

Surviving Severe ME.

by
Claire Wade

Disclaimer

This booklet is written by a person severely affected with ME and is compiled as a result of personal experience and research of other people with ME and their families. It is intended for information and guidance only. It is not intended to replace medical advice. Readers are strongly urged to consult a professional medical practitioner for a proper diagnosis or assessment before trying any of the treatments or medications outlined. As with all medications, always consult your GP, specialist or pharmacist and tell them about other medications or herbal preparations you are already taking; always read the label and patient information leaflet. The contributors to this booklet are not medically trained but all live with or have significant experience of ME. The tips may not be suitable for everyone.

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FORWARD

M.E. is a horrible illness – hard to cope with at the best of times, but when you are severely affected it's a terrifying time. So much is happening to your body that you don't understand and there are only a very few people who really understand what it is like. Doctors, friends and family have enough of a problem with less severe M.E. – they can't even begin to understand what it is like to be severely affected.

Right now you have probably got hundreds of questions, everything from how to deal with the physical symptoms, to how to cope with the emotional ones, that's why I have put together this pack. It contains hints and tips that other people with severe M.E. have found really useful. Not everything works for everybody; but the ideas included may help you to find solutions to your own problems.

Unfortunately there are problems we can't solve, for example coping with the emotions and frustrations – all we can do is let you know you are not alone, that other people have been at this stage and come through it, and you will too!

There are times when it feels never ending, and that this is how you will be for the rest of your life; but with management of the illness and careful pacing, you will get better.

Everybody has bad days or even bad weeks, which seem to last for ever, but with time, the good days will start to take over – you'll start to cope better and things won't seem so bad. You will still have bad days – when you hate the illness, fate and the world. This is only natural; but one day you will be free and this horrible illness will seem like a bad dream.

I'd like to thank everyone for taking their time and precious energy to fill out a form, to help me gather as much information as possible. I am very grateful to them and their carers and hope you will be too. They are all severely affected and they have been through what you are going through now and are all at different stages in their illness.

M.E. is different for every person – no two people have exactly the same symptoms; but by sharing our experiences we can try to overcome as many problems as possible.

If you find out anything else that helps, please send your tips in, so I can include them to help other people. The only way to get through this illness is to talk to people who have been there, and to help those who come after you. Together we will get through this dreadful experience and come through it as better and stronger people.

Hopefully one day scientific research will mean that no-one else has to go through it.

Take care and remember you are not alone. Being severely affected automatically makes you part of a club of very special people, who are there to support each other in any way they can. Our love and thoughts go out to you.

Claire Wade

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Sitting or Lying in Bed

Getting comfortable in bed is very important. It will take time and a lot of experimentation to find what works for you.

Pillows – the likelihood is you are going to need more than one pillow especially if you are trying to prop yourself up. Feather pillows are easier to mould into a comfortable shape (if you are not allergic to them), use a variety of thicknesses to get the desired height. Always make sure you are properly supported, a stiff back or neck will only make matters worse. If lying in bed use pillows under your knees to support you. If you are sitting up in bed you can use a 'V' pillow or alternatively use a stack of pillows with a beanbag on top – the more pillows you use the more you can increase the angle at which you are sitting. This is a good way to build up to being able to sit in a chair again. You can buy foam wedges to put under your pillows available from Boots or an inflatable pillow with an electrical pump from an Occupational Therapist.

Fully supported resting positions

By Kate Sweeney

Physiotherapist at Westcare ME charity (0117 923 9341)



No. 1 Crook Lying

Lie on your back with your knees bent, use as many pillows to support your knees as you feel you need. This puts the lower back in a comfortable and well supported position. Support your head with one or two pillows.

Place each arm on a pillow giving support from behind the shoulder along the length of the arm, wrist and hand.

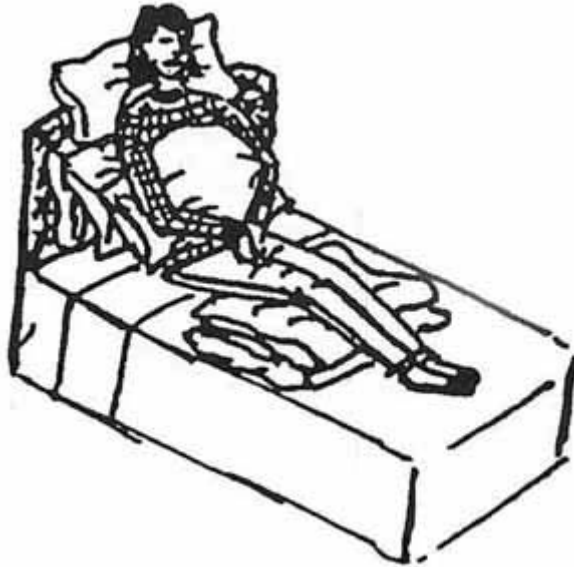
No. 2 side lying

Use as many pillows under the head as required. To support the arm which is uppermost, put a doubled pillow underneath. A pillow is then placed along the length of the back and 'tucked in' a little underneath you. This prevents you from rolling backwards. One or two pillows are placed between the knees and this puts the hips and knees into a position of comfort and prevents the pelvis from rolling forwards.



No 3 Long Sitting

This is the position that people sit in when sitting up in bed. Put as many pillows behind the head as you need to support the head so that the muscles of the neck and shoulder girdle can let go. To further support the shoulder girdle, lace one or two pillows across the front of the chest with the arms rested over the top of these pillows. One or two more pillows will be needed to support the length of the back. Beneath the knees, it is important to have the support of some pillows. If the knees are left in a straightened position in long sitting, it can stress the muscles at the back of the leg.



No. 4 Chair sitting:

Sit in a high back chair with arms. Ensure that the head is fully supported using pillows or cushions if necessary. Some people find a small roll in the lower back supportive, which can be made by folding an 8" cushion in half. To support the shoulder girdle, place one or two pillows across the front of the chest with the arms resting over the top of them. The forearms may be rested on the arms of the chair or lightly placed on the lap. Ensure that your feet are comfortably rested.



InterAction Issues 35- 40 2002 p18 - 20

ACTION FOR M.E. P.O. BOX 1302, WELLS, BA5 1YE, UK
Website: www.AfME.org.uk

**From the CFS Team at Havering Hospital
NHS Trust and BUPA Hartswood Hospital**

Pressure can develop when you lie in the same position for a long time. This is due to lack of blood flow to the affected areas. They can be sore and painful; but are preventable.

Try to change position every two hours, even if you need somebody else to move you. You can buy special pressure relieving mattresses, available from Care Shops. Alternatively there are motorised beds, which can be raised or lowered to change

position without you having to move. These are also good for gradually increasing the angle that you are lying at, which helps when you are trying to get back to being able to sit in a chair. The only problem is the motor noise may be too much for those with noise sensitivity.

Be aware of any numbness or reddening or darkening of the skin as these are the first signs of a pressure sore. If you act immediately by taking the pressure off you can prevent them developing any further.

- Ensure bed clothes are wrinkle free and no crumbs are in the bed
- Sit or lie on surfaces which support and reduce the risk of tissue damage
- Do not rub or massage the skin
- Keep the skin clean and dry. Do not use excessive amounts of skin or talcum powder
- Do not use creams or ointments without consulting your doctor or nurse.
- Protect elbows and heels by use of special garments
- Protect skin from friction

If the skin becomes broken you will need to have it dressed, contact your local nurse.

For minor redness and soreness use “Sudocrem” available from chemists. This can sting to begin with; but the pain soon wears off.

For more advice visit the Tissue Viability Society at www.tvs.org.uk

If your pressure sores get infected or you are continually developing them, seek medical advice.

If you have problems raising yourself into a sitting position, rope ladder bed hoists are available from Boots. These are strong nylon rope and white plastic runged ladders, which fasten to the end of the bed legs and lie over the top of the bed, enabling you to pull yourself into a sitting position.

In a sitting position you might find it easier to prop yourself up on either side with pillows, so that you can then rest your elbows and arms on them. Sheepskin rugs are advisable covered with a folded pillowcase, to stop pressure sores developing. It's advisable to use a moisturising cream on your elbows as this stops the skin drying out and breaking.

You can get a range of pillows in different shapes, sizes and materials. V-shaped pillows and pillowcases are available from www.thewhitecompany.com and www.toysrus.co.uk Argos and Rosebys.

Also recommended are full-length body pillows. Available from www.safefoam.co.uk and www.dreamgenii.com

For organic body pillows www.madeinwater.co.uk Cushie pillows are soft and easily mouldable. www.firebox.com

Chillow Pillows are pillows which act as cooling pads. Fill them with water which is fully absorbed into the foam core, leaving it completely dry. Once activated, it will keep on working, so it's always ready for use whenever you need it. It does not use power and is allergy free. Good for hot flushes, fevers, night sweats, headaches, eczema, muscle/joint pain.
www.soothsoftshop.co.uk/

A lot of people with M.E. find the pressure of the blankets whether sitting or lying is too much for them and causes their legs to ache. Frames are available from your GP, OT or medical suppliers e.g. Boots, Disability Living etc.

If you have been confined to bed for a long time, constantly in the same position, then you may suffer from dizziness when you try to change the position that you are used to i.e. if you have been constantly lying down and you try to sit up or alternatively if you have nausea and have been propped up all the time when you try to lie down.

The best way to overcome this is to gradually practice sitting in the new position for as long as you can manage. This may only be for 5-10 seconds at first. Try each day sitting or lying in the new position and gradually the time will increase – *don't try to push it!* It will come in time.

Lying in bed means the muscles in your legs aren't being used and so they will waste away. Some people try to have physiotherapy regularly or practise gentle exercises so this does not happen. Many people will tell you that you should do this; but it isn't the solution for everyone. Even gentle exercise can be too much. Don't push yourself, it's not worth having muscles that work when you are too ill to get up and use them.

Another concern is that you may develop Osteoporosis if you don't keep walking around. As yet there has been no research on this in ME patients. Don't let this possibility worry you as there are more important factors to think about at the moment. When you are able try to eat calcium rich food.

If you do decide to have physiotherapy make sure you find someone who is sympathetic and understands ME. **NEVER** let anyone push you into doing anything that you are unhappy about doing. It's your body and you know what's best for it.

If you are too ill for physiotherapy don't worry. When you start to become mobile again your muscles will gradually return. The most important thing is to slowly build up your activity level over a period of weeks and months.

Whilst being severely affected it is more important to be comfortable and relaxed – any unnecessary stress/pressure will only make your condition worse.

Washing and Toileting

Washing and toileting when you are severely affected can be really hard. It requires a large amount of precious energy without much to show for it.

Society makes us think that if we don't wash or bathe at least once a day we are dirty and unclean. This simply isn't true. The body has a way of cleansing itself and although it does not sound pleasant it is fine to go for at least a month, if not more, without washing your body.

Seeing this in writing will shock many people – it takes a lot to get over the normal mindset; but when regular bathing is causing you to slide further and further down the ability scale you have to work out your priorities.

Body Washing

Depending on whether it is possible to go without washing for over a month. If you have the energy in between times you can use facial cleansing or baby wipes. There are now deodorising wipes available; but they are scented and may be a problem if you are suffering from nausea. For a more thorough wash use a bowl of warm soapy water or alternatively use liquid soap. You can then wash with a flannel or sponge. Severely affected at a very low ability will find this impossible to do for themselves.

It can be very embarrassing for a parent or carer to wash you; but to minimise on this embarrassment use a towel, warmed on a radiator, to cover you up as much as possible. This also helps keep you warm. It's a good idea to keep your top or T-shirt still on, on one side of your body, while washing the other side, so as not to get too cold.

Cream deodorants are a good idea – they can be cool but not as cold as spray deodorants and aren't sticky like roll-ons. They also don't smell too strongly.

Deodorant that can help with sweating armpits include Mitchum and Driclor. However some people find them painful and itchy.

If you can cope with scents then it can be nice to use different body sprays, to make you feel special.

If you are well enough to reach the bathroom make sure there is a chair for you to sit down on and that everything is easily in reach. There are special hoists for getting in and out of the bath – see your O.T, The Red Cross or Boots. Use non-slip mats in the bath. It may also be an idea to fit rails in the bathroom. There are also special chairs available for sitting on when in the shower. Always make sure there is someone around to help you when taking a bath.

Using the toilet

This topic is a very hard one to write about – society has conditioned us into feeling embarrassed about basic bodily functions. Even having been through this, it is still very hard to talk about; but it is a very important topic.

If you can get up but are unable to keep walking to the bathroom, then a commode beside the bed is invaluable. They are available from your O.T. or all good Care Catalogues and shops. They vary in price and design.

You may find you need help getting out of bed and sitting on the commode. To begin with it feels degrading; but you soon get used to it.

Sometimes you can put the commode right beside the bed and you may be able to use the handles to manoeuvre yourself on to it with your legs remaining on the bed. This can be helpful if you are unable to stand or it's painful to put your legs downwards.

Keep a bowl of water and soap by it to wash your hands in. It is possible to wash your genitals whilst you are on the commode with a damp tissue or a jug of water.

You can get special moistened toilet tissue instead of having to use ordinary toilet paper or soapy water.

When you need to pass a bowel motion, place a layer of toilet paper or water on the bottom of the commode bowl – this makes it easier to clean. Anti bacterial or antiseptic wipes help when cleaning. After it has been emptied get a parent or carer to strike a match because it gets rid of the smell. It is advisable to empty the commode regularly, washing round with water and then adding some disinfectant that you can leave in the bowl. Sainsbury's disinfectant is good, as it does not smell too strongly. Also use antibacterial or antiseptic wipes to wipe the seat and lid, both on top and underneath, every so often, leaving the lid off and the bowl out, to air for a while.

If you can't get up to use a commode, then there are special bed bottles and pans that you can get. These can be used while still lying down. There are special male and female ones, available from Care Shops.

You can get Vernagel which turns liquid to gel, which will really help if you're using it on your own.

Keep a commode nearby to put the bedpan in when you're done if there's no one to collect it. Have something to cover it up and baby wipes nearby.
www.youreableshop.com

Use plastic/waterproof sheets on the bed. Alternatively talk to your OT about Kileys, large washable pads, which can be used instead.

You can wear Staydry pants to avoid leaks, available from Boots.

At the very worst stages your doctor may decide to catheterise you. This proves a very good option for some people because it saves a lot of energy.

If you can reach the toilet, even if it is just occasionally, you can get a seat to go over the toilet, which raises it, and it also has handles to help you get on and off easily.

Visit this shop for toileting aids.

<http://benefitsnowshop.co.uk/shop/area.asp?area=11>

Constipation

Some severely affected people experience constipation due to the lack of fibre in their diets. This can be very painful and it is worth contacting your GP or seeing a pharmacist about a gentle laxative.

Prunes are a natural laxative and can be bought from supermarkets dried, tinned or as juice. Figs are also a good option.

You can buy "Fybogel" to drink or add to food, which helps bulk up your diet without having to swallow large amounts of fibre. "Anusol" cream is available from chemists if passing motions is painful.

Periods.

Periods can be greatly affected by severe ME. They may stop altogether or become irregular; but don't worry they will return to normal as you get better.

The hormones released before and during your period can greatly affect your mood and symptoms, a combination of PMS and ME is incredibly hard to deal with; but don't worry everyone has it. Unfortunately like everything else there is no simple solution. Some people find it useful to take the Pill for a while, so that they only have a period every three months or so, which helps their moods and symptoms. Talk to you doctor about this.

It's a good idea during the time of the month to wear two pads overlapping from front to back so you don't leak when you are lying down. Also place a dark towel on the bed, which can quickly be changed if necessary.

Shaving.

It is often important for men to keep shaving because their faces feel itchy. This feeling does go away once you get used to having a beard but psychologically it can be very hard to get used to.

