies can not only be fun and give you sense of accomplishment; they also can give pleasure to other people e.g. handmade greetings cards.
- Pets - pets can be great company and fun if you're sure you are not allergic to them. Make sure you think carefully about the whether you can manage and afford to look after the pet for it's expected life-span.
- Laughter has many positive psychological and physiological effects so try to find things that will make you laugh on a regular basis.
- Be cautious of addictive forms of pleasure such as computer games which might wear you out.
- Recall happy memories and write them down for when your memory isn't very good.
- Dream about what you do when your health improves; if it helps write, draw or paint you dreams.



## 5d. Managing Stress and Relaxation.

Stress can exacerbate ME and CFS and reduce immune function so avoiding it as far as possible and relaxation exercises or anything that helps you relax are well worth practicing. Gentle music or relaxation tapes and CDs, breathing exercises etc can be helpful.

## 5e. People.

How you interact with the people around you is a very important aspect of managing your condition. Isolation really doesn't help. In section 5 below there more detail about this.

## 5f. Positivity.

A positive attitude can help, to some degree, a persons mental health but it can be very hard to maintain this when living with an illness which causes a lot of loss, grief, loneliness, frustration etc.

When you've been ill a long time, or you're severely ill and living a very deprived lifestyle it can be particularly hard to look on the bright side. It's possible to suppress, or repress, too many emotional responses which can be harmful for mental health long-term. This is where it can really help to have people who are available to off-load too. It may be too much for family members to



deal with and so having a supportive network of friends can help. Sometimes counselling may be helpful and this may be advised by your GP (see 'Managing Mental Health Issues below).

It can be encouraging to remember that people with ME or CFS tend to develop a lot more depth or character and become more caring people because they have had to persevere through a lot of difficulty; this can lead to them making more of a positive difference in the world.

Research is making some progress so there's always hope and that more effective treatments or a cure is on the way.



## 5g. Perseverance

People with ME and CFS have some incredible and really inspiring stories of perseverance to share and it's worth not giving up the fight because as mentioned above there can be things to gain. Some people still make full ,or reasonable recoveries ,after many years of being unwell.

## 5h. Diet.

There is a lot of evidence that having a healthy balanced diet containing at least 5 portions of vegetables and fruit can help support your immune system and promote better health. Protein is also important and fish is not only easier to digest than meat but it is also beneficial in other ways. Having plenty to drink can aid the bodies detoxification process and reduce faintness.

Some people discover that some of their symptoms are being caused by food intolerances or allergies and can be helped by seeing trying different diets. A nutritionalist may help with identifying problem foods. Seek the advise of your GP or specialist and/or a dietician before excluding or eliminating any foods.

## 5i Moods and secondary mental health issues.

As with any other chronic illness, people with ME and CFS sometimes develop secondary emotional and mental health issues. The reasons can be complex and can involve physiological factors (i.e. the ME or CFS, or some other health problem, having an effect on brain chemistry and function) and external factors (i.e. loss/grief, social difficulties, isolation, unemployment, work stress, financial problems etc). You may find it helpful to talk to a qualified counsellor, especially if you are having difficulty coming to terms with sudden and dramatic losses. It might be possible to see a counsellor through the NHS so you could try talking to your GP about it **and this becomes very important if you are experiencing severe depression or other mental health problems.** Otherwise there are various private qualified counsellors working within Norfolk. Some are able to provide a low-cost donations based sevice.

If you are feeling depressed as opposed to just being "fed-up" then it is recommended that you talk to your GP and make use of whatever help is available on the NHS. Clinical depression - which would include symptoms such as poor appetite, loss of interest, loss of self-esteem, worthlessness, being tearful at times - would normally require treatment with antidepressant medication. For less severe depression the herbal remedy St John's Wort may be helpful but it is still important to discuss these alternative treatments with your GP.

If drugs are prescribed it should be noted that people with ME or CFS tend to be sensitive to most

drugs that act on the central nervous system. So antidepressants need to be used with care and in some situations started at the lowest possible dose with the supervision of your GP and any other healthcare professionals you have been referred to where appropriate.

## Emotional/Morale Support

We hope that you receive a certain amount of emotional support from family and friends. If this is not the case and you feel very isolated or alone this is where a local support group like Elevate may be helpful (Please see the section on isolation and loneliness below).

