

Coping with severe ME

Lois Owen, a former therapeutic arts development worker who has suffered from M.E. for 18 years, suggests a few ways of dealing with the severest episodes of M.E. from her personal experience.

If you have a very severe form of M.E., you will find that daily life presents you with many challenges. You may be bed-bound and have difficulty in speaking, eating, toileting and accomplishing other basic activities. This can make everyday life seem like a perpetual struggle, which depletes energy resources even further. Here are a number of practical ideas to solve some of these basic difficulties and make daily life a little easier to manage for those most severely affected.

Communication

Severe ME often involves experiencing communication difficulties in various degrees but there are means of alleviating these difficulties. If you are finding normal speech a strain or hard to sustain for longer periods, try whispering (which uses half the energy enabling you to sustain speech for longer) or limiting conversation to the absolute essentials. Alternatively, you can write down messages and parts of your conversation. Alternating between whispering and writing can prevent any one muscle group becoming fatigued.

If both speaking and writing are difficult, other means of communication may be utilised. Text messaging is effective for short messages to carers as well as keeping in touch with friends and family. However, a pocket PC such as a BlackBerry, iPhone or Palm Treo gives much greater freedom as it allows longer messages for everyday conversations to be typed, facilitates the production of regular task lists for carers and facilitates emailing. Simple images can also be drawn on it. This is an expressive way of communicating with friends and family and can be more meaningful since images are often more powerful than the spoken or written word.

If all speech has been lost (which can happen), hand signals can be devised for basic requests such as *need toilet, want drink, wash hands* and so on. A homemade alphabet card can be used to spell out words and a prompt card with basic instructions on it. The latter comprises a number of boxes, each containing an instruction such as *please pass me clean clothes or heat up food more, please*.

Whatever problems you have with speech, you and others will adapt over time to your new modes of communication but be reassured that normal speech does eventually come back, even if it is after a number of months or even years.

Eating

You may also experience difficulties with eating, as that involves use of some of the same muscles as speaking. The main problem is usually chewing. Excluding crunchy foods from your diet helps. If you cannot manage any solids, invest in a food blender to reduce food to a soft mush. If moving food around in your mouth or repeatedly opening your mouth is also difficult, blend food into a liquid and consume it through a straw. Most foods blend well, providing there is sufficient liquid or juicy food – such as tuna salad or apple pie and custard. A worthwhile investment is some large thermal travel mugs that come with a hole for a straw in the lid. These are available from supermarkets, outdoor pursuit shops or mobility equipment stores, though are more expensive at the latter. They not only keep food warm if you cannot consume it all at once but also minimise spillages in bed. Drinking with a straw removes the need to lift the cup to your mouth repeatedly, which may allow you more independence with feeding. The very severely affected may find it hard to suck liquid up the whole length of the straw. If this is so, cut straws in half but shallower cups will have to be used instead of mugs. If even this is too difficult and you cannot feed yourself, transparent adult feeder cups from a disability aids shop are useful as they allow a carer to see how much food is being consumed.

Another problem can be swallowing. Those severely affected by M.E. can find the number of times they can swallow in a short space of time is very limited. Drinking a little and often, say ten sips every hour, may help. Difficulties with eating, particularly swallowing, can result in a low calorie intake. If this is so, consuming a high-energy drink such as Complan (which is in most supermarkets) or Fortisip and Fortijuice (which are available in a wide range of flavours on prescription from your G.P.) is an easy way to supplement your diet with the nutrition and energy you need. It is worth keeping some Fortisips by your bed for emergencies, such as when a carer fails to turn up to bring a meal. However, medical advice is to augment high-energy drinks with a little normal food and not to depend on them entirely.

If you cannot intake enough food orally, then artificial nutritional support is the only answer. This is achieved through either a nasogastric (NG) tube or a percutaneous endoscopic gastronomy (PEG). This eradicates the struggle with food intake but brings disadvantages of temporary hospital life – noise, light, routine and so on. When your ability to swallow and chew does return – be it in weeks, months or years – food will never taste so good!

If your problem is neither chewing nor swallowing but rather the weight of crockery and utensils, use plastic plates, cups and cutlery. They are so much lighter and easier to handle.