Women also sometimes feel the need to remove excess body hair and both genders have to weigh up the pros and cons of shaving.

Shaving can be difficult especially if the severely affected person needs somebody else to do it for them. An electric razor is easiest but the noise might be a problem, so experiment with wet shaves. Approach a relative or carer for help and advice.

Teeth.

It is important to keep brushing your teeth when you are severely affected, otherwise you can develop cavities and painful abscesses, which will cause extra problems. If you are too weak to brush your teeth then get your carer to do them for you. An electric toothbrush is effective; but is also very noisy, so you may want to stick to having them done manually. Use a toothpaste and mouthwash high in fluoride, ask your dentist to recommend one.

Oral B Brush Aways are teeth wipes that are like a little finger glove that you slip on and rub over your teeth. They require no rinsing or water and you can wipe teeth, gums or tongue. They remove that 'gritty' feeling and can be used lying down. www.expresschemist.co.uk/Oral-B-Brush-Aways.html

If you do have problems with your teeth, it is your right to have a dentist visit you at home. If you need a filling they will probably put in a temporary glass ionomer one. It won't last forever and may need replacing but will be easier to have done if you can't go to a dental surgery.

Remember to explain your illness to the dentist. Also talk to them about a procedure called Ozonation. This is a new practise where the teeth have a small cup placed over them and are covered in a special gas which kills off any bacteria, slowing down the decay until you are ready to have proper dental work done. It is painless and the only problem is the noise the machine makes, which can be combated with ear plugs. The machine is portable so you can have it done from home.

Hair.

Everyone's familiar with how their hair feels if they have not washed it for a couple of days, that itchy uncomfortable feeling – it makes you long for shampoo! The amount of energy it takes to wash it though is too great for many Severely affected people. The only advice is to try and forget about it, within a couple of weeks the feeling goes away and you feel just like normal. Although your hair does look a little greasy, it's more a sleek look, rather than the way it looks after just not washing for a couple of days.

Your hair might seem a lot thinner and will break easier; but don't worry your hair is not all going to fall out! This can be a subject of great anxiety because everyday more hair seems to be breaking; but after a while this will slow down. No damage has been done to your scalp so it will grow back in time. Hair needs a good diet and exercise to grow properly, so it's clear why you are having problems at the moment. Once both factors improve so will your hair.

You may find you have got little white bits in your hair – don't worry it's probably not head lice – this is a favourite trick of hospitals to get you to wash your hair! It's more likely to be dandruff. Because you aren't washing regularly, it stays in your hair. This too will go away when you start washing again.

If you do want to wash your hair whilst you are in bed here are a few ideas: Dry shampoo available from most chemists or a special inflatable sink can be used at the end of the bed – available from www.activemobility.co.uk .This is actually a lot easier

than it sounds. Place the sink on a low table or a couple of stacked boxes at the end of the bed, or even directly where the pillows normally go; but make sure to use lots of towels. Then lie with a towel over the bed and one around your shoulders. You may want to have a plastic sheet on the bed and wear a towelling dressing robe to catch any drips. Also have a flannel you can put over your eyes to keep the shampoo and water out.

The sink has a plug and pipe that run off it and if you place the pipe in a bucket you can catch the water that comes out. Have two basins of warm water standing by and get your carer to use a plastic jug to pour water onto your hair. Go through the normal hair washing, possibly sitting up to put the shampoo on if you are able, and then rinse.

You can use natural bristle hairbrush which naturally cleans the hair by spreading the natural oils and removing the dirt from your hair. Available from www.kentbrushes.com you can just use warm water and not do it very often.

Going without a hair cut isn't a problem for girls but can be hard for boys/men to accept. If it becomes a problem contact a mobile hairdresser and get them to do a quick, dry cut.

This whole part of the M. E. is incredibly unpleasant and degrading – it's something that nobody should have to go through, but I hope that the above tips will make it slightly easier for you to get through.

CLOTHES, KEEPING WARM AND COOL.

When you are severely affected you may find that your body temperature seems to go out of control. Rocketing from freezing cold to boiling hot. The best way to control it, is to have lots of easily removable layers. Pyjamas and loose track suits are good, especially those with buttons or zips down the front of the tops.

You can wear cardigans back to front – this makes them easier to put on and take off and keeps your front warm, especially if you have problems putting clothes on over your head.

Make sure the material is soft and comfortable – cotton, fleece or satin. Clothes should be comfortable and loose fitting – nothing that cuts off the circulation when lying in one position. You may choose just to wear a few clothes and have the heating up high.

You may also find that your extremities get very cold and refuse to warm up i.e. your hands and feet.

Feet.

It's a good idea to wear thick socks, sometimes more than one pair. It's important that the socks don't cut into your legs, cutting off the circulation. You can get special non-elastic socks from:-

Bradford Place
Simplantex Direct Ltd
3 The Park Close
Comptons Park Road
Eastbourne
E. Sussex
BN20 8AG
01323 749994

Clayton Socks
17 Oakleigh Ave
Clayton
Bradford
BD14 6QE
01274 883833

H J Hall Flysafe Socks
Country Threads
The Gatehouse
Rake
Liss
Hants
GU3 7JH
02392 632060

Hands.

You may have to resort to wearing gloves, although this reduces the amount you can do with your hands. You can wear one glove on one hand leaving your dominant hand free to do things. Totes do gloves with grip strips, which give you extra control and grip. Gloves come in various materials and sizes, it's a case of trial and error to find out what's most comfortable for you. Muffs can be good because you can easily slip your hands in and out.

It's worth stocking up during the winter period as you may find you still need them during the summer, when you can't buy them easily.

Heads.

Your head can also get very cold, even during the summer, so you can either wear a hat or you can wear a fleecy jacket with a hood. Available from most mail order places, again stock up in the winter. If you get one with a full-length zip it makes it easier for the summer.

Scarves are good to keep your throat warm and you can get nice soft ponchos or shawls for when you are really cold. Look out for spring sales when winter clothes are reduced.

KEEPING WARM

- Hot water bottles, no matter what time of the year, are essential. You can have one for your feet and one for your hands.
- Have lots of water bottles so you can rotate them, allowing one to dry out before reusing it. Always keep an eye on the rubber, as continual use can cause it to wear and a burst water bottle in bed is a nightmare!
- If you wake up when people aren't around to make water bottles, you can get your carer to leave them in a thermos/refrigerated bag, as well as keeping lunches cool, they also keep hot things hot. This method may require being able to get out of bed and lift them though.
- Wheaties are good too – these are bags full of wheat that can be heated in the microwave and act like hot water bottles.
- You can get gel packs which have a capsule inside which when squeezed causes heat to be produced, they can be boiled and reused. Available from Boots or Argos.
- You may need to have lots of blankets on you bed – these can get quite heavy though, so you can get a blanket cradle available from care shops, or alternatively you can use a laundry basket placed on it's side at the end of the

bed with the covers over it and the hole facing you for your feet to poke into. The blankets lie over the top keeping them from pressing on your legs.

- John Lewis sell some nice soft fleecy blankets.
- Sleeping bags can also be good when opened out. This covers a larger area on the bed, stopping cold air coming in through the gaps at the sides of the duvet.
- Electric blankets are another alternative for warming the bed, but some can be quite heavy.

KEEPING COOL.

For some people this can be as much of a problem as keeping warm. If you can cope with the noise electric fans are good, especially if you can adjust the speed. Try and have a window open as much as possible.

- Use a water spray filled with cold water (like the ones you use to water pot plants!) to spray your face and body.
- Have someone sponge you.
- Magicool – this is a spray that can be bought at places such as Boots and also www.coolcomforts.com It is sprayed directly onto you, which not only cools you, but also the air around you.
- Dip your wrists in some cold water. This will cool your blood, which therefore cools your body as it travels around.
- Small portable air conditioning unit from B&Q.
- Soft pliable icepacks that are put in the fridge and can be reused.
- Wear as little as possible and keep calm and relaxed!
- Put a sheet in the fridge and when cool use instead of a duvet.
- Put your feet in a bucket of ice cold water.
- Wheat bags can be put in the freezer and then used to cool you down.

Don't worry, your temperature won't always be this strange; as you get better it will too.

PAIN CONTROL

Unfortunately pain is a horrible stage that most people go through. At different times in your illness your pain levels may vary. Don't worry if you can't find anything that really helps, it will slowly get better. Generally doctors agree that the pain is in the brain rather than in a specific muscle or joint, which is why normal painkillers don't tend to work.

Some tablets that people have found useful are:

- Anadin Extra
- Tramadol
- Co-Proxamol
- Ibuprofen
- Co-Dydramol
- Amitriptyline
- Paracetamol
- Calpol
- Disprin – junior or adult

ME sufferers react differently to different drugs, some severely affected people are very sensitive. It is always advisable to start treatments on very low doses and build up. When coming off long-term medication always reduce the dosage over a period of weeks rather than days, to reduce symptom flare-ups.

Non-Drug Treatments

- Heat can help with specific areas – a hot water bottle, a “wheaty pack” heated in the microwave, or possibly a bath. If you have specific muscle pains you can direct a shower head onto the area, spraying it with warm water, possible even alternating with cold water.
- Evening primrose oil.
- Tiger balm available from most chemists to rub on painful areas, this can sting though.
- Tens unit. This is a machine that delivers small electrical pulses to an area of your body via electrode pads.

For headaches make sure your head and neck are supported. You can realign your neck by placing one hand on your forehead, the other on your neck and breathe deeply.

- Migra stick – a homeopathic substance in a vial, which you hold against your head.
- 4head stick – a stick of lotion which you rub on your forehead.

- There is a pressure point on the hand, which can relieve headaches. Choose the hand for the side of the body which is hurting. Make an 'L shape' with your thumb and forefinger. Squeeze the skin point where the two fingers meet, with your thumb and forefinger of the other hand. Hold for a minute and then gently release. Repeat for the other side, if the headache affects your whole head. This can be painful; but the benefits are worth it.
- Small gel strips used for relieving a child's fever can be placed on the forehead because they don't drip like a flannel.
- Steam inhalation for sinus problems.

You will find different people find different drugs and treatments helpful; but the main advice is to try and stay relaxed. If you get too stressed and tense, you use up valuable energy, which makes it worse. Try to distract yourself – many find relaxation breathing helps.

Breathe in slowly through your nose and out slowly through your mouth or nose depending which feels best.

Visualisation is also a useful tool. You can imagine the pain as a colour inside you, say black or red and imagine breathing it out on the out breath and breathing in a colour representing peace and happiness on the in breath, say blue or white. Or just use the breathing out for pain and in for comfort, if the colour takes too much concentration.

Alternatively imagine the pain is a ball, balloon or large coloured cloud and visualise yourself throwing or releasing it into the sky, watching it drift further and further away.

Please remember you should consult your G.P. or specialist with regard to medication as these tips come from sufferers and not trained doctors. What suits one person can upset another.

ANXIETY, RACING BRAIN AND BRAIN FOG.

Every severely affected person has times when their brain seems to go out of control, whether it is racing from thought to thought or making you feel stressed or anxious worrying about the slightest little thing.

It is very unpleasant and uses a lot of energy because proper rest is not possible and the tension in your muscles also makes you tired.

Here are a few things that have been found helpful: -

- Deep breathing in and out of the nose concentrating on the sound of your breathing and the movement of your diaphragm (just below the rib cage).
- Distraction – if you are able to do something – even if it is sticking one sticker on a card or doing something that you enjoy for a short while. This shifts the focus of your mind. After the activity try not to let your mind go back to the anxiety – force yourself to think about something else and keep forcing your mind away from the anxious thoughts each time they reappear. This is very hard to do at first and it feels like the anxiety will never leave you but with time it gets less and one day you realise you haven't been stressed in quite a while.
- “Emergency Essence” or “Bach Rescue Remedy” or “Five Flower Remedy”. These drops taken in water and sipped slowly at times of anxiety, stress or upset help to calm down your mind, nervous system and muscles and work very quickly.
They can be obtained by mail order from:

Neal's Yard Remedies
29 John Dalton Street
Manchester
M2 6DS
0161 8317875
www.nealsyardremedies.com

- Aconite is a homeopathic substance, which comes in small tablets that you suck. It is also good for nausea.
- Neal's Yard also do “Ready to Roll Aromatic Essential Oils” – the one for night time smells of lavender and when applied to the pulse points on the wrist helps to relax the body and mind very quickly.
- There is a calming acupressure point in the middle of the left hand. To find it make your left hand into a fist, locating where your middle finger ends, then open your hand and using the thumb of your other hand press on the located point firmly for a minute.
- When your brain is spinning or is stuck repeating thoughts over and over again try either “White Chestnut Bach Flower Essence” or “Calm and Clear

Australian Bush Essence” either dropped into the mouth with the pipette or sipped in water to help relieve the unwanted thoughts. The “Ready to Roll Remedy” also helps in this situation.

- The “Calm and Clear” and “Emergency” Australian Bush Flower Essences are also available in a mist spray from:

The Nutri Centre at Tesco's
7 Park Crescent
LONDON
W1
0800 9121163
www.nutricentre.com

- Around the time of the month if you experience mood swings try Woman Essence available from Neal's Yard and The Nutri centre to help calm the moods.
- Some people suffer from hallucinations when they are very tired. This can be frightening and unfortunately there is not much that can be done to overcome this. Try to stay calm and if you are able, tell your carer what is happening and get them to sit with you until the hallucinations pass.

Brain Fog

Brain fog can be a frustrating and scary experience; here are a few suggestions on how to cope with it.

1. Repeat it to yourself. Repetition will keep thoughts fresh in your mind.
2. Write it down. Whether you or someone else writes it on a calendar, in a notebook, on sticky notes or record it onto a Dictaphone.
3. Explain your memory difficulties to family members and close friends. Ask for patience and understanding.
4. Relax, the more stressed you get the harder you will find it to remember.

INSOMNIA.

Insomnia is a horrible symptom of M.E. that most sufferers, no matter what ability, experience at some point. With severely affected people this can be an ongoing problem.

There are two main approaches for dealing with long-term insomnia. One is to get someone to wake you up at the same time every day not allowing yourself to sleep during the day (this does not mean stop resting). This means you should be tired enough at a normal bedtime and that your sleep pattern stays the same as everyone else's. Unfortunately this doesn't always work.

The second approach is to allow your body to sleep as and when it needs to, thus taking the pressure off having to get to sleep. This may mean you will experience a shift in your sleep pattern. You may start getting to sleep at 1, 2 or 3 in the morning and waking up at lunchtime or early afternoon.

Alternatively you may find your sleep cycles – this means that each day you go to sleep an hour later and then wake up an hour later the next day. Therefore for some of the month you will sleep through the night; but for some of it you will sleep during the day and be awake at night.

This can be very hard on the sufferer and the family, but like many of the M.E. symptoms can't be controlled. Even if you are woken up at a certain time your body may still refuse to go to sleep at a certain time.

Dealing with Insomnia

Everyone has been there – you're lying in bed feeling tired and just about to drop off when suddenly your brain goes into "hyper mode" – suddenly you're wide awake! You can feel time passing and as the hours tick by your body gets tenser and tenser. The thought keeps going through your head – I'm ill, I'm tired and I should be asleep, I'm probably making myself worse, I'm going to suffer for this. Your heart starts beating faster and faster and your brain won't be quiet. What do you do?

The main thing is to try to stay relaxed, as hard as that may be. Like nausea or pain you cannot force your body to stop doing it. It will sleep when it's ready, you can't control it.

The one good thing about being bed bound is that you don't have to get up in the morning. Therefore you can sleep in as long as you need to and may fall asleep during the day as well. Unless of course you are trying to follow the first approach going to sleep and waking up at a certain time each day. If you have had a really bad night you might like to leave a sign e.g. throw a cushion into your doorway, or write a message to ask not to be woken up. Give yourself permission not to go to sleep. Tell yourself that you are going to stay up all night and not sleep at all. Crazy as it may sound you find that the pressure has been taken off you. So use your relaxation techniques everything from the flower essences and roll-ons to the meditation breathing. Remember if you stay relaxed and lie with your eyes closed you are still resting.