**Crisis** For emotional support in a crisis you could also try contacting the following helplines. If you are experiencing severe depression, suicidal thoughts, actions or self-harm we also strongly recommend that you speak to your GP.

- [Samaritans](#), a 24-hour befriending service offering non-judgemental support.  
Tel: 08457 909090.
- [Support Line](#), which offers confidential emotional support to children, young adults and adults by telephone, email and post.  
Tel: 01708 765200.

## 6 Social Aspects of Living with ME/CFS

Managing social life can be tricky, especially if you are housebound. Your friends may often do activities that are beyond the limits of your ability, or cause relapse if you do them. If you need to be visited at home some people may not understand why. You may be in education or employment and have difficulty with lack of understanding from students, teachers, colleagues and employers.

### 6a. Educating those around you about your condition.

i) When you have to say “no” to social invitations, and are not giving them as much because of the limitations of your health, some people can misinterpret this as anti-social behaviour. Even if you clearly state the reasons sometimes people can be doubtful that it’s a good enough excuse if they aren’t aware of the seriousness of your health condition. It can be difficult explaining your condition to people enough to gain a reasonable level of understanding and it can take time for it to sink in as people tend to forget things at first. We encourage you to persevere even if it is very difficult process because its far worse to have hurtful misjudgements and misunderstandings and people pressuring you to do thing sthat you’re not well enough too. There may be some things that can help with this process.

ii) If you have difficulty explaining it orally it may help to write a letter either to an individual or to a group of friends and family.

iii) For accuracy when explaining what ME/CFS is we suggest going to a website like the ME Association for up-to-date info and basing your description on that [www.meassociation.org.uk](http://www.meassociation.org.uk) If people are really interested you could point them to a website about it. Sometimes it’s a good idea to do that anyway because some people will Google for information about the illness and find innaccurate or unhelpful information.

iv) BOUNDARIES. Try to establish fairly clear boundaries about how much you can do socially and then communicate these to your family and friends on a regular basis.



## 6b. Isolation and loneliness

Living with ME or CFS can be isolating because you may not manage to socialise as much as the average healthy person and you may be bedbound and not able to manage many visitors. Even if you are able to see people fairly often sometimes you can still feel lonely if your healthy friends and family have little awareness and/or understanding of what you're going through; and you may feel very alienated. These things can all lead to a lack of intimacy with people as a result.

Carers can be affected by isolation and loneliness in similar ways to those described above.

With patience you may be able to explain more of what you're going through to friends but only if they will listen well.

### Local Support Groups

Many of the people who have got in touch with people at Elevate in various ways have said it has helped them to feel less alone. You may find it easier to form friendships with other people with ME or CFS, or their carers, because they have some degree of understanding and don't make you feel alienated. It's good to try to friend with people in a diverse community - not just people with the same health problems as you - and some of the volunteers at Elevate and carers do not have ME.

## 7. Education and Employment

a) Workplace. If you work you need to be sure that it isn't being detrimental to your health. Your workplace may have a 'human resources manager' or similar person. We recommend you try to explain your condition to them and be clear about the limits of your ability. ME/CFS is covered by the Equality Act 2010 which builds upon the Disability Discrimination Act - a law that provides a number of important provisions in relations to changes that an employer would be expected to make to enable a disabled employee to stay in work or return to work. The MEA has a "Management file" covering all aspects of employment and another about early retirement and how to obtain an ill health retirement pension. Action For ME has produced a both a guide for people with ME in employment and for employers and these are both available in printed or a free PDF download through the [Action For ME website](#).

b) Education. Some schools, colleges and universities are very flexible with the amount of hours that are expected and methods, so it is worth explaining your health problems and limitations to them. They may provide somewhere for you to have rest breaks. You may also be allowed extra time and rest breaks during exams. Long-distance or correspondence courses e.g. Open University may suit you better.

## Further Information

For further information about Elevate, as various aspects of living with ME and CFS, we suggest that you visit the Elevate website. There you will also find links to other sources of information.

[www.elevatedereham.co.uk](http://www.elevatedereham.co.uk)

If you are not able to find the information you are looking for you may contact us @ [elevate@wfcdereham.org](mailto:elevate@wfcdereham.org) which may help us to improve our information.

**07538 801778**

**Please let us know if you spot any  
out-of-date or incorrect information in  
this booklet, thank you.**