Toileting

Toileting is straight-forward if you can use a commode (available free through Social Services) or a porta potti (costing £60 upwards from camping equipment stores). Maintaining privacy whilst toileting is very important for self-esteem so a system needs to be established in order to ensure this. The system could be that anyone should knock and wait for your verbal agreement or agreed signal before entering your room.

However, if you are unable to sit up or move yourself onto these, toileting is more problematical. Some bedpans are too high to get onto without a carer lifting your hips; others are too heavy to handle; some urinals cannot be used successfully when lying down. The best solution I have found is the slipper urinal (available for about £8.50 from mobility equipment stores). It is light, stable, easy to use and does not easily leak. If you are unable to lift a full urinal, find a bedside surface that is exactly the same height as the bed so you can slide the urinal across onto it. Using upturned plastic baskets is a good way of building up a low table to the required height.

If you are by yourself for long periods of time, a way of storing urine is needed. One way is to have several urinals or bedpans. Alternatively, each time take the cap off the urinal and empty the urine into a bucket by your bedside. The bucket from a commode is ideal because it will hold about a day's worth of urine and has a lid which minimises unpleasant odours.

Opening your bowels can be more difficult, especially if you are unable to lift your hips onto the deeper bedpans. In addition, lying flat on your back is an uncomfortable position for straining. One solution is to lie on your side and use a plastic glove. This works well except if you are prone to diarrhoea. Each person needs to find their own effective method commensurate with their individual limitations. When toileting, a washable bed pad (60cms x 90 cms x 1cm, available from mobility equipment stores) or a disposable sheet (available in packs of 20 and 50 from care home suppliers) is useful to protect the bed from drips and spills. However, nappy changing sheets bought from supermarkets are just as effective and cheaper and, if spillages are slight, a towel does just as well and is more comfortable and homely.

Dressing, Washing and Personal Care

Pulling clothes on and off can be too exhausting. It is slightly easier when a carer assists but, if you want to retain privacy and independence, you will find applying a pacing technique a good alternative. Break the process down into manageable chunks and rest in between them. Choose soft and stretchy clothing as it makes dressing and undressing easier as well as being more comfortable in bed. It may also be helpful to wear clothes that are suitable for both day and night so that you do not have to get changed first thing in the morning and last thing at night. If it is a struggle to change underwear every day, then stop

wearing underwear! If you are female, skirts are easier than jeans and trousers for toileting and changing. Scotsmen with their kilts have a distinct advantage over other men in this area!

If you feel the cold, a good way to get an extra layer is to wear a pair of thick tights with the crotch cut out to enable easy toileting and washing. Vest tops are also useful so that you can wash under the arms without getting undressed. There is no need to worry if you cannot change clothing very often. You can stay fresh for a surprisingly long time if you are able to wash just a little. For example, when I was at my worst I could only change clothes about once every three weeks.

Washing too can be an exhausting process. A complete bedbath all at once may be impossible, so again break it down into manageable chunks. Wash half a leg one day, an arm the next day and so on. If the noise of dripping water is hard to bear, wear foam ear plugs. If even limited washes by a carer is not manageable or too intrusive, a DIY wash using baby wipes is an alternative. A supply of baby wipes by your bedside means you can freshen up whenever you have the energy to or to fit in with your pacing routine and can maintain a degree of independence. If you cannot manage much, just focus on essential areas.

Brushing your hair can also be draining of energy. It is so much gentler to simply run your fingers through your hair. I have maintained even long hair this way over a long period of time. Do not worry if over time hair becomes knotted and matted. With a little patience it is possible to undo even the worst knots when you are better. Once I was unable to care for my hair properly for two years and it turned into a solid mass of knots but when I improved in health I teased our hair by hair and successfully recovered my flowing hair.

Brushing teeth can also be problematical, especially if you cannot open your mouth wide enough to use a toothbrush. If you can open your mouth a little way, try using a child's toothbrush which is smaller and gentler. If this is not possible, resort to mouthwash which can be easily sucked up a straw.

The daily life of a bed-bound person with chronic severe ME is hard. Hopefully some of these ideas will be helpful and alleviate the suffering.