If things are getting too much try and break the atmosphere – do something you enjoy. Forget that you are trying to go to sleep.

There are a few herbal tablets that people have tried to help with their sleep e.g. St John's Wort, Serotonin 5HTP, Melatonin. Some severely affected people have found that they have helped them get enough hours sleep. The melatonin has been used to push back the time they are getting to sleep; but they sometimes find a point where they can't push their sleep back any further.

Melatonin can't be bought in this country; but you can have it shipped from the USA where you can buy it over the counter.

You can order it on: 00800 89238923
or at www.pharmwest.com

Please ask your doctor or pharmacist before trying any of these products, especially St John's Wort because it can react with other drugs.

Above all remember you are not alone. While you are lying there trying to get to sleep, there are other severely affected people across the country going through it as well.

As your body gets better your sleep will improve and one day it will all seem like a bad dream!

SENSITIVITIES.

When your body is so sensitive to everything even the slightest stimulant can seem unbearable. Sometimes it is impossible to cut these out of your life completely; but you can cut down on them

LIGHT SENSITIVITY

It is advisable to use a combination of the following tips. You may still need dark glasses, even in a darkened room.

- Thick curtains with blackout linings
- Blinds – Venetian ones are particularly good for increasing or decreasing the amount of light. Alternatively stick opaque paper over the windows.
- Dark glasses – these can be normal sunglasses; but many people have a problem with light coming in round the sides – a solution is wraparounds or specially designed sunglasses from

SolarShield
Arcade
PO Box 213
Dover
Kent
CT15 4GA

- You can also have blue tinted glasses, like the ones used for dyslexics. Irlen UK 0207 736 5752 www.irlenuk.com. Also available from opticians.
- Eye masks - these are material masks with a dark lining, which are attached by elastic round your head and are good to help you sleep or just to cut out all light when resting. Some people find the elastic round their head hard to get used to; but after a while the elastic relaxes a bit and it feels less tight.
- Using a torch – this may be easier on the eyes than normal room light and allows you to look at things in more detail e.g. cards and letters etc.
- If you can cope with a small amount of light then you could have a dimmer switch installed, so you can gradually increase/decrease the light in a room.
- Soft lights like lava lamps in pale colours can be nice to watch if you can cope with the movement. If not place them out of view; but still allow them to light the room softly.

Some people get so weak that they are unable to open their eyes at all because their brains cannot cope with even the slightest stimulation. As with everything this will go away eventually.

NOISE SENSITIVITY

Noise sensitivity can be very hard to live with because even the slightest noise like the rain or someone talking in another room, can be too much. It is often hard to cut out all noise, especially if it is coming from outside; but there are ways to reduce the problem.

- Foam Ear Plugs – these can be bought from any good chemist and also from displays of travel aids in supermarkets or large stores. Try different brands to see which are most comfortable.
Mark the base of the left earplug with a biro dot so you can tell which one is which.
Ear plugs are available from www.fastbikebits.com
www.tooled-up.com www.amazon.co.uk
- Alternatively you can buy noise-cancelling headphones. You can switch this on without having to plug them into a stereo. They are sold mainly to cut out aircraft noise when flying. severely affected people have found they work well to reduce sounds such as hoovers, lawnmowers and drills but don't reduce all types of sounds. They can be good if you find ordinary headphones and earplugs exaggerated body sounds through bone conduction. The Bose headphones are lightweight and extremely comfortable to wear. There's a slight white noise hiss but some find this quite calming. www.bose.co.uk
www.iheadphones.co.uk
- Ear defenders are another option, although sometimes the plastic ones can pick up motor vibrations and make them worse.
- If you live in a semi-detached house or flat and noise from next door is a problem – then put heavy furniture, thick rugs, carpets and curtains round the room to absorb next doors' noise.
- If there is space in the house to change rooms many people find this is the best solution – this is obviously influenced by the routine of other members of the household.
- Ask family members to keep the noise down, get them to talk as quietly as possible, and as far away from your hearing because it is extremely difficult to switch off from surrounding sounds when you are resting, no matter how quiet. They may have to resort to whispering or writing things down.
- Put plasters over doorknockers and disconnect outdoor bells to avoid loud interruptions. Put up messages for deliverymen to leave parcels in a specific place, so they don't need to knock.
- Turn down the noise on telephones. You can get a special service from BT, which means you can turn the ringing off and an automatic answer phone takes messages, which can be picked up at a convenient time. You can also

set it so that the phone only rings for a short time before the answer phone switches on.

- Suggest that people listen to music or possibly even the television using headphones. You can get special ones without leads. Make sure you explain the problem to them, so that they understand you are not just trying to be awkward.
- If you can cope with a little soft music, you can put it on to block out surrounding noise; but listening takes energy so try and have periods of complete silent rest. It is an idea to use headphones because they contain the sound, making it more confined. Try using earphones; but just in one ear because it reduces the amount of stimulation you receive.

TOUCH SENSITIVITY.

This is a very difficult symptom to live with and there is little that can be done. The main approach is to reduce contact with the affected areas.

- Wear as few clothes as possible, keep the heating turned up all the time.
- Use a blanket cradle to keep bedclothes off the body.
- Holding severely affected hand, although comforting can get very tiring and painful. Allow the severely affected person to place their hand on top of yours.
- If you have carers in, draw a diagram of wear the severely affected person can't be touched due to sensitivity. Do this for both the front and back of the body.

SMELL OR CHEMICAL SENSITIVITY

Sensitivity to smell can be very hard to live with as it is hard to cut out all smells, whether they are from the garden or come in on people's clothing.

Make sure people who come into the house use non-scented products like those made by Simple or Avon. Ask them not to wear perfume or aftershave. This can be difficult if you have lots of people coming to the house e.g. carers but try to explain the problem to them.

An air purifier can help with allergies, including hay fever and also remove smells. They are available from Kelkoo and Argos.

Keep doors and windows shut to keep smells out of the person's room and in the room they are coming from. Open the windows within the room to air the smell out before opening the door and allowing the smell to penetrate the rest of the house.

Keep the kitchen door closed to trap cooking smells and always keep lids on pans. Have a window open to extract the smell. Try to cook things that cook quickly and don't give out a strong smell.

Wash new clothes and bedding before using to remove the chemical smells. Lakeland do a Wash-It Laundry ball. This is a washing ball for the washing machine, which cleans without using a detergent.

There are a number of shops which now stock eco-friendly and chemical free products, great for people with sensitivities.

The Healthy House sell products which are good for people with smell, chemical, electrical sensitivities, S.A.D, allergies, asthma and eczema, including a range of cleaning products which don't smell, air purifiers and non-smelling.

The Healthy House Ltd
The Old Co-Op
Lower St
Ruscombe
Stroud
Glos
GL6 6BU

01453 753533
www.healthy-house.co.uk

Alternatively try Ecover cleaning products, wash powder, washing up liquid etc and E-cloths with water to clean glass/mirrors. Available from some leading supermarkets.

Bio-D cleaning products are chemical free, Faith in Nature Shampoos and Jasons toothpaste, face cream etc, all available from <http://www.honestycosmetics.co.uk>

Non perfumed deodorants without chemicals can be found at health shops and Lush www.lush.co.uk

Green People have a range of products. www.greenpeople.co.uk
Marks and Spencer's have also brought out a natural range. www.marksandspencer.com

Natural odour free paints can be bought from www.eco-paints.co.uk

NAUSEA.

Nausea is a difficult condition to live with but here are a few suggestions to help ease it.

- “Seabands” that people use for travel sickness can be bought at a chemist. It is advisable to take the Seabands off for a while each day, otherwise they can make your wrist sore.
- The Seabands work on a pressure point, which you can apply pressure to, with a finger. Press three finger widths below the crease on the inside of your wrist, between the two tendons, for two minutes.
- Ginger – capsules to take or make into a tea (or just to smell if feeling very nauseous)
 - ginger biscuits to nibble
 - crystallised ginger nibbles
Lakeland Ltd Mail Order
015394 88100
www.lakelandlimited.co.uk
 - ginger ale to sip

These can be hard to take; but are worth a try.

- Nux Vom homeopathic pills to suck – Nelsons 6c sold at some chemists and Natural Health stores, suck 1 or 2 every hour or as needed.
- Aconite homeopathic pills also to suck – these also have an anti-anxiety property.
- L-Glutamine powder or capsules from health food stores e.g. Holland and Barrett.
- Weleda – Melissa Comp dissolved in water from Natural Health Stores.
- Domperidone and Clyclazene (Valoid) Tablets available from chemists or prescribed by your doctor. Only take ¼ tablet at first and build up the dose, because of severe M.E. reactions to drugs.
- Nabilone is also a very good drug for nausea; but because it is a cannabinoid extract it can only be prescribed by specialists via hospital pharmacies and is very expensive so many doctors are reluctant to prescribe it.

The most important thing is to KEEP DRINKING to prevent dehydration see the section below on Making Eating and Drinking Easier.

Eating & Drinking

Eating is such a normal part of everyday life that you take it for granted until you are unable to. ME can affect your digestive system in the same way it does other parts of your body, causing pain and fatigue. Even the smallest meals can be exhausting. Look for foods that are easy to eat and digest. It can be very hard having to live on the same food; but with time you will be able to eat more. For the moment try to be creative.

The food that Severely affected can manage varies from person to person. Generally your body craves the things it needs – so listen to it! Even if this is just having chocolate nearly all the time.

Some people manage to eat crunchy crispy foods that go down to nothing and are then easy to swallow. Others have one piece of normal food e.g. a sandwich or a piece of cake, which they can slowly eat throughout the day, so they don't have to sit up for long periods. If you have problems swallowing and digesting food, due to the muscles in your oesophagus/throat or stomach, then you may only be able to manage liquids like soup, yoghurt, milkshakes/smoothies or fruit/vegetable juices.

Small meals little and often are good. Food takes energy to digest as well as to eat, so rest after every meal. Some foods take more digesting than others, particularly red meat, rich food and anything with lots of additives. Some people find it helps staying off these.

Your carer can make simple, easy to swallow meals by cooking a casserole of meat (optional if your vegetarian) and vegetables. If you can't swallow solid food then you can just eat the gravy or you can blitz it in a blender/food processor. You can get handheld ones, which are useful.

When pureeing food keep different items separate and lay them out on a plate in separate sections the way you would normal food. Try to make it as attractive as possible.

Babylicious make a range of frozen baby foods, which are a good ready to heat option. They are available from Iceland. Check on their site for other stockists and information on the areas covered by home delivery. www.babylicious.co.uk

People with swallowing problems may need extra liquids to help food down. Serve everything with gravy or soup. Try a range of packet soups, sauces and gravies to add variety.

Some people have problems with starch grains scratching their sensitive throats, so you can avoid using potatoes or anything you have problems with. If you don't have this problem then rice, potatoes, pasta or dumplings can be added to cook in the casserole to add a bit of variety.

Mashed potato and other vegetable purees can be a good soft meal.

Cheesy Mash

Cut 900g floury potatoes into chunks. Place them in a pan of water and boil for 20 minutes, or until tender. Drain and transfer to a bowl. Add 2 crushed garlic cloves and 1/3 cup (80ml) cream, and mash, and then beat until fluffy. Season well. Stir in 300g grated Gruyère or Cheddar and beat again until the cheese is melted. Season to taste. Makes 1½ cups (500g). Serves 4.

Creamed Spinach Puree

Wash well and roughly chop 1kg Spinach. Heat 60g butter in a heavy-based pan and cook the spinach over high heat until it is wilted and the liquid has evaporated. Place in a food processor or blender with ½ cup (120ml) cream and purée until smooth. Season with salt, pepper and nutmeg. Mix everything together well and serve. Makes about 2 cups (500g). Serves 4.

Pea Purée

Melt 50g butter in a pan over low heat and add 2 crushed garlic cloves. Stir briefly and then add 500g frozen peas and cover. Increase the heat to moderate and shaking the pan occasionally, cook the peas for 5 minutes, or until they are tender. Mash with a masher or food processor. Season well. Makes about 2 cups (500g). Serves 4.

Roast Pumpkin Purée

Preheat the oven to moderately hot 200°C (400°F/ Gas Mark 6). Remove the seeds from 750g pumpkin and cut into pieces. Place them in an oven tray, brush with olive oil and roast for 35 minutes, or until the pumpkin is tender and the edges are a little blackened. Remove from the tray; cool slightly, then peel off the skin. Place in a food processor or mash with a masher until you have a purée, then add ¼ cup (60ml) sour cream. Season well. Makes about 2 cups (500g). Serves 4.

Beetroot Purée

Preheat the oven to moderate 180°C (350°F/ Gas 4). Wrap 500g unpeeled beetroot in foil and bake for 50 minutes, or until they feel soft to the touch. Cool, then peel off the skin and cut into pieces. Fry 1 chopped onion in 1 tablespoon olive oil until soft, but not browned. Add the beetroot and 1 tablespoon balsamic vinegar and stir until heated through. Mash with a masher or in a food processor, then stir in 2 tablespoons cream. Makes 2 cups (500g). Serves 4.

Butterbean and Rosemary Purée

Heat 2 tablespoon olive oil in a pan over a low heat and add 2 crushed garlic cloves. Stir briefly until softened then add 4 x 300g cans drained butter beans and 2 tablespoons chopped fresh Rosemary and cook until heated through. Season well, then mash with 2-4 tablespoons olive oil, until smooth. Drizzle with a little extra olive oil if desired. Makes about 1 ½ cups (375g). Serves 4.

Soups are good and very nutritious. It is a good idea to get some special soup recipe books, these can be ordered from the library. Have a go at different ones and see what works for you. You may only be able to manage a small amount at a time, so freeze the rest if the recipe says you can. Complan and Slimfast make filling soups, don't use all of the packet at once - it is very strong!

To make the soup more interesting swirl in some cream, yoghurt or sour cream. Fry small pieces of bread or breadcrumbs to make croutons. Use different oils to fry the in, to add flavour.

FRUIT.

Stewed or tinned fruit can be served as it is or pureed. You can also have grated apple or mashed banana. Any of these can be mixed with yoghurt and honey, cream, crushed meringues, custard or ice cream. Different supermarkets do a wide variety of mousses, yoghurts, crème caramels and creamy desserts. It is worth rotating where your carer shops, therefore increasing the amount of variety of desserts you have to eat. All these desserts may give you ideas of some to make up on your own .

JELLY.

This can be made with a little extra water to make it thinner or by substituting half of the water for milk or lemonade. Why not add some fruit into the mix before it sets. You can buy pre-made pots to keep in the cupboard.

BLANCMANGE

Packet mixes can be bought in a variety of flavours from the supermarkets. Again add a little extra milk to make them less solid.

CUSTARD.

Fresh custard can be bought from all good supermarkets. Add extra milk to make it thinner. You can even get chocolate custard, delicious served with ice cream and/or tinned fruit, especially pears.

You can also get packet mixes of custard to keep in the cupboard or small ready made pots – these come in lots of different flavours.

You can make your own custard and sauces to add variety to a wide range of foods, especially fruit or ice cream.

Crème Anglaise

Put 3 egg yolks into a bowl with 2 tablespoons caster sugar and beat with a balloon whisk until light and fluffy. Heat 1 ½ cups (375ml) milk in a pan and bring it to scalding point, then pour into the egg mixture, stirring with the balloon whisk until well combined. Return to a clean pan and heat over low heat, stirring constantly to ensure that the custard thickens evenly. Do not let the custard boil or it will curdle. The custard is ready when it coats the back of a spoon and you can draw a line through it, which will hold its shape. Stir through 1 teaspoon vanilla essence. If you are not serving straight away, cover the surface with a piece of plastic wrap. Serves 6-8.

Vanilla Custard

Place 1 cup (250ml) milk and 1 cup (250ml) cream in a pan, stir to combine and bring to the boil. Remove from the heat. Whisk together 3 egg yolks, ½ cup (90g) caster sugar and 2 teaspoons corn flour in a heatproof bowl. Slowly add the hot milk and cream mixture, whisking continuously, then return mixture to the pan and stir over low heat until the custard thickens. Remove from the heat and add 1 teaspoon vanilla essence. Serves 6-8.

Hot Blueberry Sauce

Combine 50g blueberries and 2 tablespoons balsamic vinegar in a non-metallic bowl, and leave for 30 minutes to macerate the fruit. Place in a pan with ¼ cup (60g) caster sugar and cook, stirring, over low heat to dissolve the sugar. Bring to the boil and simmer for 2-3 minutes. Serves 6.

Chocolate Fudge Sauce

Serve a delicious warm chocolate fudge sauce. Heat a 284ml pot of double cream. Add 2 tbsp golden syrup, 25g (1oz) butter, 150g (5oz) chopped dark chocolate and stir to melt.

Chocolate Orange Sauce

Place three pieces of chocolate orange in a heatproof jug or bowl and heat in the microwave for one minute. Remove and stir. If the chocolate hasn't completely melted, return to the microwave and heat for a further 10 seconds. Continue to stir and then heat until the sauce is completely smooth. Serves one.

Butterscotch Sauce

Place 125g butter and 90g soft brown sugar in a pan and stir over low heat until the butter has melted and the sugar has dissolved. Bring to the boil, then add 2

tablespoons golden syrup and ½ cup (125ml) cream. Reduce the heat and simmer for 10 minutes, or until slightly thickened. Serves 6.

Bananas with Ice-cream & Chocolate Topping

Make a small split in the skin of each banana, place under the grill and cook, turning regularly until the skin has blackened. Carefully split open the skin, top with a scoop of ice-cream and sprinkle with either crushed Crunchie, chocolate buttons or cut up marshmallows.

Bananas with Chocolate and Marshmallows.

Peel the banana and cut down the centre. Place pieces of chocolate and marshmallow in between the two halves and then wrap in foil. Cook in a hot oven or on a BBQ until the chocolate has melted.

MILK PUDDINGS.

Flaked rice, tapioca, rice pudding, creamola, macaroni, ground rice and porridge/ready brek can all be bought in packet form and made up. Add sugar, honey, jam, fruit sauces, maple syrup or chocolate spread for a variety of flavours. You can also add drinking chocolate powder and less sugar to the milk when making it up to give a different flavour e.g. white chocolate, mint and orange.

PEARL TAPIOCA AND SAGO (DAIRY + SUGAR FREE)

Place a small amount with water (natural/bottled is best) and leave in a fridge overnight. The next day, put it through a fine sieve and pour boiling water over it. It goes like jelly and is now ready to eat.

TURKISH DESSERT

Mix 1-2 tbsp flour and 3 tbsp ground rice to a paste with some milk. Bring 2 pints of milk and 3 tbsp sugar to boil. Add paste slowly, stirring constantly until it thickens. Add 3 tbsp orange blossom or rose water, stir and cook for 2 minutes. Stir in 4ozs of ground almonds. Cool.

HOT DRINKS

Different flavoured drinking chocolates are available. Milo is a good brand as it is high in nutrients and is called "a food drink". You can also heat two cardamom pods in a cup of milk or add a grating of nutmeg for an alternative flavour.

Warm milky drinks are an easy way to take in nutrients e.g. hot chocolate, horlicks etc, as are Complan and other convalescent food drinks available from chemists. Hot drinks are also a good way of warming up your hands. Biscuits dunked in a hot drink are easier to eat!!

Hot Chocolate

Make a deluxe hot drink using 25g (1oz) of good-quality plain or bitter-sweet chocolate for every cup of hot milk. Stir until dissolved.

Build Up Drinks / Milkshakes contain all the necessary vitamins and minerals and give you a boost of sugar; but may be too sweet for people suffering from nausea.

SMOOTHIES.

Smoothies are great. You can blend your favourite fruit with milk and possibly ice cream or yoghurt for a refreshing, nutritious and tasty drink. Use soya or rice milk for a dairy free alternative. Add sugar, honey or fruit sauces to taste. Some tasty fruit sauces are available from Lakeland Ltd although intended for yoghurt they can be used for anything.

Here are a few recipes to give you some ideas of combinations.

Strawberry and Mango Smoothie (2 glasses)

Place the fruit 1 large ripe mango and 250g strawberries in a blender and whiz until smooth. Add 2 tbsp Greek yoghurt and 250ml cold semi-skimmed milk and whiz again. Pour into glasses, garnish with a strawberry and serve immediately.

Fruits of the Forest

Place 60g of frozen fruits of the forest in a blender with 150ml of fruit juice, 1 heaped tablespoon of natural yoghurt and 1 tablespoon of runny honey, (or to taste). Whizz and drink!

Coconut Milk, Mango and Lime

Blitz the flesh from one ripe medium sized, non-fibrous mango with 200ml coconut milk and the juice of a lime. Thin with a little water if necessary. This is a dairy-free smoothie.

Blackberry and Yoghurt Smoothie

Place 350g of blackberries in a food processor with 300ml of natural yoghurt and 150ml of cold water. Whizz until smooth, then add sugar or honey to taste. If you prefer you can replace whole strawberries for the blackberries.

Banana Frappé

Stir 25g (1oz) white chocolate and 300 ml (½pt) milk together in a pan until melted. Place the chocolate mix, together with a banana and 4 scoops of vanilla ice cream, in a blender and whiz until smooth.

Virgin Mary

Skin 4 or 5 ripe tomatoes then squish them through a sieve with the back of a spoon. Tip the juice into a blender and blitz with a good handful of fresh coriander, a couple of pinches of crushed black pepper and the juice of half a lemon, (or to taste). Serve in a chilled glass with a big wedge of lemon and coriander leaves to garnish.

OJ, Banana and Lemon

Blitz a small chopped banana with 150ml of orange juice, honey and freshly squeezed lemon juice to taste.

Parsley, Pineapple, Ginger and Lime

Blend 150g chopped pineapple flesh (about a quarter of a large fruit), 1 tablespoon of chopped fresh ginger, a small handful of chopped fresh parsley and 250ml of water. Push through a sieve before drinking. Serve with Ice.

Pineapple, Passion fruit and Grapefruit

Put 150g chopped fresh pineapple (about a quarter of a large fruit) into a blender, whiz for a minute, then add the freshly squeezed juice of a pink grapefruit and whiz again. Pour into a glass, then stir in the seeds and pulp scooped from a passion fruit, although this is optional.

Strawberry with lime and mint

Put 2-3 cubes of ice in a glass. Blend half a punnet of strawberries with the juice of 1 lime, 6 fresh mint leaves, 1 tablespoon of honey and 1 tablespoon of sugar (or to taste). Blend, garnish with a sprig of mint and serve immediately over the ice.

Pear and Raspberry with Maple and Vanilla

Peel a very ripe pear and cut into chunks. Drop into a blender with half a punnet of raspberries, 150g vanilla yoghurt and maple syrup to taste. Blend, serve garnished with a few more raspberries. You can replace the yoghurt with vanilla ice-cream if you fancy a milkshake.

Dried Apricot

Soak 6-8 semi-dried apricots in a glass of fresh orange juice overnight (they should come no more than a third of the way up your glass, or the smoothie will be too thick). Then blitz in a blender, adding a squirt of fresh lemon juice to sharpen it a little if you like sharp drinks. Great for when there is no fresh fruit.

Melon and Ginger

Slice the flesh from a half ripe Gallia melon into a blender. Grate a 1cm piece fresh root ginger, then put the pulp in a sieve (a tea strainer is ideal) and press through with the spoon to extract as much juice as possible. Blitz. Unless the melon is already cold, serve over ice.

N.B. Melon curdles in milk-based smoothies.

Smoothie Essentials.

- Freshly squeezed orange juice: this is a good addition if you want a shot of vitamin C. It is also a good way to thin out a smoothie.
- Ginger: Fresh and clean tasting, ginger is also helpful in boosting digestion, easing nausea or fighting off a cold.
- Lime: If you want to add a fresh, sharp-tasting edge to any fruit concoction, then add the juice of a lime.
- Low Fat Yoghurt or Bananas: Either of these ingredients will give your smoothie a thick and creamy consistency, while keeping low in fat.
- Mango: The flesh of a ripe mango is a useful way to sweeten your smoothie without sugar. It gives you an antioxidant boost too. Choose non-fibrous varieties such as Kent or Keitt.
- Raspberries: Not only do raspberries add a glorious colour, they also help to balance sweet fruits such as mango. Keep them in the freezer and put straight into the blender.
- Smooth Peanut Butter: Excellent if you want a substantial smoothie with lots of protein, peanut butter is also a good addition if you're simply feeling indulgent.
- Sieve smoothies to remove any pips.

Fruit or vegetable juices are a good option; but may be difficult if you are affected by the acidity of foods. It's amazing how sharp apple juice is! Juicers are available from John Lewis, Argos and other good electrical suppliers.

Maxijul powder or dried milk powder can be added to food/drinks to give you an extra boost – it's a good idea for the carer/parent to slowly build up the amount in food/drink so the severely affected person does not taste it. As the severely affected person begins to recover this can slowly be decreased.

For more recipes and tips on eating visit www.easytoswallow.co.uk

It can be very hard for a carer, who has spent hours preparing a meal that is then too difficult/painful to eat. It is essential that they remember this is not your choice, if you could eat it you would and you are not just being difficult. It is always worth having stand-by foods in the fridge that you know you can always swallow.

No matter what you can eat it is important to keep up your sugar-levels because if you go hypoglycaemic you will feel sick, dizzy, get a bad headache and generally feel worse than you do already. It is a good idea to have a bowl of chocolate beside you to keep nibbling on throughout the day. Chocolate buttons are good because they slip down easily, even if you have to break them into quarters if you are feeling

really bad. Eating chocolate then makes you need a drink, so is a good way to keep up your fluid levels, which is essential to avoid dehydration and admittance into hospital to be put on a drip for rehydration.

You'll be amazed at how different chocolates can have different tastes. Here are a few ideas.

- Chocolate buttons – white, milk, strawberry if available
- Caramac
- Animal Bars (Nestle) and Wildlife Bars (Cadburys)
- Walnut Whips – different flavours (Marks + Spencers do nice ones)
- Milky Bars (white chocolate)
- Milky Way Stars
- Kinder Eggs
- Aeros and Wispas (takes energy to bite)
- Chocolate Orange and White Chocolate Snowballs
- Milky Way Crispy Rolls
- Chocolate Teacakes
- Maltesers
- Revels if able to chew

Gluten and dairy-free chocolate is available from
D&D Chocolate Ltd
Centenary Business Centre
Attleborough Industrial Estate
Nuneaton
CU11 6RY
02476 370909
www.d-dchocolates.com

Hotel Chocolat Ltd
Mint House
Royston
Hertfordshire
SG8 5HL
0870 442 8282
www.hotelchocolat.com

Leave chocolate on radiator in winter to soften but not for too long!
Easter is a great time because there are so many different chocolates available, so stock up on lots of eggs. Get someone to break the eggs into small pieces so they are easy to eat.

Making Eating & Drinking Easier

To make eating and drinking easier always have food and drink easily in reach. Keep a table beside you on which you can put anything that you may need. Place a

tray on top to stop things rolling off. Buy a domed shape cover to put over food to keep flies away in the summer.

Drinking

It is essential that you keep your fluids up to prevent dehydration and the need to go in to hospital.

First thing in the morning get your carer to measure out at least two litres into a jug. From this you can then make sure you drink the minimum requirement of water necessary each day to prevent dehydration. You can get pretty plastic jugs with lids from places like Morrisons and Homebase, mainly during the summer. It's worth getting a couple so there is always one clean. Always have two glasses poured. This ensures that you have always got something to drink, even when resting and alone. Get your parent or carer to refill them when they come back.

Straws are useful because they save you having to tilt the glass. To make it easier to drink from cut the straw so that it is just a couple of centimetres above the rim of the glass. This means you don't have to chase the end when going for a drink. Buy pretty, colourful straws from supermarkets or alternatively use straws from fast food restaurants. These are good because they are wider and you can drink more in one go.

Cups with lids and straws are also an option because they prevent spilling or use a cup with a spout. If you get very weak then a carer can squeeze water into your mouth through a sports drinks bottle or you can be fed with liquid on a spoon or suck a flannel or sponge.

During hot weather ice cubes are an option, as the liquid slips down your throat without you realising. For an alternative you can freeze fruit juice or suck ice lollies.

You can now get mini fridges to keep in your room, good for storing drinks and yogurts. Available from www.minicoolers.co.uk It does have a fan; but it is quiet. If you find it too noisy you can keep it in a wardrobe or cupboard.

Water dispensers can be sat on a top with easy access and no need to lift a heavy jug, available from Argos www.argos.co.uk . Stand the dispenser on a tray to avoid leaks/spills.

Make sure you have regular little sips of water from a small glass, possibly using a straw.

It is also important to keep your blood sugars up because hypoglycaemia causes nausea and dizziness. You can get a special powder called Maxijul (on prescription) to add to water to boost the sugar levels. Start on a very small amount, e.g. a tablespoon in a litre of water and then gradually increase it so that you can't taste it.

At times drinking can seem impossible and it feels easier not to bother because you feel worse afterwards; but the alternative is having to go into hospital and be put on a drip. While this is nothing to be scared about, it is something to avoid if possible.

Eating

Lap trays are essential if you can eat more than a couple of mouthfuls at a time. Place a non-slip mat on top to stop things moving. Inflatable swimming pool food and drink trays also provide a stable alternative.

Use plastic plates, bowls, glasses and cutlery as these are lighter and easier to use and can be bright and colourful. Alternatively use children's cutlery and teaspoons to eat. If you have problems holding cutlery then specially adapted ones are available from care shops. Bowls are easier to eat and feed from. They hold more liquid/gravy than plates.

Have a flannel or damp tissue by you to wipe your fingers on. Keep a towel and box of tissues close in case of spills.

Crumbs in bed are uncomfortable to lay on and can cause pressure/friction probs. You can now buy crumb pets which roll along and pick up crumbs. They are quieter than a Hoover and quite light. www.legendcookshop.co.uk

Feeding.

Some severely affected people become too weak to feed themselves and need help. This is very hard and you feel like a baby again; but sometimes it is the only option.

Feeding someone/being fed is a refined art and at first will be quite messy, especially if you have problems opening your mouth or if you can't sit up. Get your carer to cover you and the bed with towels, just in case. Get them to use a small spoon and take it slowly.

Make sure the food is at the right temperature, severely affected people become very sensitive to temperature and may need it a lot colder than they would normally have it.

If it takes a long time to eat, then divide the food into two halves, keeping one half warm as you use the other.

If you have problems swallowing you may feel like you are gagging and about to choke/throw up. This is an instinctive reaction and one that is hard to overcome. Try and stay relaxed, telling yourself you are not going to be sick and that everything is okay. Concentrate on breathing regularly and always have a drink at hand.

Books.

Some good books to get are:-

Soft Options – for adults who have difficulty chewing – by Rita Greer.

Laurel's Kitchen Caring Cook Book – by Laurel Robertson
Published by Ten Speed Press, 1997

Smooth and Juicy – by Joanna Farrow
Published by Aquamarine

The Big Book of Juices and Smoothies – by Natalie Savona

The Recipe Collection: Easy-to-swallow meals. £2 from the Motor Neurone Disease Association. 01604 611870. helpline@mndassociation.org

A free eating and drinking leaflet s available from www.mndassociation.org

Visit www.easytoswallow.co.uk for more information.

Mail Order Meals.

Frozen meals can be bought from special companies who deliver to your door. Some offer meals for special diets and soft food options.

Home Choice Meals
0845 602 1123
www.homechoicemeals.co.uk

Wiltshire Farm Foods
0800 773773
www.wiltshirefarmfoods.com

Barbara's Kitchen Ltd
Unit 16
Ely Valley Business Park (East)
Pontyclun
South Wales
CF72 9ES
0845 1306297
www.barbaraskitchen.co.uk

For gluten-free, vegetarian and vegan foods contact
Zedfoods
The Old Station Bakery
Mill Lane
Llanfyllin
SY22 5BG
01691 648029
www.zedfoods.co.uk

For organic and diet foods and natural toiletries visit
www.GoodnessDirect.co.uk
0871 8716611

Weight Loss & Gain

Severely affected people seem to be divided into two categories: - the ones who lose weight rapidly and the ones who put on weight despite eating less. Both situations can cause problems.

Severely affected people are often accused of being anorexic due to such a great weight loss and people find it hard to understand how tiring eating is. If you lose a lot of weight then it is an idea to eat calorie rich food as much as possible. You can get special build up soups and drinks, which have extra calories

Other severely affected people who can eat relatively normally put on weight easily as their body is not burning the food. This can be very hard emotionally but is often unavoidable. Stick to a healthy balanced diet and try to tell yourself that you will lose the weight when you are better.

The best advice is to eat when you feel you need to, make sure that you choose foods that appeal and always keep drinking.

Tube Feeding.

Tube-feeding is not something to be scared about. Many severely affected people are tube-fed and although not a pleasant experience, it is something they get used to.

Although this pack can't give you all the medical information on tube-feeding it can give you some tips on how to make tube-feeding easier.

Most people have a Nasal-Gastric (NG) tube, this is one that is put down the nose into the stomach. Some severely affected people even put their own tubes in.

If the NG tube becomes a problem, especially if you keep being sick, then you can have a Percutaneous Endoscopic Gastronomy (PEG) this is a tube that is placed directly into your stomach through an incision in your abdomen. This can be a good option if NG tubes aren't possible; but great care has to be taken to avoid infections.

Inserting the Nasal-Gastric Tube.

- RELAX as the tube is being put in. The natural reaction is to tense up but this will make things harder.
- Silk tubes are easiest to go down and are thinner, so are more comfortable. Also long term tubes are a lot more flexible and can last up to six months before changing e.g. Freka tubes.
- Most tubes have markers &/or numbers along them, so you know how far it has to go in. Keep a note of the number so you can tell the nurses when the tube is changed.
- Soak the end of the tube in water to soften it first. You can use Aqua gel but this has a strong taste, which can aggravate nausea.
- If possible try to swallow calmly and regularly as the tube goes down, pausing between each swallow. This makes it easier. Then try and have a drink afterwards.
- You can have an anaesthetic spray to help numb your throat before the tube is put down.
- It is possible to have a slight sedative to help you relax. It is very light and you are fully conscious, it just helps your throat relax.
- If you have been tube-fed for a long time you may develop scar-tissue in the nasal passage, which can make inserting the tube difficult. You can use a nasal spray for polyps, which opens up the nasal passage.
- To check the tube is in your stomach and not your lung you can connect an empty syringe to the NG tube and draw back some fluid. Test the fluid with

litmus paper. If it turns bright pink then you have drawn stomach acid and the tube is correctly positioned.

- If the tube does accidentally go into your lung, you usually know straight away, because you will start coughing and gagging - even if you are semi-conscious. However, the moment the tube is pulled back out you will be okay again.
- If you are sick, pull the tube out of your nose and then consult a doctor about having a new one put back in.
- Stick the tube to your cheek rather than your nose as it is more comfy and doesn't get pulled as easily. You can then tuck it behind your ear out of the way.
- If you have sensitive skin and are allergic to normal adhesive tape you can use hypoallergenic Micropore or Hypafix. Alternatively put the tube through a hair clip.
- The most common feeds are Jevity & Ensure, but they can be thick & heavy on your stomach. You can get different specialised feeds. "Perative", is a semi-elemental ("pre-digested") feed. "Elemental 028" is usually used for people with Crohns or Coeliac Disease; but if you have problems absorbing a heavy feed then this is a good option. It's fully elemental ("pre-digested"), so your stomach doesn't have to struggle to break down the feed to get the goodness from it.
- If you have allergies make sure you check the ingredients of the feed.
- Depending on what type of feed you have, you can liquidise food to put down the tube; but consult with your doctor. Make sure the feed is completely smooth as it is very easy to block your tube.
- If you are loosing a lot of weight you can be prescribed "add-ins" of extra calories, protein, vitamins and minerals. After a while you may start putting on too much weight and then you should consult your dietician about slowly reducing the amount you are receiving. They may not be keen on this; but stick to your guns.
- Have the feed put down slowly, especially if you suffer from nausea. You can gradually increase the speed as you get used to it. Some people eat small amounts during the day and are tube fed at night.
- Some people enjoy the cold feel of the feed; but you can have it warmed up.
- Liquid medications are easiest to put down the tube but can aggravate nausea. Tablets can be ground up to a fine paste with a pestle and mortar and then mixed with cold water, so they don't block the tube.

- Constipation can be a problem, so you can put fruit juice down the tube very slowly, using the pump, when the feed isn't going through. Prune juice is the best one; but doesn't look very nice and can cause nausea. Any fruit juice is good.
Don't use bulk forming products like "Fibrogel" as this will swell and block the tube.
- Always flush your tube out with at least 10-20mls of clear water after putting anything down.
- If the tube gets blocked then there are several things that can be put down it, while it is still in the stomach, to clear it out. Try coke, lemon juice or bicarbonate of soda.
- You can be tube fed at home, this does mean a lot of work for the carer; but it depends what is the best option for you and your family.

Staying in Hospital.

There may be times during your illness when going into hospital is the only option due to severe dehydration or weight loss.

Although it is not easy being in hospital it is nothing to be scared about. Many severely affected people have to go in at some point and they get through it.

Before you go into hospital make up a bag of things you will need. If you are well enough to do small activities then take in some things to do.

Items to take with you.

Toiletries

- Brush
- Small mirror
- Soap
- Toothbrush and paste
- Flannel and towel
- Deodorant and Deodorant wipes
- Tissues
- Baby wipes
- Water spray to spray on your face and neck to keep you cool and hydrated
- Lip balm to stop your lips drying out

Sensory Protectors

- Earplugs – several pairs in case you lose one
- Dark glasses
- Eye mask

Medication

- Any medication you are already on. It may help to have written down exact dosages and times as well as a list of any medications you have had bad reactions to.

Clothes

- Change of clothes/pyjamas
- Cardigans/hooded jacket
- Change of underwear
- Dressing gown
- Slippers

Activities

- Magazines
- Books
- Simple craft kits
- Pen and paper
- Stamps
- Address book

- Walkman/Discman
- Music or Story tapes to play on your walkman
- Watch or Clock
- Torch
- Any special food or chocolate
- Spare change for magazines, chocolate and payphones

ME Information

- Books and leaflets on ME
- Doctors letters, notes or files

Being in hospital is very tough for severely affected people and carers alike. Suddenly being surrounded by doctors and nurses twenty-four hours a day can be very difficult, especially if they don't understand ME.

It is hard trying to explain a medical condition to the very people who should understand; but this is often what needs to be done. Don't feel intimidated by them, you know the condition best, so tell them what you want/need. They may not be happy; but you're the one that will suffer if you allow them to force you into doing something that you can't.

If the doctors or nurses are talking to you for too long and you start to feel ill ask them to leave you for a while so you can rest, keep yawning to add emphasis! Feigning sleep also helps if you need some peace. It is hard to tell if your eyes are open or not behind dark glasses or a mask!

They may try to pressure you into things, like having a bath or washing your hair; but stand your ground. You will learn to tune out when they start on the same subjects. Be firm but polite; try not to upset them, as this will make things much harder. Explain to the doctors and nurses what your symptoms are and why you have to do what you do. Give them leaflets and books on ME to prove you aren't making it up.

Sometimes it helps to have an ME specialist talk to the medical team about ME, as they believe it more coming from a trained professional. Contact an ME charity to see if they can put you in touch with someone who can help.

The more we educate people the easier it will be for us and severely affected people who come after us. Remember not all doctors and nurses disbelieve in ME. You will meet some lovely, caring people who understand. Get them on your side and things will be a lot easier.

Hospitals can be very noisy places so it is a good idea to try to get a single/side room or at least ask to be in the corner of a ward away from most of the daily hustle and bustle.

If you are under eighteen your carer maybe allowed to stay in your room with you at night. Sometimes a camp bed is available, but it is better to take in your own. Get your carer to help you use the toilet etc., and offer to change your bed for you as this makes life easier for the nurses and reduces contact. If your carer has to leave

you to go and get food or to use the phone then try and do it when the nurses are handing over at the end of their shifts or when they are taking their meal breaks. They are so busy that you will be left alone in peace.

It is important to feel comfortable in hospital, try and make your room/area as like your own room as possible. Tell your family and friends you are going into hospital and ask them to send you pretty cards. It's not only nice to receive cards but you can put them up around you to look at. Bring any favourite family photos, so you don't feel so alone. Take in a cuddly toy to keep you company and you can also use it as an extra pillow or neck/arm rest.

Wear dark glasses/masks and earplugs to cut down on stimulation and to help you sleep/rest whenever you need to.

If you use special pillows or beanbags at home then take them with you. If you need hot water bottles then bring them. The hospitals don't like them so it is advisable to get a carer to quietly do them in one of the bathrooms. If you are discreet you can get away with a lot of things.

Hospitals often have ice machines, which are a godsend if you are having problems drinking. Get your carer to find one and keep getting supplies.

If you have a drip, wear a cardigan back to front, with your good arm through the sleeve. Change the cardigan regularly, thus giving the impression you are changing all your clothes.

Before having a canuler put in or blood taken, make sure you warm your arm up under the covers. This will cause the veins to swell and therefore make it easier to insert the canuler. It is not as scary or painful as it sounds so don't worry! The more relaxed you are, the easier it will be.

The bedside cabinet is on wheels so move them round the bed, so that they are on the side of your drip-free arm, allowing you to reach things easier.

It can be very difficult if your sleep cycles when you are in hospital. Get your carer to ask the nurses to do your temperature and blood pressure when you are awake, rather than waking you up.

If possible get the nurses to leave tablets by you, so you can take them when you are awake and need them.

Tablets are a great way to drink lots of water in one go, thus increasing your fluid levels, so try to drink as much as possible.

If you suffer from very bad nausea some of the tablets can be given in suppository form. This does not sound pleasant, but is actually ok, don't feel embarrassed, nurses do them for people all the time. It doesn't hurt it just feels slightly strange. They are so easy you can do them yourself.

If you suffer from swallowing problems you can get special soft option meals made. See the hospital menu for details.

If there are any special foods that you eat then take in your own supply, for example chocolate buttons or grapes.

Carers should explain to family members that it might be difficult for them to call at this time, especially if they are trying not to leave their SAM on their own. Instead write general letters, which can be photocopied and sent to friends and relatives.

During your time in hospital you may or may not feel up to having visitors. Let people know your wishes and make sure that any visitors know that you can only see them for a short while and get them to leave when you ask.

Sometimes you don't have to go into hospital to have a nasal-gastric tube put in. depending on your GP, you may be able to have it done at home, with regular visits from a district nurse.

The most important thing to do while you are in hospital is to try and stay relaxed, stress will make you feel much worse, although it is hard to avoid.

Look on your time in hospital as necessary for you to receive treatment that you couldn't get at home. Concentrate on getting through the days and then go home to rest and recuperate.

Paralysis.

Paralysis is one of the most frightening symptoms that some severely affected people suffer and one that is extremely hard to deal with. There is little that can be done except to get your carer to sit with you and try to keep calm.

- Place a bell by you to call for company. If you suffer paralysis in your arms then put it by your feet. **(See Forms of Communication)**.
- Get your care to gently move your limbs to keep the blood circulating. This may be the only time possible to touch you due to touch sensitivity.
- If the paralysis always comes on at the same time e.g. early evening then make sure you get someone to place you in a comfortable position, supported by pillows.

When caring for someone who is semi or fully paralysed, it is important that the carer is careful when moving them, not only for the severely affected person; but also for their own health. A bad back will add extra problems.

Mobility.

A section on mobility for someone who is bedbound, may seem quite strange; but there are times when it's necessary to be moved – the quicker, the easier, the better.

Wheelchairs

Wheelchairs can be hired from the Red Cross, bought from mobility shops or obtained from Social Services – talk to your G.P. You can get some with head supports or some that fully recline, so you can go out even if you have a problem sitting up. Electric wheelchairs are an option; but they take a lot of effort to drive, as does trying to wheel yourself.

Wheelchairs are a great way of getting around; but just because you are not walking does not mean you are not using energy.

Pace yourself and don't try and do too much. It is better to be able to go out for lots of short trips than to get out for one long journey once in a blue moon.

Although wheelchairs are good for outside, most houses don't have room to manoeuvre them in. You can get commodes on wheels, which are narrower than wheelchairs. With the lid on they can be used as mini wheelchairs and you can be pushed round the house on them. They are not as easy to push as wheelchairs., sometimes it's better to pull them backwards.

Blue badges are a good idea, available from your Social Services Department. They allow you to park nearer to where you want to go.

Driving a wheelchair is a very precise art, it can be a very terrifying first time experience. Try to stay calm, although this is often easier said than done! Ask the person to go slowly and make sure they are paying attention to what they are doing! A seatbelt on the wheelchair is a very good idea. Don't worry if you accidentally bump into people or scrape the paint off doorways as you go in – everybody does it! Just smile, apologise profusely and blame it on the driver.

Going out in a wheelchair for the first time can be really hard. You may feel embarrassed and as if everyone is looking at you; but don't let it get you down. Those who have been unlucky enough not to be able to go outside for long stretches at a time would tell you how much they would love to go out in a wheelchair, no matter what people thought! You won't be in a wheelchair forever and for the moment it is a tool to use to allow you to do the things you enjoy.

Getting Downstairs.

Stair lifts are a godsend. They give you access to a part of the house that may not be possible if you can't cope with stairs. You can apply for a grant to get one. Contact your GP, physiotherapist or OT about this.

Walking.

If you can walk a short distance then there are different aids to help you – walking sticks, crutches or Zimmer frames. All are available from your O.T. or mobility supplier. You can decorate them with stickers or tinsel to make them look more fun.

Always make sure there is someone around when you are walking and that there are things to hold onto. Keep chairs and stools in strategic places in case you need to sit down suddenly.

Travelling In a Car.

If you have to travel in a car make sure you are comfortable and safe. Support yourself with pillows and sheepskins. This also reduces vibrations.

To make a bed seat, recline the front passenger seat fully and sit on the seat directly behind it with your legs up on the reclined seat.

If you have an “estate” car you can make up a bed in the back using pillows, duvets and sleeping bags to make it as comfortable as possible.

Take a supply kit of earplugs, sunglasses, tissues, food, drink and anything else you may need for the journey.

Travelling is exhausting so only do it when you have to.

Pacing and Switching.

A generally approved approach to M.E. is pacing and switching. This means you alternate between periods of rest and activity. There are many misconceptions about resting. Resting is not listening to music/story tapes or watching TV even if you are lying down. Resting is a period of time when you are relaxed with your eyes closed, in a comfortable position. You must reduce all stimulation that your senses are receiving, to allow your body to rest and create more energy. This is not easy though, as the boredom can become unbearable and without something to focus on all your symptoms will seem to get worse.

Meditation is a good way to pass the time you can visualise yourself surrounded by different colours e.g. the colours of the rainbow. Alternatively you can picture yourself in a meadow. Visualise walking around the meadow looking at different flowers. You can substitute the meadow for a beach or a mountain or any other place you feel relaxed in. There are books available with meditations like these, which you can get a carer to read to you or alternatively read onto a tape so you can listen to them when you feel up to it. These can be better than bought meditation tapes, as most tapes contain background music and this can provide too much stimulation for severely affected people.

There are various relaxation tapes/CDs reviewed at
<http://members.lycos.co.uk/justrelax/relaxation/tapes.htm>

These types of meditation take a certain amount of concentration. You may find it easier to just concentrate on your breathing, become aware of your inhalation and exhalation, possibly counting how long each take. Try to breathe slowly and rhythmically but don't make yourself uncomfortable. There are yoga exercises specifically for breathing - these can be found in books and on tapes. Which involve breathing gently in and out through your nose. There is one specifically aimed for people in bed and another for people with M.E. by: -

Angela Stevens
"Laminga"
South View Road
Wadhurst
Sussex
TW5 6TL
01892 782865
www.Angela-Stevens.co.uk

You should aim to rest for at least half an hour at a time, as this allows enough time for you to settle and get into a good state of relaxation. Some people find this very difficult though, so it's worth aiming for 15 minutes and then gradually increasing the length of your rest by just a minute each time. In no time at all you'll be up to half an hour or possibly longer if you feel it's what you need.

Boredom and frustration while resting undoes all the good effect. If your body is tense then it's using energy and therefore making you more tired. The best thing to

do is to accept that you must rest, as hard as this may seem. Look on it as a way to make some energy for you to be able to do something you enjoy.

You can set yourself a goal, e.g. if you do a certain number of rests you will buy yourself a treat, possibly something from a mail order catalogue, or treat yourself to your favourite food. This will make the resting seem more worthwhile.

Activities.

Being severely affected can be very monotonous, and the lower down the scale you are the harder it is to change this.

There may be weeks or months when you are too ill to do anything at all. This can be hard to deal with; but often you are feeling so ill that you aren't actually interested in doing anything.

When you do start to feel better and want something to do, it is important to find something that you get pleasure out of. Even if it is just doing one sticker on a card a day - the pleasure and sense of achievement will outweigh the tiredness and help reduce frustration. It is important that you know your limits. If you get tired after doing one sticker don't force yourself to do two until your body is ready to. If you do an activity for a certain period of time and find that the next couple of days you are too ill to do anything then you have done too much. Next time reduce the amount you do. It is very difficult accepting how little you are now able to do; but pushing yourself will only make you worse.

This principle applies to everything from making cards, listening to music or watching TV. Don't beat yourself up if you do push yourself too far, everybody does it. Learn from your mistakes and make sure that you don't do it again. You will know when you are well enough to do a bit more. Something inside your head will tell you when you can do another sticker or read an extra sentence in a book. You may feel tired after doing that little bit extra but you should not feel exhausted or terribly ill. If you do then perhaps you are still pushing it too far.

Different parts of the brain control different activities and so it is important to alternate the parts of the brain that you are using by alternating the activities. For example if you make a card, after you rest do something different like listening to music or a story tape. If you have watched some TV after your rest don't try and use the computer. You may find it useful to plan a day of activity.

For Severely affected of a low ability percentage this may only contain one or two activity periods of just a few seconds during the better part of their day or night. With time you will slowly build up to do things for longer periods of time.

Some people find it useful to keep a diary of their activities and symptoms. This allows them to see whether an increase in symptoms directly relates to an increase in activity, showing them that they need to slow down and rest more. This concept is explained in the book "Better Recovery From Viral Infection" by Darrel Ho Yen.

Essential Items

No matter what activity you do - a lap tray is great for working on or for leaving on the bed, with easy to reach items. These are trays with a beanbag bottom - they mould to your legs or the bed to provide a stable surface. They are available from Lakeland Ltd; but you can get cheaper ones from many different stores e.g. QD.

Have a cupboard or trolley by the bed with anything you may need on/in it. This allows you to be more self-sufficient. There are some good plastic drawers on wheels available from Big W and Homebase. They can be easily moved and provide extra tabletop space by the bed.

Activity Suggestions.

Different activities appeal to different people- it is important to find something that you enjoy and feel you have achieved something at the end, no matter how short a time you can concentrate for.

CRAFTS.

Crafts are a great way to fill your time. There are wide ranges of different crafts available from good mail order suppliers. Even if you only have a small amount of mobility in your hands and have to do it lying down you should be able to find something that you will enjoy, with the extra benefit of something solid to show for your time and energy at the end e.g. a card or craft which you can keep yourself or send to a friend

Card Making

You can make a basic card by folding a small piece of coloured card or alternatively buying pre-folded cards from craft shops. This you can decorate in a number of ways: -

- Stickers
- Ink Stamps
- Cut out pictures from magazines or old cards
- Drawings in pencil or crayon
- Glitter Glue
- Foam Shapes
- Various Collage materials

The only limit is your imagination. Some great craft suppliers are: -

Baker Ross
Unit 53

Millmead Ind. Estate
Millmead Rd
London
NI7 9QU
0870-2411867
www.bakerross.co.uk

Centagraph
18 Station Parade
Harrogate
N. Yorks
HG1 1VE
0800-328-5237
www.centagraph.co.uk

Smitcraft
Unit 1
Eastern Rd
Aldershot
Hampshire
GU12 4TE
01252 342626
www.smitcraft.com

Hama Beads

These are plastic beads which when placed on a special board can be used to create different patterns and pictures. Get a parent or carer to place a sheet of greaseproof paper on the top and iron the design, causing the beads to melt slightly and stick together. Once cool you have a hard plastic picture or shape, which can be used as a drinks mat.

These can take a bit of concentration and can be quite fiddly; but if you have the energy they are well worth having a go at. They are available from: -

New Era Direct
PO Box 6361
Wellingborough
NN29 7ZR
01933-223509
www.neweradirect.co.uk

Jewellery Making

This is a fun and very rewarding hobby. It can be broken down into stages of just one bead a day. It is advisable to start on a small project at first, for example earrings, as they give you quick results. You will need to buy some basic supplies to begin with or

alternatively there are kits available which supply everything that you need to make earrings, necklaces and bracelets. All you will need to buy in addition is a pair of pliers and wire cutters.

If you can only do a couple of beads at once, put blue tac on both ends of the wire or earring pins to stop the beads from falling off.

Some good jewellery suppliers are: -

The Bead Book
The Rocking Rabbit Trading Co.
226a High St
Cottenham
Cambridge
CB4 8RZ
0870-6061588
www.rockingrabbit.co.uk

The Brighton Bead Shop
Beads Unlimited
PO Box 1
Hove
BN3 3SG
01273-740770
www.beadsunlimited.co.uk

For more craft suppliers get a craft magazine e.g. Popular Crafts available at W. H. Smith or any good newsagent. They also supply ideas for craft projects.

Drawing and Painting

Drawing and painting can be very therapeutic no matter what your artistic ability. Try experimenting with different mediums e.g. pencils, wax crayons, charcoal, pastels, oil pastels, chalks or watercolour pencils. It is advisable to have a damp cloth or bowl of water close by so you can wash your hands. If you don't feel up to drawing something yourself, then there are lots of good picture books available, that you can colour in.

If you enjoy painting there are now lots of kits available. These cover everything from painting by numbers to glass and ceramic painting. Alternatively get your carer to check out a local toy store or craft shop for easy to complete activities.

Growing Things.

You can get lots of kits now to grow different plants and flowers, available from garden centres. These can be easy and fun to do.

A darkened room is good for growing bulbs e.g. hyacinths and crocuses. Alternatively if the plant needs light to grow, get your carer to take it somewhere else and keep bringing it back for you to see. Be careful not to grow anything scented if you are sensitive to smell.

If you are not very green fingered then have pre-grown plants instead, as they are easier to keep alive than seeds.

Listening to Audio Books and Music.

Listening to things can take a lot of energy, but if you use an Mp3 player or iPod it is something you can do on your own. You may only be able to listen to a few seconds at a time; but if you are alone e.g. awake at night, it can act as a distraction- almost like having company. You can listen to a bit at a time, when you feel up to it. As you get better you will be able to increase the amount that you are able to listen to.

Audio books are available from the library and are free of charge if you are bed bound. You can borrow them for three weeks and then renew them up to three times, thus giving you a total of nine weeks to listen to the tape. You can order specific tapes using the library's computer, get an assistant to show your carer how to do it.

Once you have exhausted their range why not try Calibre Cassette Library. It is a charity, which has been set up for people who have difficulty reading and is completely free to members. To join you will need to get a medical professional to fill out a form, to confirm your disability e.g. Doctor or Occupational Therapist.

Calibre Cassette Library
Aylesbury
BUCKS
HP22 5XQ
01296-432339
info@calibre.org.uk

Alternatively you can buy tapes from the following mail-order shops.

Chivers Press
Windsor Bridge Rd
Bath
BA2 3AX
01225-335336

Podcasts are a great way to listen to a wide variety of things, including audio books, reviews and fan information about your favourite television programme or film and

the best bits from your favourite radio shows. You can also get podcasts which teach you new languages or take you on virtual tours of museums. Visit www.apple.com

BBC Audio Books
Customer Services
BBC Audio Books
St. James' House
The Square
Lower Bristol Road
Bath
BA2 3SB
0800 136919

Listen 2 Books
Retreat Farm
St. Lawrence
Jersey
Channel Islands
JE1 1LB
0870 191 3415
www.listen2books.co.uk

The Talking Bookshop
11 Wigmore St.
London
W1U1PE
02074914117
www.talkingbooks.co.uk

The catalogues are a good way to find out what is available, even if you then order them from the library.

You may find that you have a problem listening to things read aloud; but can cope when it's recorded on a tape, as you can listen to it as and when you feel up to it. Get your carer to record articles, letters and stories onto a tape for you to listen to. They may feel embarrassed at first doing it; but this will wear off.

Get family and friends to look out for funny stories or anecdotes, in magazines and newspapers - Reader's Digest is particularly good for this.

Listening to music can also be quite difficult, especially with the beat of the bass, which can cause your head to ache; but if you want to try to listen to a little, you may find it easier if it is played in another room at a level that you are just able to hear. You can even put an earplug in one ear and lay your head against a pillow to muffle the sound. You can then listen to as much as you feel able and then either ask someone to turn it off or put your other earplug in to block out the noise.

Some people find that relaxation music is pleasant to listen to and they can cope with it better than more modern pop music.

New World Music
Freepost ANG 4441
Beccles
Suffolk
NR34 8BR
01986 781 682
www.newworldmusic.com

You will have to experiment to see whether you find it easier to listen to something over speakers or alternatively over earphones- earphones mean that the amount of stimuli your brain receives from external sources is reduced. If you find that you can't cope with noise in both ears, then just use one earphone. Try to get a set of earphones with a volume switch on them, as these give you greater control over the volume. A good set is MDR-E829V by Sony, available from Argos.

If you are using a stereo/tape recorder you may find that the whirring and clunking of the mechanism is too loud. Walkmans can be placed under a pillow and you can place a pillow or towel over the top/front of stereos, to cut down on the noise. Be careful not to cover the air vent on the stereo, as this will cause it to overheat and can be dangerous.

Watching TV

Watching television is a very popular activity and can be very addictive, as it is a way to escape reality. Unfortunately it is one of the most exhausting activities because it stimulates the eyes, ears and brain all at once; therefore it uses up a lot of energy.

You need to be aware of how much television you physically can cope with watching, before you feel tired. It may be an idea to set a timer so that you don't exceed your limit.

It is particularly important to alternate activities when watching TV. After watching it, have a rest and then do something that uses a different part of the brain e.g. making something. Find what works best for you. Watching things on video is a good idea because you can stop and start whenever you need to. Record programmes off the television and watch at a time and pace that suits you best.

If you have exhausted your local video store, then there are mail order video suppliers who rent films for a period of time for more details visit: -

www.moviem.co.uk
www.blockbuster.co.uk
www.Qflick.co.uk

You can also rent videos and DVDs from some libraries for a week at a time.

If you are too ill to watch TV, but are missing your favourite programmes, it is possible to record the sound from the programme onto an audiotape or minidisk. All you need is a tape recorder/ minidisk player and a Jack Plug-to-Plug lead. You plug one end of the lead into the headphone output in the TV, with the other end into the input or microphone socket on the tape recorder or minidisk player. You then play the video with the TV on and start recording on the tape recorder/minidisk. You can then listen to it at your own pace. It's advisable to listen to something you know quite well to start with because you can visualise what's going on. It's possible to get scripts down off the internet for some of the American shows, e.g. Buffy, Charmed and Friends. If you can't do this yourself why not ask a sibling, friend or carer to do it for you.

If you have been unable to watch TV for a while then the only way you are going to know if you are ready to watch it again is by trying. You will soon know if it is too much for you. Don't try watching a whole programme to begin with – just look at the screen for a second and turn it straight off again. If you feel up to it, try again in a day or two's time. This glimpse may be all you can cope with for weeks or months; but slowly you will be able to increase the amount you can watch. Don't try and force it because it will only make you ill and therefore it will be even longer until you can watch it.

Cooking.

Cooking can be a fun activity, which produces delicious results that all the family can enjoy! You can even do some cooking from your bed. The simplest are crispie cakes. Get a sibling or carer to melt a bowl of chocolate in the microwave and bring it to you to add the rice crispies or cornflakes. Spoon the cakes into bun cases and leave to cool. Then ENJOY!

Remember the chocolate and bowl will be hot so be careful and always make sure there is someone around to help, especially if you get tired and need somebody to take over.

There are also some great cake mixes that come with most of the ingredients ready prepared. All you need to add is an egg or some water and then you can bake the cakes or biscuits. Cake mixes are available from most supermarkets. Some good ranges are Cadburys, Jane Asher and Greens. They do a wide variety of cakes from caramel shortbread, to chocolate chip muffins and lemon drizzle cakes.

Alternatively look for an easy cookbook, possibly one meant for children. Get someone to measure out the ingredients and you can mix them. It's advisable to use a tray table so you have a firm surface to work on.

To become more involved with daily life why not help plan meals, especially if you can only eat certain things. You can even help prepare some of the vegetables.

Games

Playing games of all types can be a fun way to spend some time. Most games can be played in stages and left part way through, so are ideal for people with low energy.

Travel games are great because they are small and often magnetic, so can be easily moved around the room.

Here are some games to try:-

Card games e.g. Snap, 21, Poker, Rummy and Old Maid.
Uno
Connect Four
Happy Families
Cluedo
Monopoly
Top Trumps
Battleships
Backgammon
Draughts
Solitaire
Chess
Chinese Checkers
Scrabble, Boggle, Upwords.

Cards can be held with large card holders available from

Keep Able Ltd
Unit 38C
Telford Way
Telford Way Industrial Estate
Kettering
Northants
NN16 8UN

01536 525153

They also supply large playing cards, which are good when used in a darkened room.

It's worth investing in a book of games; you will find many games that you have never heard of before. Two good books are

- Family Games – Edited by Brian Burns, Grange Books
- 10 Minute Card Games - William A Moss, Parragon.

Using the Computer

Using a computer/laptop can be great fun and is a good way to communicate with the outside world via email and the Internet. The only downside is that it can be very tiring because it uses so many senses and it is very tempting to do more than you ought to! A timer is a very good idea!

If you can't use the computer why not get a friend or carer to go on for you.

Internet shopping is also a good way to buy things without leaving the house. Most shops have their own sites so get your carer to look out for details.

There are online directories that guide you through the range of mail order outlets.

- www.mechat.co.uk/db/shop.htm
- www.lifestyle.co.uk
- www.shopperuk.com
- www.surgerydoor.co.uk (Health Multi Store)

Some good sites that compare prices for the cheapest places to buy are

- www.kelkoo.co.uk
- <http://uk.pricerunner.com/>
- www.priceguideuk.com
- www.onlinepriceguide.co.uk
- www.bookbrain.co.uk
- www.toystoresonline.com
- www.price-tracker.co.uk

Always buy from secure sites and watch out if you are buying DVDs that you buy Region 2.

E-cards are a great way of keeping in touch with people. There is a wide variety and many are free to send.

- www.hallmark.com/hmk/Website/hallmark_home.jsp
- www.yahoo.americangreetings.com/
- www.mesupport.bigstep.com
- www.bluemountain.com

Remember the most important factor about activities is that they are fun and that you can enjoy doing them without wearing yourself out.

Breaking up the monotony.

After a while you may start to get bored with your usual activities. To try and break up the monotony think of ways to change your normal activity periods.

The best form of inspiration comes from special days of the year e.g. Chinese New Year, Shrove Tuesday, Easter, Independence Day and Thanksgiving. Bring elements of these days into your room in the form of pictures, cuddly toys, flags and banners. Let your imagination run wild. Design decorations to hang up and think of related craft activities.

If the day has special foods associated with it and you are able to eat them, then have a special feast. If not, have some of your favourite foods.

During the summer when everyone else is going away on holiday, why not have a virtual holiday. You can visit any country in the world without leaving your bed. Get your carer to order books from the library or go on the Internet, so that you have some information and pictures of your destination. Think about the sites, sounds and smells.

Holidays From Home is a voluntary organisation which provides free virtual holidays to people who are bed or housebound. For information visit www.holidaysfromhome.com.uk

At first you may feel embarrassed doing these kinds of activities; but if you include your friends and family you can have a lot of fun. The only limit is your imagination. Just because you are ill doesn't mean that you can't do some fun things and make fantastic memories.

Forms of Communication

Communicating with the outside world can be very difficult when you are bedbound, even getting the attention of someone in the same house can seem impossible. There are several ways though to call people even if you can't speak.

- Indoor Bell – these can be purchased from Argos & Homebase and work in the same way as a normal doorbell. The bell can be moved around to different areas in the house and you are left with a control button, which you can push to make the bell ring. You can work out different ring patterns for different needs:
e.g. One ring for company
Two rings for the toilet
Three rings for an emergency
- An intercom – you can use an intercom or baby alarm to talk to a person in a different area of the house. If you can't speak then you can use a rattle, whistle or anything that makes a noise.
E.g. A teddy bear that squeaks
- A mobile phone by the bed – if you have a mobile phone it is an idea to keep it switched on but on "silent". You can then have numbers programmed in for speed dial.
E.g. House phone number
Parent/carers mobile phone or work numbers if you are left on your own
- If you are unable to speak, then you can get a carer to make up a board or piece of card with important words, photos or pictures on it – like food, drink, toilet, yes/no, which you can then point to. You can also have the alphabet if you need to communicate something that is not on the board.
- The board can be difficult if you are in a darkened room, so you can use fingers as signals. Your carer can feel for your hand and the number of fingers.

e.g. One for drink
Two for food
Three for medication
Four for the toilet
Thumb for Yes
Little Finger for No

If the severely affected person is paralysed, then the carer will be the best person to learn what they want. This can be extremely difficult and frustrating for both people involved; but over time you will develop your own system. e.g. flicking eyes for attention, deep breathing or sighing as a specific yes or no.

Communication with the Outside World

Contact with the outside world can be a mixed blessing, at times it's nice to know that there are other people out there, thinking of you; but at other times it can be difficult hearing what is going on, while you are stuck inside.

It's good to have friends with ME, who, if not entirely understanding, have an idea of what it's like to be ill. Some ME charities run pen pal schemes which are a good way of meeting people in a similar situation.

Often a pretty card or postcard is more valuable than a long letter. It's the receiving of something that matters - allowing you to look forward to the arrival of the postman. This is also a good way to stay in contact with people without hearing too much of what is going on with their life. Suggest this to family and friends.

To let other people know how you are doing or about a special event like your birthday you can dictate a letter to a carer or record it on a Dictaphone, possibly only doing a couple of lines a day. They can then write/type it out and then photocopy/print off more than one copy.

This is a good way to stay in contact with lots of people with the minimum of effort for you and your carer. Letters can be decorated with stickers, ink stamps or little drawings. In the same way you can also make little cards to send to people. Fold a small piece of oblong card in two and decorate. There are some beautiful stickers available from garden centres, craft shops and mail order catalogues. This is great, even if you have to get a carer to lift off a sticker for you to put in place on the card. It takes a little effort; but is very satisfying.

Visits.

During your time as severely affected you may or may not want to have visitors. If you do decide to see people then get your carer to explain the situation to them. Devise a method to show them when you need to rest.

- Use a timer and get your carer to set it for a slightly shorter time period than you think you can cope with. This means you don't over do it. Either keep the timer in the room or get your carer to hold onto it and come and collect your visitors when the timer goes off.
- Have a card warning system like in football. Place a yellow card on the bed as you start to feel tired and then a red card to show you need them to leave immediately.
- Alternatively just ask them to leave when you start to feel tired. This can be very difficult to do at first but if you say something like "I'm sorry I need a rest now". This is simple and to the point, without being rude.

Think about topics of conversation beforehand, so you aren't stuck trying to think of things to say.

Texting.

Text messages are a great form of communication; but they require a certain amount of energy and concentration, unless you've got a willing carer or relation to whom you can dictate a message. It's an idea to get them to type somewhere else as the noise can get too much. There are phones available with keyboards on which you can type easily just like on a computer e.g. the Nokia 6800. These take a lot less energy.

Talking on the phone

Some people enjoy talking on the phone or even just listening as a friend talks to them. Get someone to explain to the person that you might not be able to concentrate for the whole of the call or might have to end it suddenly. Use a special phrase to ask them to stop talking. There are special phones available that are like headsets, so that you don't have to hold the phone up to your ear. (See Argos Catalogue)

Email & The Internet

This is another form of communication; but takes a lot of concentration and energy unless you have a computer literate carer. It can still take a lot of energy just having someone in the same room using a computer, so it's a good idea for them to do it in a different room and print off things to bring in and show you. If you can use the computer, a laptop is great. It can be placed on a pillow, lap tray or on a table beside you. You can turn down the brightness of the screen and have an extension lead for your modem. It can be quite addictive using a computer and may be worth setting a timer, so that you don't over do it.

Tape Recorder

Tapes are a great way of recording your thoughts and feelings and allow you to dictate letters when you are on your own. Recording your own voice can be a very strange experience. The best advice is to relax and not to worry how you sound. You can dictate letters onto a tape to be written out by a carer or you can send the tape directly to the person to listen to. Perhaps they could record a message on the end to send back to you.

Just because you are bed/house bound doesn't mean that friendships have to end. It can be hard hearing what other people are up to and if necessary you can get a carer to ask people not to talk or write about certain things. At the end of the day it is important to know you are not alone.

***'Friends are like stars
You can't always see them
But you know they are always there'***

Bedrooms

It is important to make your bedroom as beautiful and comfortable as possible. Spending so much time in it means that you should make it interesting to look at.

Have lots of pictures up on the walls - use pin boards, card stands and holders. These allow you to regularly change the pictures or cards. Stand cards on any available surface. You can stick them with blue-tac onto the edges of shelves. Calendars are good because you have a different picture each month and it gives you something new to look forward to.

Have a music stand beside your bed - this can be used to prop up pictures or photo books. There are beautiful pictures in magazines, especially home and garden ones. Get family and friends to look out for them when they are reading magazines and cut them out for you. There are also a number of art and photography books available. These have large pictures in which you can lie and look at. You can make a game of it by making up a story to go with the picture. Some good books are 365 Days of Earth from the Air, The Milk series (Moments of Intimacy, Laughter and Kinship) and the Phaidon Series- check out your local library to see if there are any you can borrow.

Mobiles and crystals make interesting things to look at especially if you are lying down. You can get mirror mobiles, which even sparkle in a darkened room. You can use a torch on them and get someone to make them move for a wonderful light show. Wind Chimes are another alternative if you don't have a problem with sound.

A Galileo's Thermometer is fun to watch. It consists of a sealed glass tube filled with water. Floating in the tube are five glass spheres filled with liquid. Each sphere represents a temperature and as the room temperature changes the liquid in the spheres expands/contracts, causing the spheres to rise and fall. It is fascinating to watch, and the movement is very gentle. They are available from www.a1gifts.co.uk/Galileo-Thermometers.asp?source=Google&gclid=CPWo15HbuZMCFRWT1QodSTujBw

If light isn't a problem there are a lot of new accessories available - different types of fairy lights, lava lamps, mirror balls, fibre optic lights. All add variety to a room.

Have lots of cuddly toys and soft cushions (you can get lots of different shapes and colours now) around the room.

A variety of duvet covers give you something to look forward to, especially after having to use a lot of energy to allow bedcovers to be changed. You can even get some that glow in the dark.

Ornaments around the room are good - if there is something you like, i.e. Winnie the Pooh suggest it to friends and family for gift ideas.

Rubik's cubes/little puzzles can be good to keep you occupied and gradually increase strength in your hands.

Wind up torches are great as they don't need batteries, available from www.dot2shop.com or www.robertdyas.co.uk/ or search www.kelkoo.co.uk

Water fountains are nice to watch; but the noise can get too much for people with sound sensitivity.

Bubble machines are beautiful to watch and can be used for a few seconds at a time, available from Argos, Woolworths www.woolworths.co.uk and www.thedoghouse.co.uk

Electric propagators are good if you want to grow exotic plants or any seeds even in winter. You may need someone willing to water them and put soil in pots for you though. Available from Amazon www.amazon.co.uk

For someone who is lying on their back for a lot of the time, it is important for the ceiling to be interesting - get someone to stick pictures or glow in the dark shapes on it. You can now get them in various types e.g. stars and dolphins. Use a torch on them to make them glow. You can also put these shapes on the floor.

You can now get Rainbow in My Room which projects a rainbow onto the wall and ceiling. It's particularly effective in the dark; but isn't too bright. Available from www.iwantoneofthose.com or www.amazon.co.uk/Uncle-Milton-Explore-Rainbow-Room/dp/B000TK8440/ref=sr_1_1?ie=UTF8&s=toys&qid=1211367671&sr=8-1

They also do a Moon in My Room which projects the phases of the moon onto a moon shaped disc. Again this is a great way to bring nature into your room, even with the curtains closed!
www.amazon.co.uk/Brainstorm-Uncle-Milton-Moon-In-My-Room/dp/B000EUHKUE/ref=sr_1_2?ie=UTF8&s=toys&qid=1211367671&sr=8-2

It's nice to have fresh flowers in the room. If you can stand a bit of light you can try growing your own. You can buy some pretty flowers from a local shop. If you suffer from nausea then it might be advisable to stay away from strong smelling ones like lilies. Get friends and relatives to look out for interesting stones, flowers, leaves and feathers to bring you. This is a great way to keep up with the seasons, seeing a snowdrop in spring, a daisy in summer and a leaf in autumn. If it snows get someone to bring a washing up bowl or tray full of snow. You can then enjoy playing with the snow without going outside. You can even make a mini-snowman!

The most important thing about your room is that it is YOURS - at times it will feel like a prison as if the walls are closing in and there is nothing you can do; but try to make it as comfortable and as decorative as possible. Give your eyes lots to look at and try to prevent boredom as much as possible.

If you do start getting bored, get a carer to move a few things around - it's amazing how you start seeing things as if for the first time.

CHRISTMAS AND BIRTHDAY CELEBRATION ALTERNATIVES

What makes a birthday or Christmas special is individual – it's up to you to find something memorable. Here are a few ideas to start you off.

- Build up to the event slowly. Enjoy the preparations and don't leave things to the last minute.
- Order presents well in advance. Write Christmas cards in stages over the months leading up to December. You could even make your own cards or send e-cards.
- Spread your Christmas and birthday over days or even weeks – make the event last as long as possible, spread out the enjoyment.
- Don't use a month's energy in just one day; you'll regret it later and any good memories will be replaced with bad ones.
- Get other people to help open presents – brothers and sisters love this. Possibly get people to leave them unwrapped. Instead put them in pretty bags or use crepe/tissue paper and ribbons instead of sellotape.
- Spread out opening presents. Don't try and open them all at once, possibly opening them as they arrive and just leave presents from close family and friends for the actual day. You could have non-wrapped presents in a pretty box or bag and do a lucky dip whenever you feel up to it or are alone and bored.
- Decorate the bedroom/living room with balloons, banners, streamers or anything that sparkles. Helium balloons from florists are good value because they last for a long time. For Christmas get a mini-tree available from garden centres and supermarkets. For a few weeks before you could help make the decorations e.g. paper chains
- Include your friends by having a long distance party. Make up party bags to send out with a candle, a piece of cake or some chocolate, a balloon or some streamers. Alternatively have a spa day, send out face mask packs with a candle and possibly a herbal tea bag.
You could choose a theme for the day bringing it into your bedroom and party e.g. Caribbean, pirates, fairies, 60's or 70's. Enjoy the preparations!
- Wear special/new pyjamas/clothes, even if you have to change into them a few days before. Get someone to paint your nails and maybe even wear a necklace or ring on the day.
- Put your cards up around the room.
- Get friends and family to record messages onto a tape if you are too ill for visits.

Presents

Some of the best presents are things that take no energy to use, if you can sit it by you and look at it occasionally when you have the energy then it's perfect for someone of a low percentage. Here are some suggested ideas:-

- Crystal gardens/trees are great to watch and take no energy.
www.hawkin.com
- Pretty ornaments to look at.
- Glow in the dark shapes to stick to the ceiling, walls or put on the floor.
- Mobiles, crystals all look pretty, even in the dark.
- Galileo's Thermometer.
- Cuddly toys, although sometimes people can get too many. An idea is buying one cuddly toy from somewhere like the Bear Factory www.thebearfactory.co.uk and then buy different outfits to dress the toy in.
- Balloons www.bizzyballoons.f2s.com/index.html
www.looneyballoon.com/acatalog/
www.simply-balloons.com/shop/
- Pictures, landscapes or scenes are best, looking at people doing things like swimming, walking etc can be upsetting.
- Calendars (this can be a dodgy area as some people don't like to think about time passing; but I enjoyed a new picture each month)
- Audio Books
- E-tokens www.amazon.co.uk www.hmv.co.uk
- Chocolate a staple of most Severely affected people diets.
www.thorntons.co.uk/
- There is a Chocolate Tasting Club where you get sent a new box of chocolates every month or alternate month with new chocolates to try. Available from www.hotelchocolat.com
- Nightshirts, pyjamas, slipper socks
- Pretty blankets Lakeland www.lakelandlimited.com and John Lewis www.johnlewis.com do some nice ones.
- Different textured pillows.
- Flowers though choose a non-scented variety if the person has smell sensitivities. www.charityflowers.co.uk
- www.hawkin.com have some great stuff for Severely affected people like touchable bubbles and glow in the dark ducks.

Things to avoid unless told otherwise.

- Smellies, make up, scented products, brushes, mirrors
- DVDs, Videos, Books, Music CDs
- Writing sets, diaries
- Vouchers that have to be used in a shop
- Non-nighttime clothes

Food on the Day.

- Buy some pretty paper cups, plates and straws for using on the day.
- Choose food you enjoy to eat, even if it is only your favourite chocolate bars or ice cream.
- A fun and easily swallowed cake is a Baked Alaska – ice cream covered with meringue baked in a sponge flan case. Candles can be put in this.

BAKED ALASKA

Sponge Base

6 eggs (separated)
6 oz (175g) plain flour
5 ½ oz (160g) caster sugar
½ pot of strawberry jam
½ tub of vanilla ice cream

Italian Meringue

4 oz (110g) egg whites
8 oz (225g) caster sugar
2 fl oz (55ml) water

Method

For the Sponge:

1. Have a 10 x 12 inch (25cm) tray lined with greaseproof paper. Use a round tin if you want to just make one large cake.
2. Place the egg whites into a mixing bowl, whisk until stiff and gradually add sugar. Once all whisked in, add one egg yolk at a time and combine. Once all combined fold in the flour.
3. Place the mixture into your prepared tray and spread evenly, bake at 400°F/220°C/gas 6 for 10 minutes until springy to touch.
4. Once the sponge has cooled, cut out 3½ inch (9cm) rings and place ready on a baking tray with a dessertspoon full of jam in the middle. Alternatively use a slice of bought jam sponge roll or a bought sponge flan case.

For the Meringue:

1. Place sugar and water into a thick-bottomed pan over a medium heat. Using a sugar thermometer, take the caramel mixture to 115°C (soft ball), this is achieved by leaving to boil for about 3 to 4 minutes.

2. When the sugar is almost at 110°C turn on your machine and start to whisk your egg whites, and then pour over the sugar mixture very slowly – little by little. Be very careful, this sugar mixture is very hot and will burn you if spilt.
3. Once all combined, the mixture will increase in size. Leave on the machine mixing until cool, about 3 minutes.
4. Once cooled, place into a piping bag with a star nozzle. Alternatively use a packet mix of meringue.

To Complete:

Place a ball of vanilla ice cream onto the jam in the middle, and then cover with meringue from the sponge base to the tip of the ice cream. You need to make sure all the ice cream is covered with meringue and all sealed. Do them in trays of 4 to 6.

Bake at 210-220c/400-425f/gas 6-7 for 3 to 4 minutes, until golden brown on top. Serve immediately with Crème Anglaise or pouring cream.

Alternatively leave the sponge whole and make one large baked Alaska.

- For an ordinary cake use number shaped candles (on sale at Sainsbury's) so that you do not need to blow out so many candles.
- Bubbles can be blown round the room.
- Indoor sparklers and fireworks can be fun if you can cope with the noise and light. www.talkingtables.co.uk supply sparklers and table rockets.
- Fairy lights in the garden outside the bedroom are pretty.
- Try and do things you enjoy for the day. Don't try and recreate previous birthdays – do new special things, if possible.

Some severely affected people may not want any celebration at all. This is up to the individual and they should not be pushed into doing something they don't want to. This can be very hard for the family, especially if it is Christmas; but try to make the time special for everyone else, away from the severely affected person. Set aside periods to just sit with the severely affected person even if they aren't taking part in the festivities.

With time they/you will begin to enjoy life again and take part in things the way they used to.

Lack of Understanding

Throughout your illness you will come into contact with many different attitudes towards ME. Some people will understand and some won't. The only approach is to explain to the person what you are going through and give them information to read for themselves. This will help some people; but others will be unable to understand no matter what you say or do.

This can be extremely hard to deal with, especially if you were previously very close to the person. You may even find that seeing them is too much, if they keep making tactless comments. You have to do what's right for you and if that is stopping contact, at least while you are severely affected, then don't feel guilty. You can rebuild relationships when you are better.

Many doctors also have a problem believing in ME, despite the findings of the Government Report. Some still say that ME is all in the mind. This is because they cannot find any obvious cause and therefore put it down to psychological problems. Every day they see patients with illnesses that they understand and have been taught what to do. They cannot understand ME and it makes them feel threatened not knowing what to do. They can't come to terms with things that they can't cure.

Avoid these professionals if possible. If not always keep copies of letters both sent and received, and write down/record phone conversations, for later reference.

Don't let other people's insecurities affect the way you live. You are not going mad and there are people out there who understand and believe you. Denial is the first stage of acceptance, and although it may take a long time, hopefully one day everyone will understand and believe in ME.

Alternative Therapies

During your illness many people will tell you about treatments that cured a friend of a friend. They will swear it worked for this person and try and push/ encourage you to try it. It can be very tempting to give these treatments a go, no matter how weird and wonderful they are, because you and your family are desperate for you to get better. It is up to you whether you do try anything, but remember if there was something that cured ME then it would be all over the news and everybody would be taking it.

This doesn't mean all treatments are a waste of time. Some like Reiki, spiritual healing or acupuncture can be very good at helping you relax. This is important for all ME sufferers, especially severely affected people, as it gives your body chance to heal itself.

The best advice is don't spend lots of money and don't do it if it makes you feel worse. The statement that you have to get worse, before you get better, is not always true.

People recover from ME in their own time and at their own pace. You will get better; you just have to wait for the right time, when your body is ready to start working again. Waiting is very hard; but it will happen, you will recover.

A Note to Carers.

Looking after someone who is severely ill, no matter what the condition, is extremely hard. This is even worse when the illness is ME, as so little is understood about it and there is very little that can be done.

There are times when everything is an uphill battle and the severely affected person seems to keep getting worse no matter what you do. This is heartbreaking to watch, the powerlessness is unbearable; but remember you will get through it. Things will get better, they will just take time.

You may find it necessary to get in extra help from carers provided by social services or hired privately. For more details contact: -

Crossroads
0845 4500350
<http://www.crossroads.org.uk/>

The British Nursing Association
0800 657575
www.bna.co.uk

You can get a copy of the Carers' Guide to Assessment, about help available from Social Services. There is also a book on caring for people, called Caring For Someone At Home, available from Amazon and the Carers Association.

www.carers.gov.uk

Contact the Carers National Association for help and advice. The carers line is open 10-12 am and 2-4 pm Monday – Friday.
08457 573369

Make sure you explain the situation to the carer. As with everyone you will find some will understand, others won't. You may have to change carers until you find the right one for you.

Don't feel ashamed or embarrassed for asking for help. You need as much support as the sufferer. You may find it useful to talk to a counsellor. Some carers have to take anti-depressants like the sufferer, what's important is doing whatever you have to, to get yourself and your severely affected person through this hard time. It will get better!

The most important thing is to keep your sense of humour. Look out for ME advantages in every situation and don't dwell on what could have been. Just deal with the now. Remember one day this will all seem like a bad dream.

Emotions and Frustrations.

As with everything there is no simple answer to this one. There will be days or even weeks when you just want to cry or scream or shout. The feelings can be so strong that you don't know what to do, and you feel like you are being overwhelmed and are unable to cope. Don't bottle up your emotions, talk to someone. This can be very hard to do, especially with the fear that getting upset will make you worse; but you'll be amazed at how much better you feel after a good cry, even if you feel tired for the next couple of days, you will feel better for getting it out of your system.

There will be days that you feel like you want to give up, that you just can't cope anymore. All you can see in the future is endless days of exhaustion; pain and frustration - don't give up! Stop thinking about the future, just concentrate on getting through the day. If this seems too long then just think about the next minute. The day will pass without you realising. Sometimes it helps to think to yourself "Just get through today, let tomorrow take care of itself."

The days will seem to drag by, which is why its important to try and do one thing you enjoy, no matter how small, so you feel you have achieved something. (See Section on Activities)

If you concentrate on taking each day as it comes you will suddenly realise one day that its been a few days since you had a bad day, then a full week, then a month and so on until the bad day only happens occasionally. Ironically they then feel even worse because you've been doing so well, but try to remind yourself how well you've been doing, although this can be very hard.

If you get very depressed about the situation then contact your GP about anti-depressants, which can be very helpful. Ignore the stigma that is attached to them. Those who scorn them have rarely been low enough to need them.

There are herbal alternatives e.g. St Johns Wort, talk to a health therapist for more advice and always check with your GP if you are taking any other medication.

Some people find that writing things down can help, or even just writing a word or two. If you can't write you could draw a picture or do a scribble in a colour which matched your mood, or you could dictate it onto a tape if your feelings are too personal or painful to talk to someone else about.

The most important thing to remember is that you will get through this. It will take time and you will have bad days, but don't ever give up! People have been where you are now and they are completely recovered and you will too! There is so much waiting for you so just hold on.

Nobody would chose to be severely affected, but it does make you appreciate life and shows you what is important. You will feel like you are wasting your life, that time is slipping by you as the rest of the world gets to lead their life; but your time will come and you will make up for lost time. You will not waste a second of your future and you will be happy because you will know the price it has come at and you will not take it for granted the way most people do.

Useful Addresses.

ME Related

- 25% ME Group
4 Douglas Court
Beach Road
Troon
Ayreshire
KA10 6SQ
enquiries@25megroup.org
- Action For ME
PO BOX 1302
Wells
BA5 1YE
www.Afme.org.uk
- The Association for Young people with ME (AYME)
Box 605
Milton Keynes
MK2 2XD
01908 373300
www.ayme.org.uk
- Tymes Trust
P.O. Box 4347
Stock
Ingatestone
Essex
CM4 9TE
- **For more tips and addresses go to www.metips.co.uk**

Medical Supplies

Check your yellow pages for local suppliers or alternatively try these mail order companies.

- Careshop
Slater Street
Bolton
BL1 2HP
0845-6001204

- www.conformuk.com/
- www.activemobility.co.uk
- Mobility Care Centre
0800 3289136

- Lakeland Plastics
Alexandra Buildings
Windermere
Cumbria
LA23 1BQ
01539-488100
www.lakelandlimited.co.uk
Lap-trays, plastic glasses and cutlery.

- British Red Cross
027 – 2355454
for details of local branches, for borrowing equipment - wheelchairs, commodes etc.

- G. P. Special Projects Ltd
P. O. Box 25
Portishead
BRISTOL
BS20 6NJ

- Ability Net
P.O. Box 94
Warwick
CV34 5WS
0800-269545
<http://www.abilitynet.org.uk/content/home.htm>

- The Pain Society
9, Bedford Square
LONDON
WC1B 3RA

- Pain Concern (UK)
P.O. Box 252
Crawley
RH10 3GY
01293-552636

- www.dlf.org.uk

- Contact the Department of Health for a Practical Guide for Disabled People:
Where to find information, services and equipment.

- Tissue Viability Society at www.tvb.org.uk
- Visit this shop for toileting aids.
<http://benefitsnowshop.co.uk/shop/area.asp?area=11>
- Neal's Yard Remedies
29 John Dalton Street
Manchester
M2 6DS
0161 8317875
www.nealsyardremedies.com
- The Nutri Centre at Tesco's
7 Park Crescent
LONDON
W1
0800 9121163
www.nutricentre.com
- Melatonin: 00800 89238923 or at www.pharmwest.com
- Dark glasses –
SolarShield
Arcade
PO Box 213
Dover
Kent
CT15 4GA
- Blue tinted glasses-
Irlen UK 0207 736 5752 www.irlenuk.com.
Also available from opticians.
- Earplugs-
www.earplugstore.com
tom@earplugstore.com
- Keep Able Ltd
Unit 38C
Telford Way
Telford Way Industrial Estate
Kettering
Northants
NN16 8UN
01536 525153

Carers

- Crossroads
0845 4500350
<http://www.crossroads.org.uk/>
- The British Nursing Association
0800 657575
www.bna.co.uk
- www.carers.gov.uk
- Carers National Association. open 10-12 am and 2-4 pm Monday – Friday.
08457 573369

Shops

- Argos
www.argos.co.uk
0870 6002020
- John Lewis
<http://www.johnlewis.com/default.asp?tabID=01>
- Home Free
London Road
PRESTON
PR11 1FP
- <http://store.securehosting.com/stores/sh203340/shophome.php>
- www.talkingtables.co.uk supply sparklers and table rockets
- www.GoodnessDirect.co.uk supply organic, vegetarian and vegan foods and toiletries.
0871 8716611

Clothes

- Bradford Place
Simplantex Direct Ltd
3 The Park Close
Comptons Park Road
Eastbourne
E. Sussex
BN20 8AG
01323 749994

- Clayton Socks
17 Oakleigh Ave
Clayton
Bradford
BD14 6QE
01274 883833
- H J Hall Flysafe Socks
Country Threads
The Gatehouse
Rake
Liss
Hants
GU3 7JH
02392 632060

Food

- Home Choice Meals
0845 602 1123
www.homechoicemeals.co.uk
- Wiltshire Farm Foods
0800 773773
www.wiltshirefarmfoods.com
- Barbara's Kitchen Ltd
Unit 16
Ely Valley Business Park (East)
Pontyclun
South Wales
CF72 9ES
0845 1306297
www.barbaraskitchen.co.uk
- Zedzfoods
The Old Station Bakery
Mill Lane
Llanfyllin
SY22 5BG
01691 648029
www.zedzfoods.co.uk
- D & D Chocolate Ltd
Centenary Business Centre
Attleborough Industrial Estate
Nuneaton
CU11 6RY

02476 370909
www.d-dchocolates.com

- Hotel Chocolat Ltd
Mint House
Royston
Hertfordshire
SG8 5HL
0870 442 8282
www.hotelchocolat.com

Relaxation

There are various relaxation tapes reviewed at
<http://members.lycos.co.uk/justrelax/relaxation/tapes.htm>

- Yoga-
Angela Stevens
"Laminga"
South View Road
Wadhurst
Sussex
TW5 6TL
01892 782865
www.Angela-Stevens.co.uk
- New World Music
Freepost ANG 4441
Beccles
Suffolk
NR34 8BR
01986 781 682
www.newworldmusic.com

Craft Shops

- Baker Ross
Unit 53
Millmead Ind. Estate
Millmead Rd
London
N17 9QU
0870-2411867
www.bakerross.co.uk
- Centagraph
18 Station Parade
Harrogate

N. Yorks
HG1 1VE
0800-328-5237
www.centagraph.co.uk

- Smitcraft
Unit 1
Eastern Rd
Aldershot
Hampshire
GU12 4TE
01252 342626
www.smitcraft.com
- New Era Direct
PO Box 6361
Wellingborough
NN29 7ZR
01933-223509
www.neweradirect.co.uk

Some good jewellery suppliers are: -

- The Bead Book
The Rocking Rabbit Trading Co.
226a High St
Cottenham
Cambridge
CB4 8RZ
0870-6061588
www.rockingrabbit.co.uk
- The Brighton Bead Shop
Beads Unlimited
PO Box 1
Hove
BN3 3SG
01273-740770
www.beadsunlimited.co.uk

Tapes

- Calibre Cassette Library
Aylesbury
BUCKS
HP22 5XQ
01296-432339
info@calibre.org.uk

Alternatively you can buy tapes from the following mail-order shops.

- Chivers Press
Windsor Bridge Rd
Bath
BA2 3AX
01225-335336
- BBC Audio Books
Customer Services
BBC Audio Books
St. James' House
The Square
Lower Bristol Road
Bath
BA2 3SB
0800 136919
- Listen 2 Books
Retreat Farm
St. Lawrence
Jersey
Channel Islands
JE1 1LB
0870 191 3415
www.listen2books.co.uk
- The Talking Bookshop
11 Wigmore St.
London
W1U1PE
02074914117
www.talkingbooks.co.uk

Video + DVD Rentals

- www.moviem.co.uk
- www.blockbuster.co.uk
- www.Qflicks.co.uk

Internet sites.

- www.mechat.co.uk/db/shop.htm
- www.shopperuk.com
- www.surgerydoor.co.uk (Health Multi Store)
- www.kelkoo.co.uk

- <http://uk.pricerunner.com/>
 - www.priceguideuk.com
 - www.onlinepriceguide.co.uk
 - www.bookbrain.co.uk
 - www.toystoresonline.com
 - www.price-tracker.co.uk
-
- www.hallmark.com/hmk/Website/hallmark_home.jsp
 - www.yahoo.americangreetings.com
 - www.mesupport.bigstep.com
 - www.bluemountain.com

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Patents Act of 1988 to be identified as the author of this work.